School of Occupational Therapy and Social Work

Maintaining Relationship Satisfaction in Couples Raising a Child with Autism Spectrum Disorder

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Doctor of Philosophy
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Author's Declaration

I declare that this thesis is my own account of my research and contains, as its main content, work which has not previously been submitted for a degree at any tertiary education institution.

To the best of my knowledge this thesis contains no material previously published by any other person except where due acknowledgement has been made. This thesis contains no material which has been accepted for the award of any other degree or diploma in any university.

The research presented and reported in this thesis was conducted in accordance with the National Health and Medical Research Council National Statement on Ethical Conduct in Human Research (2007) – updated March 2014. The proposed research study received human research ethics approval from the Curtin University Human Research Ethics committee (EC00262), Approval Number OTSW-05-2014.

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Abstract

Raising a child with autism spectrum disorder (ASD) can have a pervasive, dynamic and enduring impact on the entire family system, the keystone of which is the couple relationship. Couples' responses to these challenges are diverse and it is unclear why some couples adapt positively while others do not. To date, research has focussed predominantly on negative processes leading to conflict, relationship dissatisfaction and separation. Little attention has been given to positive outcomes despite evidence that relationship satisfaction can be a protective resource in families managing the challenges associated with raising a child with ASD. Therefore, the overall aim of this thesis was to explore relationship satisfaction in couples raising a child with ASD and the factors couples considered important to its maintenance.

The thesis comprised of six individual studies, presented as peer-reviewed journal manuscripts. Chapters 2, 3 and 4 detailed research that set the scene for the thesis and confirmed research needs, identified gaps and guided the development of research in Chapters 5, 6 and 7.

Chapter 2 constituted a systematic review and meta-analysis conducted to compare relationship satisfaction in couples with and without a child with ASD and determine the factors associated with relationship satisfaction. Thirteen databases were searched with 26 articles meeting the criteria for inclusion. Seven articles were included in the meta-analysis that revealed that couples raising a child with ASD were at risk of experiencing lower levels of relationship satisfaction than their counterparts raising a child without a disability. However, narrative synthesis revealed that some couples maintained a strong, fulfilling relationship. A number of risk and protective factors were attributed to these diverse outcomes, including: challenging child behaviours, parental stress, psychological wellbeing, positive cognitive appraisal and social support. The interrelatedness of the implicated factors was captured in a theoretical model that provided a foundation for future research and clinical practice using family systems and strengths-based approaches.

Chapter 3 and 4 each comprised of a study summarising a secondary analysis of cross-sectional data from a previous West Australian population-based study to ascertain the relevance of the systematic review findings to a local population of families and determine the need and direction of future research. Chapter 3 explored the co-parenting experience of parents raising a child with ASD and its associated factors. Logistic regression analysis of data from 496 families revealed that 29% of caregivers indicated that their child's ASD symptomology had a very negative effect on their relationship with their partner, which was associated with three factors: 1) Family stress; 2) A negative parent relationship with their children without ASD; and 3) Greater distance to the nearest medical facility. Chapter 4 explored stress in 543 families and the factors associated with severe stress levels. Findings showed that 44% of families reported severe family stress, 54% reported mild to moderate stress and a minority 2% reported no stress associated with having a child with ASD in the family. Severe family stress was associated with four factors: 1) Reduced ability to socialise; 2) Not having accessed individual therapy; 3) Negative co-parenting relationship; and 4) High out-of-pocket expenses due to the costs associated with raising a child with ASD. Together, findings from these studies showed that a child with ASD can impact upon the family through various levels of the family system and that ecological factors, such as family relationships, may play a more important role than sociodemographic and child variables. This confirmed the importance of a family-systems approach to the capture the dynamics between stress, coping and relationship satisfaction.

Several gaps in research were identified including: the limited recognition of positive outcomes; lack of dyadic data; failure to treat relationship satisfaction and dissatisfaction as independent but related dimensions; and lack of variability in research designs. The research of Chapters 5, 6 and 7 were designed to bridge these gaps and explore research territories previously unchartered.

Chapter 5 comprised a cross-sectional survey investigating the factors associated with a *satisfying* relationship. Data from 127 caregivers revealed a majority (65%) who reported relationship satisfaction and this was associated with low levels of parenting stress, reduced use of negative dyadic coping and increased use of positive dyadic coping strategies. Positive dyadic coping was found to have a greater influence on relationship satisfaction than negative dyadic coping, supporting a strengths-based approach to intervention.

Chapter 6 detailed a phenomenological study that explored the lived experience of relationship satisfaction in a purposely recruited sample. Data from 11 couple interviews were used in thematic analysis to explore how each couple maintained satisfaction in their relationship. The overall essence that emerged from the data was captured in the quote “We are in this together” and encapsulated three main themes; shared beliefs, teamwork and shared experiences.

The research of Chapter 7 applied Q-methodology to explore the viewpoints of caregivers raising a child with ASD regarding factors important to maintaining relationship satisfaction. A total of 54 statements were developed from the concourse of interview data and presented to 43 caregivers to sort according to their relative importance to relationship satisfaction. Varimax factor analysis generated a two factor (viewpoint) solution; one highlighted the importance of building trust through effective communication, while the other prioritised the importance of building a strong partnership by working as a team to share the responsibilities associated with raising a child with ASD.

Overall, the findings of this thesis revealed that despite an increased risk of poor relationship satisfaction in couples raising a child with ASD, the majority of couples maintained a satisfying relationship with their partner. This positive adaptation may be explained by the use of positive dyadic coping strategies (including shared beliefs, teamwork and communication). A final model has been developed which shows dyadic coping as a mediator between the challenges associated with raising a child with ASD and relationship satisfaction. Future research should evaluate this model in a number of different contexts, and examine the protective effects of relationship satisfaction on family functioning and outcomes in the child with ASD. For families that are struggling, this finding helps to balance the negative picture too-often portrayed in the literature and media, and can offer hope and possibility for a better future. For researchers and clinicians, it offers a framework to guide the application of family-focussed ASD interventions.

Acknowledgements

I wish to acknowledge and extend my sincere gratitude to the many wonderful people who supported me in my research journey and made this PhD possible.

Firstly, thank you to the participating families without whom this research could not have been realised. Your time, energy and enthusiasm towards ASD research is highly valued and your contribution goes a long way toward improving the lives of people with ASD and their families.

My deepest gratitude extends to my supervisory team, Professor Torbjörn Falkmer, Associate Professor Reinie Cordier, Dr Sharmila Vaz and Dr Sofi Fristedt. Thank you for sharing your expertise and shaping me into a researcher! Each of you provided unique insights and guidance that challenged my thinking and facilitated my growth both professionally and personally. Torbjörn, your optimism and unwavering belief in me kept me motivated even through my seemingly endless life challenges! Thank you for the flexibility and opportunities you afforded me to get over the finish line. Reinie, I have deep appreciation for your investment in me and my work, helping me towards the high standards needed to meet my perfectionistic tendencies. Sharmila, your kindness, friendship, and genuine desire to see me achieve. Sofi, your expertise in Q methodology and support from afar. I look forward to working with you all again in the near future.

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you also goes to my kind husband who offered continued support and never doubted my ability to accomplish my goals. I am truly grateful.

Dedication

I dedicate this thesis to my dad, Leslie William Chamberlain.

I grew up seeing a reflection of a girl who could do anything in your eyes. You started this PhD journey with me and you were so proud! I wish you were here to see it completed. I miss you dearly.

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List of Publications

This doctoral thesis consists of the following publications:

1. Sim A, Cordier R, Vaz S, Falkmer T. Relationship satisfaction in couples raising a child with autism spectrum disorder: A systematic review of the literature. Research in Autism Spectrum Disorders. 2016; 31:30-52. doi:10.1016/j.rasd.2016.07.004, impact factor 2.9, cited 5 times.

2. Sim A, Cordier R, Vaz S, Netto J, Falkmer T. Factors associated with negative co-parenting experiences in families of a child with autism spectrum disorder. Developmental Neurorehabilitation. 2017; 20(2):83-91. doi:10.3109/17518423.1069414, impact factor 2.1, cited 3 times.

3. Sim A, Vaz S, Cordier R, Joosten A, Parsons D, Smith C, Falkmer T. Factors associated with stress in families of children with autism spectrum disorder. Developmental Neurorehabilitation. 2018; 21(3):155-165. doi:10.1080/17518423.2017.1326185, impact factor 2.1, cited 1 time.

4. Sim A, Cordier R, Vaz S, Parsons R, Falkmer T. Relationship satisfaction and dyadic coping in couples with a child with autism spectrum disorder. Journal of Autism and Developmental Disorders. 2017; 1-12. doi:10.1007/s10803-017-3275-1, impact factor 3.3.

5. Sim A, Cordier R, Vaz S, Falkmer, T. “We are in this together”: Experiences of relationship satisfaction in couples raising a child with autism spectrum disorder. 2017. Under review.

6. Sim A, Fristedt S, Cordier R, Vaz S, Kuzminski R, Falkmer T. Viewpoints on what is important to maintain relationship satisfaction in couples raising a child with autism spectrum disorder. 2017. Under review.

Key Abbreviations

ASD: Autism spectrum disorder

CCET: Couple Coping Enhancement Training

CSI: Couple Satisfaction Index

DCI: Dyadic Coping Inventory

DSM: Diagnostic and Statistical Manual of Mental Health Disorders

OT: Occupational therapist

PSS: Parental Stress Scale

SEIFA: Socio-Economic Indexes for Areas

Explanation of Terms

There is ongoing debate amongst members of the autism community regarding terminology and, currently, there is no universal consensus on how to describe autism[1]. In this thesis, person-first language was used to describe people with a diagnosis of Autism Spectrum Disorder, for example, *child with autism spectrum disorder*. Person-first language attempts to challenge the beliefs that people are defined by their disabilities by referring to the individual first, then their disability only if necessary[2]. Many researchers, educators and health professionals have been trained in the use of person-first language and continue to show a preference for its use in describing people with autism[1]. Thus, person-first language was deemed appropriate for use in the context of this thesis given its readership. *Autism spectrum disorder* was chosen over other terms to describe autism, in keeping with the Diagnostic and Statistical Manual of Mental Disorders, fourth (DSM-IV) or fifth edition (DSM-5). This included people with Asperger's Syndrome and Pervasive Developmental Disorder – Not Otherwise Specified, as formerly delineated in the DSM-IV.

The term *couple relationship* was used throughout the thesis, defined as "two people usually residing in the same household who share a social, economic and emotional bond usually associated with marriage and who consider their relationship to be a marriage or marriage-like union. This relationship is identified by the presence of a registered marriage or de facto marriage"[3]. The term *relationship satisfaction* was used to describe the outcome variable in the thesis research, that being, the subjective evaluation of satisfaction in the couple relationship[4]. There is a long history of conceptual ambiguity that has led to the use of many interchangeable terms used to describe the quality of couple relationships, including *marital* (or, more

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[1] Kenny L, Hattersley C, Molins B, Buckley C, Povey C, Pellicano E. Which terms should be used to describe autism? Perspectives from the UK autism community. Autism. 2015; 40(4):442-62. doi: 10.1177/1362361315588200

[2] Foreman P. Language and disability. Journal of Intellectual and Developmental Disability. 2005; 30(1):57-59. doi: 10.1080/13668250500033003

[3] Australian Bureau of Statistics. Couple relationships. Retrieved from http://www.abs.gov.au/websitedbs/censushome.nsf/home/factsheetscr?opendocument&navpos=450

[4] Fincham FD, Rogge R. Understanding relationship quality: Theoretical challenges and new tools for assessment. Journal of Family Theory and Review. 2010;2(4):227-42.

generally, *relationship*) *adjustment, quality, happiness and satisfaction*[5]. The term *relationship* was chosen over *marital* due to the increasing numbers of couples choosing to cohabit without the formalities of marriage, and to be inclusive of less conventional unions such as same sex relationships[3]. The term 'satisfaction' was chosen to represent the positive dimensions of a couple relationship, recognising that relationship quality is not a continuum; satisfaction and dissatisfaction can be conceptualised as separate but related dimensions[4]. It is also important to differentiate relationship satisfaction from relationship stability; satisfied couples may experience relationship dissolution, while dissatisfied couples may remain together over extended periods of time[6]. The focus of the thesis was on satisfied couples who maintained their relationship.

The thesis followed the format of a thesis by publication. Accordingly, the research has been published (or currently under review) in peer-reviewed journals and included as separate chapters that constitute the main body of the thesis. As each chapter must be a stand-alone manuscript for publication, there is some inherent repetition throughout the thesis.

Vancouver referencing style and Australian grammar and spelling were used consistently throughout the thesis. The exceptions to this were the four published manuscripts (Chapter 2, 3, 4 and 5). These have been included as PDFs of the published versions and, as such, adhered to the grammar, spelling and referencing style required by the journal. Furthermore, manuscripts varied in structure (i.e., headings, abstract format) in accordance with individual journal guidelines.

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[5] Heyman RE, Sayers SL, Bellack AS. Global marital satisfaction versus marital adjustment: An empirical comparison of three measures. Journal of Family Psychology. 1994;8(4):432-46.

[6] Karney BR, Bradbury TN. The longitudinal course of marital quality and stability: A review of theory, methods, and research. Psychological Bulletin. 1995;118(1):3-34.

Preface

When I began my PhD, I was keen to approach my research in ASD from a holistic, family perspective. My experiences providing services as an occupational therapist (OT) in community settings, as well as receiving services as a mother of a child with ASD, had made me somewhat disheartened and cynical about claims of family-centredness. Certainly, some boxes were ticked; most service providers promoted collaboration with families and their involvement in goal setting, decision making and therapy. However, services still remained highly focussed on the child's needs, with little evaluation of family contexts. Furthermore, there were huge expectations of commitment and follow through from families, without assessment of their capacity to do so or the provision of necessary supports to ensure success.

As an OT, I had the pleasure of developing close therapeutic relationships with many families and I quickly became aware of the chronicity and pervasiveness of the challenges they faced, their lack of support and unmet service needs. Then, as a mother of a child with ASD, I gained first-hand insight. I became acutely cognizant that child outcomes were dependent on more than just the therapy itself; family wellbeing played a crucial role.

What I noticed over the years was that despite the many similarities in experiences raising a child with ASD, family responses varied greatly. Some appeared to function well, and these families seemed more attuned to their child's needs, more receptive to information and better able to embed therapeutic strategies in their daily life. What was it about these families that enabled them to not only weather the challenges, but grow stronger from them? Could they have insights that could help strengthen other families who may be struggling to cope?

I reflected on these experiences often as my PhD research evolved. I was also spurred on by the positive responses I received from individuals with ASD and their families, as I realised how meaningful my research was to them. In particular, I will never forget the response from a colleague when I relayed my research ideas to him: "About time! We are bombarded by the negative aspects of autism and how burdensome we [people with ASD] are to our families, which really hurts. Imagine being blamed for your parent’s divorce! It’s great that someone is finally looking at positive family outcomes – it’s not just doom and gloom!”.

It is my hope that this research contributes to a more balanced portrayal of the experiences of couples raising a child with ASD and helps create a sense of hope and optimism for families.

Chapter 1 Introduction

1.1 Raising a child with autism spectrum disorder

Autism Spectrum Disorder (ASD) is a life-long, multifaceted and pervasive neurodevelopmental condition characterised by impairments in social communication and interaction, and the presence of restricted, repetitive patterns of behaviour, interests or activities (1). As it is a spectrum of disorders, the severity and expression of characteristics manifest differently across individuals. Comorbid developmental, intellectual, psychological and medical conditions are common (1-5). Although ASD symptoms and associated challenging behaviours may abate over time (6-8), the child often requires support and intensive caregiving into adulthood (9, 10). According to the Centers for Disease Control and Prevention (11), prevalence rates are currently estimated at 1 in 68 children in the United States and ASD can occur across all racial, ethnic and socioeconomic groups. Prevalence rates in Australia are lower at 1 in 150 (12, 13), however, this is likely an underestimate due to inconsistencies in data collection (14). Furthermore, families with one child with ASD can have up to an 18% chance of having a second child with a similar diagnosis (11, 15, 16). Thus, there are many couples raising one or more children with ASD who could benefit from support in managing the associated challenges.

Symptoms of ASD can manifest early in the child's development and endure throughout the family lifespan, requiring long-term management (9). However, the needs of children with ASD change over time and there are key developmental stages in which caregivers experience greater stress and require more intensive support.

1.1.1 The diagnostic period

Obtaining a clear ASD diagnosis can be one of the greatest challenges faced by caregivers and this period has been associated with elevated levels of stress and depression (17-21). Many parents are alerted to their child's delayed milestones or behavioural differences long before a diagnosis is formalised, prompting them to search for answers (21-25). Sometimes, these initial concerns are dismissed or misdiagnosed, leading to frustration and lengthy delays in service receipt (22, 24-

29). Once initiated, the assessment process can be an intense, complicated and drawn out process, with the eventual ASD diagnosis accompanying a range of emotions from shock, confusion, denial, loss, grief and self-blame, to relief, validation and empowerment (21, 22, 24, 25, 30). Parents learn that early intervention is imperative for optimal behavioural and developmental outcomes; yet, many report a lack of clear guidelines as to how to proceed and find themselves with the overwhelming responsibility of identifying, understanding and accessing interventions (23, 27, 31). The diagnostic period is a critical time for information and family support, which may alleviate some of the associated caregiver stress (9, 19, 21, 32).

1.1.2 The early intervention period

Following the ASD diagnosis, parents typically embark on a steep journey of learning as they try to gain an understanding of child development; ASD and its management; and services and resources available (9, 30). Early intervention is touted as best practice (33); yet, parents report a number of barriers, including lengthy diagnostic processes; contradictory and controversial information; little professional guidance and parental education; rigid eligibility criteria for services; complicated referral processes; long waitlists; limited resources and funding; lack of continuity across services and lack of family centred practices (21, 22, 24, 28, 34-36). Furthermore, parents report that not all health care providers are helpful or have the appropriate expertise to treat ASD and understand the associated challenges for the family (28, 37).

For parents raising a child with ASD, the array of treatment approaches can be daunting. There is little consensus regarding the best treatment options and a lack of clear guidelines to assist parents in decision making (23, 37). Given the diversity of ASD presentation and the variation of intervention, many parents employ an assortment of pharmacological, dietary, behavioural and educational interventions concurrently and this requires consultation with professionals across multiple disciplines (23, 37, 38). Altogether, families can access up to 7-12 forms of treatment at any one time (24, 39). This can make it extremely difficult to ascertain which treatments are attributable to the outcomes achieved (24, 37). Moreover, parents are encouraged to assume the role of therapist and educator to incorporate learning opportunities into everyday activities and promote the generalisation of skills to community environments (33, 40). In some cases, parents are required to engage in therapy up to 40 hours per week (41). Consequently, family life can begin to centre around the child with ASD as parents become overburdened with continuous high levels of care, a multitude of appointments, coordination of services and managing associated costs (38, 41, 42).

1.1.3 The school years

Given their challenges in communication, social functioning and difficulty generalising skills, children with ASD and their families commonly require more support through the transition to school than other children (43-45). Yet, transitional policies and practices tend to be generic, lacking the individualisation required to meet the unique needs of a child with ASD (43, 44).

Parents must educate themselves about special education services and rights, and advocate for inclusive opportunities (9). Choosing the right school is fraught with challenges; parents are plagued by diverse and conflicting professional opinions and contradictory educational policies and practices (45-47). Moreover, parents report being confronted by stigmatisation, discrimination and exclusion by schools because of their child’s ASD diagnosis, despite the promises of school inclusion policies (46, 47).

Parental education and advocacy does not end with the placement of their child with ASD at school. They must continually fight to have their child’s needs understood; obtain required supports and individualised interventions; receive proper management of behaviours and safety concerns; promote active engagement in the classroom and social inclusion; and address bullying (25, 38, 43, 45, 47). Parents report facing ongoing judgement, the need to deal with negative communications and disempowerment as decisions regarding their child’s education are taken from their control (38, 46).

The transition from primary to secondary school may see many of these issues revisited, or exacerbated (48). In addition, adolescence often accompanies behavioural changes triggered by hormones; safety concerns as the child becomes bigger and stronger; and health and sexuality issues (9, 21). During this time, preparation should begin for a successful post-school transition (49). However, study findings reveal that parents receive little information and support around this time (50).

1.1.4 The transition to adulthood

Many individuals with ASD do not attain normative outcomes in adulthood and remain dependent for aspects of daily living (6, 7). Transitioning to adulthood accompanies many changes and new challenges as adolescents move into post-secondary education and/or employment, community participation, and independent living (9, 26, 49). Yet, parents report little guidance with this important transition (9, 51). They experience a loss of previously held supports that they no longer qualify for and must deal with new service systems and providers that frequently do not have the specialised knowledge to meet the needs of people with ASD (9, 52).

1.1.5 The multiple roles of parents

Parents raising a child with ASD report the demanding need to assume multiple roles beyond the parenting requirements of raising children without ASD (30, 53). Such roles include: Caregiver, Researcher, Coordinator, Advocate and Therapist.

1.1.5.1 Caregiver

The caregiving demands of raising a child with ASD can be relentless and pervasive, infiltrating parents' thoughts, plans and actions for much of any given day and night (21, 23, 24, 54). As one parent described: “You quickly find that you don't have a life” (24, p. 146). Parents have to manage a complex array of pharmacological, dietary, behavioural and education interventions (26, 37, 55). Children with ASD require more direction, repetition and supervision than other children (42, 56). Parents describe a need for hypervigilant parenting to anticipate triggers and pre-empt outbursts in behaviour (23, 36, 56). The anticipatory planning, continued monitoring and adjusting to meet the child's needs can be exhausting (25, 31, 57).

1.1.5.2 Researcher

There is no clear consensus as to the best intervention approach for ASD and parents report receiving limited information regarding ASD and available services, leading them to engage in their own extensive research (23, 24, 30, 58). The role of researcher is continuous as parents attempt to stay abreast of their child's changing needs, new research as it emerges and changing sources of funding and supports (9).

1.1.5.3 Coordinator

As previously mentioned, ASD is a complex diagnosis that often requires a range of interventions and services by multiple providers. This requires strategic and organised coordination by parents and collaboration to ensure consistency between services (23).

1.1.5.4 Advocate

Parents of children with ASD play a key role in advocacy across their child's life span (9, 22, 24, 59, 60). They have described it as "fighting all the way" with regards to making the system work for them and their child, and improving services for other families in the future (56, p. 1081). For these parents, advocacy involves self-directed learning; becoming more direct in seeking needs; and educating professionals, family, friends and the wider community who demonstrate a lack of understanding of ASD (9, 24, 25, 56).

1.1.5.5 Therapist

Best practice in ASD promotes the active participation of parents in the child's therapy (40, 55). Parents often take up the role of therapist by incorporating principals of treatment in daily life or as part of a highly structured programme (27). The benefits are many; parents are the most stable and knowledgeable in their child's life and can provide relevant information on the needs, preferences and history of their child, and they can assist with problem solving and setting of meaningful and achievable goals (55). Furthermore, parent involvement maximises the amount of intervention a child receives and facilitates the generalisation of skills into home and community environments (33, 40, 55). While empowering, the intensity, daily effort and time constraints of parent involvement can increase stress, resulting in the counter-productive outcome of reducing the efficacy of interventions (37, 61).

1.1.6 Parental stress and coping

Raising a child with ASD can, paradoxically, be both a challenging and rewarding experience. ASD can have a significant physical, emotional and financial impact on the entire family system and its ability to function, thrive and support the child with ASD (9, 35). Stress has been conceptualised as a transaction between an individual and their environment in which the demands are perceived to outweigh the available resources and threaten wellbeing (62). Parenting stress is considered the product of complex and persistent challenges associated with the care of a child (63). Families of children with ASD have reported higher levels of stress than families raising children without ASD (54, 64-69). For many parents, the stress begins prior to diagnosis and continues to persist over the course of their child's development into adulthood (70, 71), and has been described as "never-ending" (34, p. 706). Parent stress has been attributed to the unique direct and indirect demands of raising a child with ASD in culmination with the pile up of everyday stressors experienced by all parents (17, 72, 73).

Studies have revealed a number of factors predictive of stress experiences in parents raising a child with ASD. A number of child characteristics have been associated with stress, including ASD severity (17, 54, 74-77). However, even parents of children with high functioning ASD have reported greater stress than those of children without developmental delay (78). The social skills deficits characteristic of ASD appear to be particularly stressful (69, 79-81). Furthermore, the presence of comorbid conditions are highly prevalent (2, 5, 82) and may increase the risk of high stress (26, 68). Specifically, the challenging behaviours associated with ASD (e.g., tantrums, aggression and self-harm) may be a greater predictor of stress than core symptoms (32, 65, 71, 83-88). In reciprocation, parenting stress can exacerbate child behavioural challenges (71, 85, 89). It can also reduce parenting self-efficacy (90), as difficulties managing behaviours can lead to feelings of inadequacy, guilt and failure as a parent (29, 90-92).

Another commonly reported stressor in parents of a child with ASD is the inability to socialise and the resultant social isolation (17, 23, 32, 34, 38, 56, 57, 93-95). One study found that 82% of families raising a child with ASD felt they received minimal support from friends or neighbours, and 35 % reported having little or no leisure time

(57). Caregivers are constrained in their ability to socialise by their child's challenging behaviours, time constraints, exhaustion, social stigma, difficulty relating to friends, limited respite options and the need for excessive planning (23, 24, 34, 38, 57, 96-98).

Parents have reported that the lack of public awareness around ASD and associated stigmatisation contributes greatly to their stress experiences (24, 31, 98, 99). ASD has often been referred to as an *invisible* condition with no outward signs to account for perceived inappropriate behaviours (31, 38, 98). Thus, parents have reported frequent staring and criticism from others who attribute the inappropriate behaviours to poor parenting (24, 98). This results in feelings of embarrassment and guilt, and parents often isolate themselves to protect themselves and their child (34, 56, 66, 100). Furthermore, a child with ASD is at risk of being marginalised and bullied; a great source of stress for families (26, 34).

Stress in parents of children with ASD has also been associated with socioeconomic factors (101). Raising a child with ASD can generate substantial costs to the family, both in terms of intervention and lost employment due to caregiving demands (24, 36, 38, 66, 97, 102, 103). Financial earnings have been shown to be lower in families with a child with ASD compared to families of children with other disabilities or no disability; for example, one study revealed that 53% of families with a child with Down syndrome had dual incomes, compared with only 29% of families with a child with ASD (57). Commonly, it is the mother who reduces her work hours or leaves the workforce altogether (24, 26, 36, 104-106) and this forced obligation and loss of personal options can impact on her wellbeing and access to sources of support (23). The result can be feelings of isolation, lack of fulfilment, low self-esteem, reduced psychological wellbeing and increased stress associated with the primary caregiving role (50, 107-112).

Despite the multitude and chronicity of demands associated with raising a child with ASD, many parents demonstrate effective stress management explained by their appraisals of stressful events and utilisation of coping resources (24, 32, 68, 77, 113). While these parents may use both adaptive and maladaptive coping strategies, a review showed that they primarily adopted two strategies; problem-focused coping (including positive reframing and sense-making) and seeking social support (114).

Coping is influenced by the meanings given to family experiences and even when faced with stressors, parents of children with ASD can often describe positive gains associated with caring for their child with ASD (38, 113, 115-119). A number of studies have demonstrated the protective role of positive cognitive appraisals against stress (100, 120-122). For example, one study showed that parents who perceived their situation as more predictable, manageable and meaningful (sense of coherence) experienced less stress than those with a low sense of coherence (77). Furthermore, hardiness (i.e., the belief in the ability to influence life events and anticipate change as beneficial) has also been associated with decreased stress (123). In an interview study, caregivers identified the importance of staying positive as a means of coping with service delivery experiences and provided examples of how they chose to reject the negativity of others, be less critical, and focus on the strengths of their child and situation (59).

Social support is another beneficial coping resource for parents raising a child with ASD; those with high levels of support have been found to experience lower stress and greater wellbeing (68, 73, 124-126). As previously mentioned, however, caregivers are at risk of social isolation and diminished social support. Thus, for couples, support from a partner may take on prioritised importance (31, 127, 128). Partner support may also be valued due to the need to “live it to understand it” (23, p. 931). Parents raising a child with ASD share many of the same experiences that people outside of the family simply cannot comprehend (56). It has been argued that social support is more effective when provided by those with similar values and characteristics, and who have experienced similar stressors (129, 130). Parents with a strong co-parent alliance may mitigate the impact of stress through a coordinated approach to parenting in which responsibilities are shared, challenges are jointly solved and families are unified under a stable team (90, 131, 132).

Without adequate coping resources, the cumulative and chronic nature of stress in parents raising a child with ASD can take its toll both physically and psychologically (133), and this can, in turn, impact on the child with ASD (86). Studies have demonstrated lower health related quality of life for parents raising a child with ASD compared to their counterparts raising children without a disability (134, 135), with 41% of parents in one study perceiving little or no activities to maintain or improve family health (57). Fatigue is a commonly reported symptom (30, 34, 42, 136). Parents have also been shown to experience poorer psychological wellbeing, particularly increased anxiety and depression (76, 137-139). Stress and compromised mental health can in turn lead to less effective parenting practices, increased behavioural problems in children with ASD and sub-optimal treatment outcomes (61, 85, 140).

Family relationships are often affected by the stressful demands of raising a child with ASD. Caregiving demands can result in less time and energy for other children, leading to feelings of guilt and failure as a parent, and potential distress and resentment in siblings (24, 29, 34, 36, 97, 141, 142). Stress can also spill over into the couple relationship, which will be discussed further in section 1.1.4.

1.1.7 Positive experiences parenting a child with ASD

The literature and media have emphasised the negative processes and outcomes of raising a child with ASD, and for a good reason; these families clearly endure significant hardships. However, it is important to recognise that many caregivers identify positive experiences and undergo adaptive processes that enable them to successfully negotiate the challenges (68, 113, 118, 143). Raising a child with ASD has been described by many as a transformative journey that incites the close scrutiny of belief systems (118). In an attempt to make meaning of their situation, parents reframe their world views, values and priorities, and this can lead to acceptance, appreciation of the positives, a sense of control, empowerment and hope (23-25, 113, 118, 144). By accepting the situation for what it is and refocusing on strengths, parents may be better able to mobilise resources for change and their increased resourcefulness can make them less reliant on formal supports and resources (121, 144, 145).

While parenting a child with ASD can demand extreme patience, energy and time, parents have described the rewarding experiences of successful outcomes and learnt to celebrate even small accomplishments (23, 42, 119). Furthermore, a number of studies have described the personal enrichment experienced by caregivers, which includes the strengthening of empathy, tolerance, selflessness, humility, assertiveness, determination, perseverance and unconditional love (24, 38, 106, 113, 117, 119, 146). Raising a child with ASD can also create opportunities for the family to work together, and some parents have reported that the shared experiences ultimately brought them closer (24, 117, 147). Furthermore, opportunities for new social experiences and friendships are often created through support groups and other activities related to ASD (24, 117).

1.1.8 Impact on the couple relationship

Stress plays an important role in understanding the quality and stability of close relationships (148). There are three conduits by which stress can affect relationships; 1) One partner’s stress can spill over to the other, due to the interdependent nature of relationships; 2) Both partners can experience the same stressor directly; or 3) Stress can originate within the relationship (149). Stress has the capacity to compromise relationship satisfaction and stability by triggering negative interactions, communication and coping efforts (149, 150). Furthermore, stress can reduce the time, energy and emotional resources available to nurture the relationship and maintain connectedness (149, 151).

The transition to parenthood can be especially stressful and studies from the general population have shown that the average couple experience an abrupt decrease in relationship satisfaction during this time (152-154). However, satisfaction trajectories differ between couples. Recent research found that highly satisfied couples experienced less decline in relationship satisfaction over time than couples who were initially distressed (155). Thus, at risk couples need to be identified and offered early intervention to mitigate declines in relationship satisfaction using a strengths-based approach (156). One group at high risk of poor relationship satisfaction is the parents of children with ASD; not only have they reported less satisfaction than their counterparts raising a child without a disability (96, 104, 157-160), they have also reported less satisfaction than parents of children with intellectual disabilities, for example, Down’s syndrome (158, 161). Moreover, they have shown a continued decline in relationship satisfaction through childhood and across their child’s transition to adulthood (162), a time when other parents are typically enjoying an upturn in satisfaction (153, 163).

The demands of raising a child with ASD (in particular, the challenging behaviours) can have a largely negative impact on relationship satisfaction in couples and may lead to a breakdown in communication; negative interactions; conflicts regarding family management and discipline; less quality time together; and a deterioration in partnership and commitment (31, 36, 38, 96, 97, 146, 157, 164, 165). The cumulative stress on the relationship may ultimately lead to its dissolution, and many parents have made this attribution (23, 36). However, the evidence is mixed when it comes to the divorce rate in couples raising a child with ASD; some research suggests it is higher than the general population, while other studies have found no significant difference (166, 167).

Clearly, the demands of raising a child with ASD can place stress on the couple relationship, however, some couples have claimed that the experience ultimately brought them closer (38, 117, 146, 147). One reason for this could be the personal growth and enrichment that some parents experience as a result of caring for a child with ASD; qualities that have benefited them in their couple relationship. Another explanation could be the unity brought about by shared experiences and common goals (38, 106, 113, 117, 146, 147). Studies have shown that many parents believe in the need to work in partnership to effectively manage the challenges of raising a child with ASD, and this requires coordinated parenting, healthy communication and a commitment to their relationship (117, 132, 147). There is emerging evidence that a strong co-parenting alliance improves relationship satisfaction (131).

1.2 Theoretical frameworks

1.2.1 Family systems theories

This thesis will be underpinned by family systems theories, which regard the family as an organised whole made up of interdependent members and subsystems (168). Accordingly, change in one individual can have ripple effects through the family (168, 169). Family systems theories provide a multidimensional framework capturing the complex processes of family adjustment in which individual, family and extra-familial factors are examined, and in doing so, a child with ASD is considered in regard to their environment and decentralised as ‘the problem’ (170, 171).

Family systems theories regard the couple relationship as the foundation of family functioning and, hence, a vital area of child development research (168). The couple relationship reciprocally impacts on the child through the parent-child triad and the parenting system in complex ways (169).

Family systems theories are based on several principles applicable to the study of families with a child with ASD, which have guided the development of this research:

- Families are considered hierarchical; not only can they be broken down into smaller systems, they are embedded in higher level systems, such as extended family, friends, schools, community groups and services that can affect and be affected by a family functioning (169). For example, the relationship in couples raising a child with ASD can be influenced by the availability of formal and informal supports (172).
- Families interact in circular patterns rather than in a cause-effect manner, and as such neither parents, nor the child with ASD, can be attributed fault (173). This means that the couple relationship not only influences the child with ASD; the child reciprocally exerts an influence on relationship quality (75, 173, 174).
- Families evolve and change across time in response to life events (170). A transitional point for any family member can challenge the entire system causing it to reorganise in an attempt to maintain stability (168, 169). This adaptation can be functional or dysfunctional, creating resilience or vulnerability (169). Such a response can be observed in families of children with ASD, as they often restructure around the changing needs of the child (42).
- Individuals are regarded in context of the entire family, and an inclusive approach to intervention and research is promoted (170). This principle questions the credibility of existing research in families of children with ASD, which predominantly captures mothers’ perspectives as representative of family experiences (70, 170, 175).
- Families are considered to be similar in many ways, but are ultimately unique, and, as such, the heterogeneity of families with a child with ASD should be considered (170).

- Recognition of both positive and negative aspects of family functioning is vital to inform holistic, strengths-based approaches (170). There is ample evidence that families experience both challenges and rewards associated with raising a child with ASD and should be acknowledged as having inherent strengths and capacity for change (23, 38).
- Family systems theories support the application of multiple method research designs (170). The benefit of quantitative approaches is that they apply standardised measurements, permit the generalisation of findings and can utilise appropriate statistical procedures to capture the interdependency inherent in family systems. Qualitative designs can supplement this by capturing the subjective experiences and complex patterns within families.

1.2.2 Family resilience frameworks

Family resilience frameworks (145, 176) are grounded in a systemic orientation, looking beyond the concept of individual resilience to focus on risk and resilience in the family as a functional unit. It assumes that raising a child with ASD can impact on the whole family with the potential of disrupting functioning, yet, families are capable of recovery and growth as a result. Despite the documented challenges of raising a child with ASD, there are many reports of families tapping into strengths and finding their own solutions to challenges resulting in positive adaptation (113, 143).

The family resilience framework identifies key family processes believed to reduce vulnerability and foster empowerment in challenging situations. These key processes have been synthesised into three domains of family functioning:

1. Family belief systems – A family’s appraisal of a situation and the way it is managed is directed by shared beliefs. These shared beliefs help family members to make meaning of adversity, facilitate a positive outlook and offer spiritual moorings.
2. Family organisational patterns – Families organise themselves in various ways in preparation for a challenge. Resilience is fostered when a family has a flexible structure, connectedness, and social and economic resources.

3. Communication/problem solving processes – Resilient families communicate effectively to bring clarity to adverse situations, encourage open emotional expression and problem solve collaboratively.

Family resilience frameworks have been chosen to guide this thesis for a number of reasons. Firstly, they posit that families have inherent strengths, and focus on successes rather than failures, thereby removing blame. Secondly, they assume that families are heterogeneous and that no single model fits all; families should be considered in context of their unique values, structure, resources and life challenges. Thirdly, family functioning is considered to change over time as challenges unfold and families evolve across the life cycle. ASD is a life-long condition of unknown aetiology and family resilience frameworks refocus from causes and cures to promoting family resourcefulness and confidence in managing future challenges.

1.2.3 Strengths-based perspective

This thesis has been guided by a strengths-based approach (177), which provides a contrast against the problem-focused frameworks that commonly steer research exploring relationships in couples with a child with ASD. Such research emphasises negative outcomes, such as poor relationship satisfaction, marital conflict and divorce (104, 166), and overlooks the capacity of couples to display positive adaptation despite challenging circumstances (178, 179). Conversely, a strengths-based perspective attempts to understand individuals and families in terms of their strengths; by promoting these, people can discover their own solutions, heal and change (177, 178, 180). Importantly, this perspective does not negate family challenges but acknowledges them as vehicles for testing family capacities and reaffirming human connections (181). This approach supports the importance of investigating how couples raising a child with ASD have managed challenges, the resources they have utilised, the useful parts of their struggle and the constructive learning experience restore hope and highlight new possibilities (177).

1.2.4 Systemic-transactional model

The systemic-transactional model (STM; 149, 182, 183) describes stress and coping in couples beyond traditional models of interpersonal communication and social support. It posits that couples share stress experiences and this process triggers a joint coping response (dyadic coping). The engagement of both partners in this process can reduce stress, increase relationship satisfaction and personal wellbeing.

Dyadic coping can be categorised into four types (182). The first three listed describe positive forms of coping:

1. *Supportive* dyadic coping – occurs when one partner provides support to the other to help them adapt to a stressful situation without taking over the coping efforts. It has the secondary goal of reducing the supporting partner's own stress and maintaining the wellbeing of the relationship because unresolved or poorly managed stress in one partner inevitably impacts on the other. Strategies can be either practical or emotion-focused, such as giving practical advice; expressing love, empathy, solidarity or validation; or helping with relaxation.
2. *Delegated* dyadic coping – occurs when one partner explicitly asks the other to take over their responsibilities to reduce their personal experiences of stress. These consist primarily of problem-oriented strategies in a practical context. For example, a mother might ask her partner to take their child to an appointment that she usually attends.
3. *Common* dyadic coping – a joint coping process in which both partners work together to manage a stress event that affects both of them directly. Strategies can be problem- or emotion-oriented; for example, sharing parenting tasks, coordinated problem solving, seeking information together, relaxing together or mutual sharing of emotions. Common dyadic coping instils a feeling of togetherness and mutual solidarity.
4. *Negative* dyadic coping – describes unhelpful coping strategies, such as hostility, ambivalence and insincerity.

The application of the systemic-transactional model of dyadic stress and coping to this thesis is supported by the highly valued role of partner support for couples raising a child with ASD, and the importance of identifying coping resources intrinsic to relationships that can enhance the positive adaptation of couples.

The frameworks chosen for this thesis complement each other by taking into account the contexts in which a child with ASD lives, and the transactional relationships that exist within families. Furthermore, they acknowledge family strengths and the potential for positive outcomes.

1.3 Research significance

Due to the increasing prevalence, complexity and lifelong course of ASD, there is a call for a systemic approach to ensure caregivers receive the support they need to nurture their child with ASD and achieve the best outcomes possible (33, 40, 184). Family systems theorists have long emphasised the couple relationship as the nucleus around which the family functions and its pivotal role in creating a positive family environment (168). Thus, a healthy, satisfying couple relationship may be a protective factor for families managing the pervasive and enduring challenges associated with raising one of more children with ASD (185, 186). Focusing purely on children with ASD is incomplete, since the couple relationship is overlooked as the key element in the family system (187).

The quality of the couple relationship can influence personal wellbeing, cross-sectionally and longitudinally (188). Relationship dissatisfaction has been strongly associated with emotional distress and increases the likelihood of already vulnerable individuals developing or maintaining mental health problems (189). Conversely, a satisfying relationship has been shown to moderate the adverse effects of various types of emotional strain (190). For example, one study showed that couples with trajectories of middle and high levels of relationship happiness showed a decrease in depressive symptoms, whereas those with low relationship happiness did not (191). Couple therapy has also been successfully applied in the treatment of depression, anxiety and other mental health conditions (189, 192). This finding is highly relevant to couples raising a child with ASD, as they commonly experience greater stress and decreased psychological wellbeing when compared to parents raising children without a disability (64, 193). Furthermore, there is evidence of complex associations between child challenging behaviours, parent stress, wellbeing and relationship satisfaction in parents of children with ASD (76, 89, 162, 185).

In general, the quality of the couple relationship can influence child development and, therefore, outcomes in children with ASD may well be improved by strengthening this relationship. For example, it is well established that couple conflict is associated with negative parenting practices and is a primary risk factor for child adjustment problems, especially behavioural challenges (194-197). Conversely, there is convincing evidence that positive couple interactions, constructive conflict strategies and conflict resolution can improve parent-child relations, and enhance child wellbeing, emotional security and prosocial behaviours (197-200).

Therapeutic outcomes in children with ASD may also be influenced by the couple relationship. This is because “Parents serve as the gatekeepers to their children’s access to services” (37, p. 58) and successful implementation of therapy is influenced by parental coping (55, 61, 92). Strengthening the couple relationship may provide additional coping resources for caregivers and provide the critical foundations for long-term therapeutic caregiving.

It is clearly evident that raising a child with ASD can have a negative impact on caregivers. Therefore, it is essential to identify and strengthen protective factors that can mitigate negative outcomes (201). As outlined above, satisfaction in the couple relationship may be a protective factor and has the additional benefit of being amenable to change (187, 202, 203). Despite this, few studies have explored relationship satisfaction in couples raising a child with ASD, and even fewer have done so from a strengths-based perspective. Couples who report having a satisfying relationship with their partner are an important, yet overlooked, source of first-hand information from which much can be learned if family-centred ASD interventions are to be meaningful and effective.

1.4 Overall aim

The overarching aim of this thesis was to explore the experiences of relationship satisfaction in couples raising a child with ASD and identify factors important in its maintenance.

1.5 Thesis structure

This thesis consists of two traditional chapters; Chapter 1 Introduction and Chapter 8 Discussion and conclusion: Mapping the future. These chapters bookend the content of the thesis, which comprises six individual studies, presented in the form of peer-reviewed journal manuscripts. Chapters 2, 3 and 4 set the scene for the thesis and confirm research needs. They identify gaps and areas of unchartered territory in ASD research, which guide the development of studies in Chapters 5, 6 and 7. References are included at the end of each chapter. Figure 1-1 provides an overview of the thesis structure and the chapters and manuscripts therein.

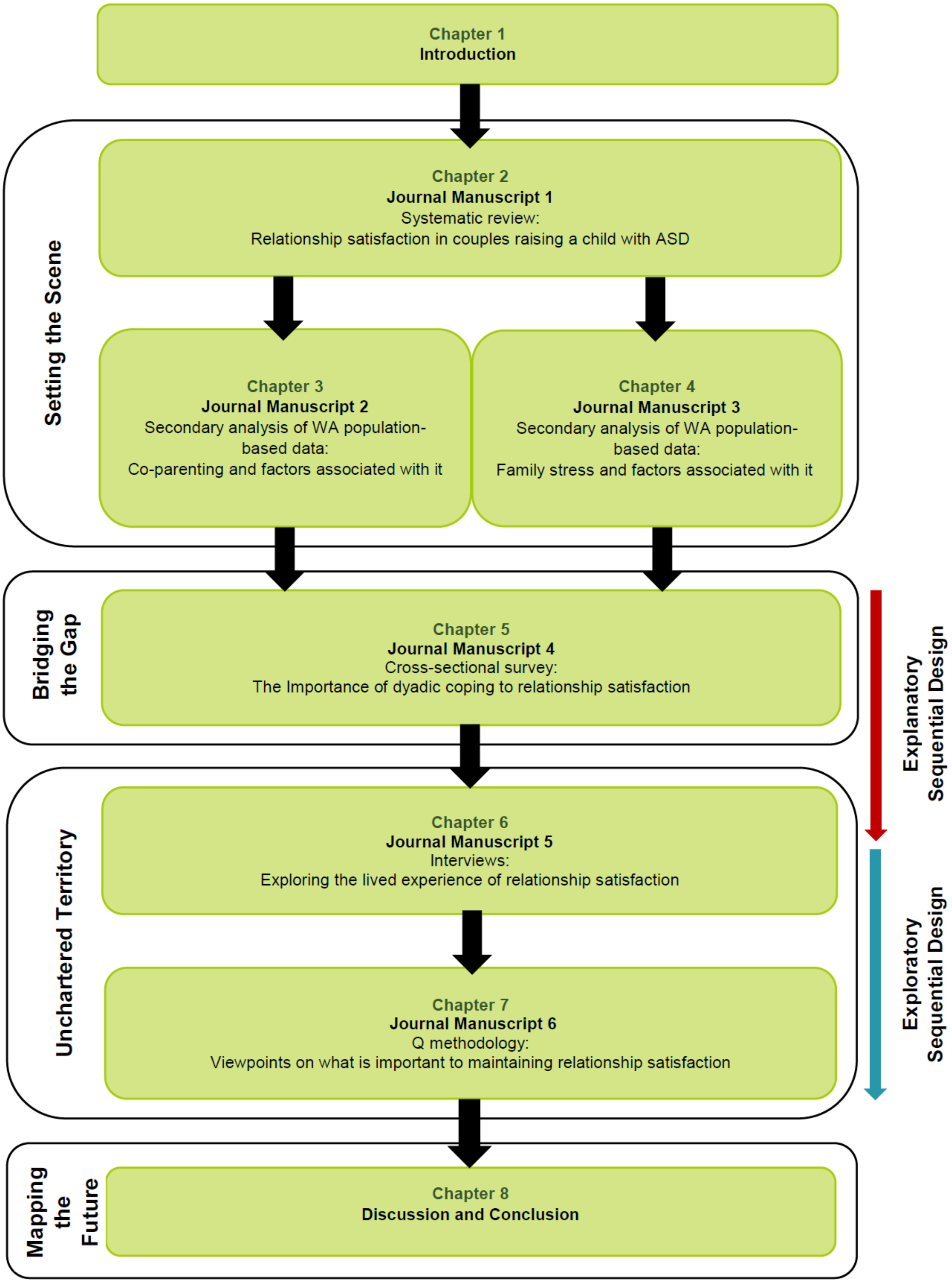

Figure 1-1. Overview of thesis structure.

1.5.1 Setting the scene

Chapter 2 comprises a systematic review of the literature to accurately and reliably summarise existing evidence and justify the development of new research (204, 205). The results are discussed in detail in Chapter 2, addressing the following research objectives: 1) To compare relationship satisfaction in couples with and without a child with ASD; and 2) To determine factors associated with relationship satisfaction in couples with a child with ASD.

Chapter 3 and 4 constitute studies carried out to ascertain the relevance of the systematic review findings to a local population of families with a child with ASD. Cross-sectional data containing information about the effects of raising a child with ASD on the partner/co-parent relationship and family stress were obtained from a previous Western Australian population-based study. Chapter 3 investigates the co-parenting experiences and the factors associated with a negative co-parenting alliance. Chapter 4 explores stress in families with a child with ASD and the factors associated with severe stress levels.

1.5.2 Bridging the gap

Chapter 5 bridges the key gaps that were revealed while *setting the scene* of the thesis research. It comprises a cross-sectional study investigating the levels of relationship satisfaction in couples with a child with ASD and factors associated with a satisfying relationship. Results are discussed with regards to two key factors; dyadic coping and parental stress.

1.5.3 Unchartered territory

Chapter 6 comprises a phenomenological study to explore, in depth, the lived experience of relationship satisfaction through couple interviews in a purposely recruited sample. It progresses from Chapter 5 using an explanatory sequential design, whereby the cross-sectional survey findings are used to inform the development of the interview questions in an attempt to give deeper meaning to the findings. Additionally, the survey results are used to purposively screen interviewees.

Chapter 7 describes a study that applies Q-methodology to identify characteristics of parents raising a child with ASD that share common views with regards to the strategies important to maintaining relationship satisfaction. The progression of Chapter 6 to Chapter 7 is consistent with an exploratory sequential design; the interview data were used as a concourse from which the factors for maintaining relationship satisfaction were derived and converted to statements for sorting in the Q-activity.

1.5.4 Mapping the future

The final chapter of the thesis synthesises the research findings and provides a theoretical model to map future work with families of children with ASD. Research outcomes are discussed with regards to strengths and limitations, and recommendations for future research and clinical practice are outlined.

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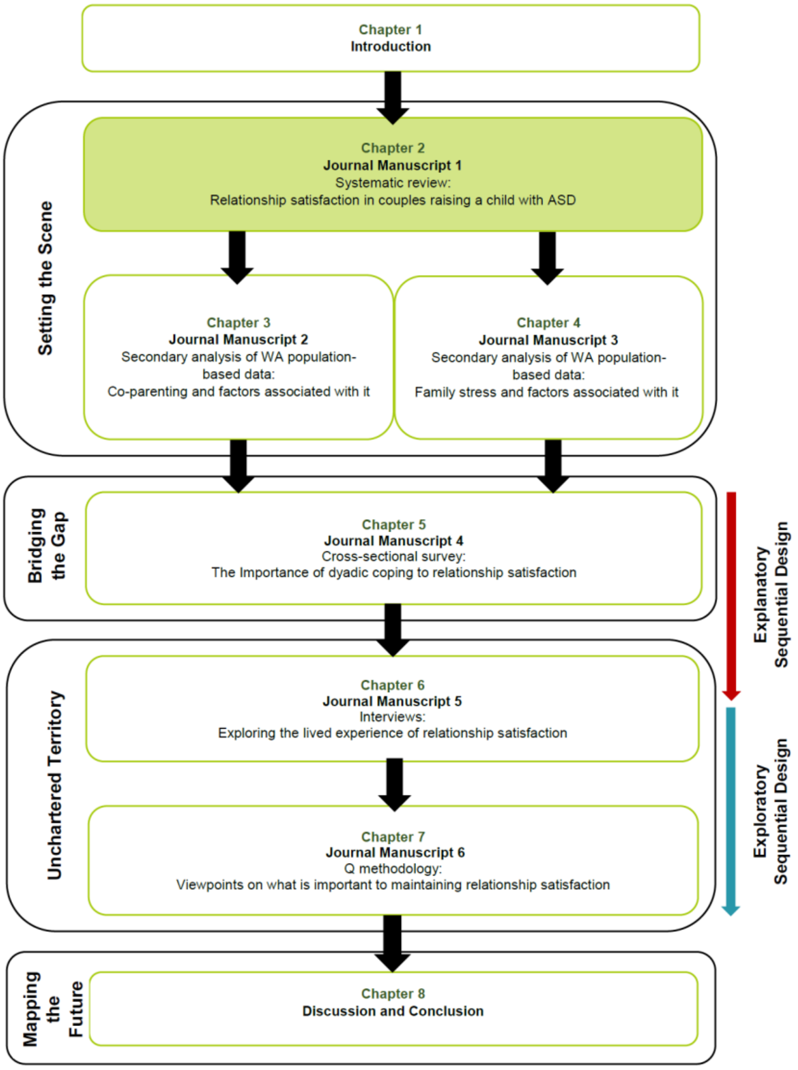
Chapter 2 Systematic review

Chapter 2 comprises the first of three chapters that constitute *setting the scene* for the thesis research. It details a systematic review of research literature conducted to compare relationship satisfaction in couples with and without a child with ASD and to identify factors associated with relationship satisfaction in couples raising a child with ASD.



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Relationship satisfaction in couples raising a child with autism spectrum disorder: A systematic review of the literature

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2.1 Abstract

Background: Couples raising a child with autism spectrum disorder (ASD) face challenges that may impact on their relationship. The purpose of this review was to compare relationship satisfaction in couples raising children with and without ASD and to identify factors associated with satisfaction in couples with a child with ASD.

Methods: Thirteen databases were searched and studies were systematically screened against predetermined inclusion criteria. Twenty six articles, ranging from good to strong methodological quality, met the criteria for inclusion. Of these, seven were included in a meta-analysis comparing relationship satisfaction in couples raising a child with ASD with couples raising children without disabilities.

Results: The meta-analysis showed that couples raising a child with ASD were found to experience less relationship satisfaction than couples raising a child without a disability (Hedges's $g = 0.41$, $p < 0.001$); however, evidence from the narrative synthesis was mixed when compared with couples raising children with other disabilities. The most consistent evidence implicated challenging child behaviours, parental stress and poor psychological wellbeing as risk factors, and positive cognitive appraisal and social support as protective factors.

Conclusion: Findings demonstrate that couples raising a child with ASD would benefit from support to assist them in maintaining satisfaction in their relationship with their partner. However, further studies are needed to gain a greater understanding of the risk and protective factors and how these co-vary with relationship satisfaction over time. A theoretical framework has been developed to scaffold future research.

Keywords: appraisal, challenging behaviours, parent stress, psychological wellbeing, social support

2.2 Introduction

Autism spectrum disorder (ASD) is a life-long neurodevelopmental condition characterised by impairments in social communication and interaction, and the presence of restricted, repetitive patterns of behaviour, interests or activities (1). These characteristics and associated behaviours may create multiple challenges for all family members (2, 3). For parents, the challenges of caring for a child with ASD may impact on their relationship with their partner, lowering relationship satisfaction (4-6). However, the impact on relationship satisfaction may not be entirely negative as couples adapt differently in response to a child having a disability (7).

Relationship satisfaction is conceptualised as both an outcome and an interpersonal process in the literature. Some researchers define it as the subjective, global appraisal of a romantic relationship (8-10); while others consider it to be a pattern of interactions (11). Operationally, some researchers have synthesised these approaches often blurring any distinction between the two (10, 11). This conceptual ambiguity has resulted in the use of interchangeable terms such as relationship/marital satisfaction, adjustment, quality and happiness (12). The result has been a wide breadth of research across clinical and non-clinical populations that provides superficial insight, rather than extending upon existing knowledge (11, 13).

The transition to parenthood can accompany decreases in relationship satisfaction for many couples, even in the absence of having a child with a disability (14). However, some studies suggest that couples raising a child with ASD may experience lower levels of relationship satisfaction when compared with both couples who do not have a child with ASD (5, 6, 15-17) and couples raising a child with disabilities other than ASD (16, 18, 19). Furthermore, couples raising an adolescent or adult with ASD (mean age 20.18 ±67.63) showed a decline in relationship satisfaction over a seven year period (20), the same period in which couples with a child without a disability are showing increased satisfaction (21). Variability in this decline was significantly associated with changes in behaviour in the grown child with ASD (20). For couples raising a child with ASD, there are transitional periods that may be especially challenging, such as the initial diagnosis, transition to school and the transition to adulthood (22). Individuals with ASD often continue to have high caregiving needs into adulthood, a time when their peers without ASD are reaching independence and moving out of home (20, 22-24).

A number of factors have been implicated in the experiences of relationship satisfaction in couples raising a child with ASD. Empirical evidence has mostly failed to support a direct association between the severity of ASD symptoms and relationship satisfaction or relationship dissolution (5, 25-30). Little research has been conducted into the impact of comorbidities, despite the high prevalence of additional conditions, such as intellectual disability (1), ADHD, anxiety, conduct disorders (31, 32), seizures and sleep dysfunction (33). An exception is the investigation of challenging behaviours, which commonly present with ASD, regardless of the severity of core ASD symptoms (5, 34). Not only are they prevalent, but challenging behaviours persist well into the child's adolescence and adulthood, despite evidence that ASD symptoms do abate over time (24). The association between challenging behaviours and relationship satisfaction in couples with children with, and without, ASD has been consistently demonstrated (35-39). Furthermore, a seven year longitudinal study, which sampled mothers of adolescent and adult children, found that fluctuations in the grown child's behaviour co-varied with relationship satisfaction over time, while no such relationship was found for ASD severity (20). The findings suggest that the need to manage challenging behaviours may be a more salient predictor of relationship outcomes than ASD severity.

The caregiving demands associated with raising a child with ASD can generate stress in parents (5, 40-43). High levels of stress have been associated with low relationship satisfaction in parents of a child with ASD (27, 35, 44, 45). Stressors include the severity of ASD symptoms and associated challenging behaviours (5, 46-48), time demands for care and therapy (49), sacrifices to own life and needs (47, 50), stigma (18); and reduced social support (27, 51). However, not all sources of stress relate directly to parenting a child with ASD (52-54). Furthermore, consideration should be given to the impact of the accumulation of everyday stressors, as one study found that a decrease in pile-up of family demands predicted an increase in relationship adjustment over 12 months (45). Stressful events can impact on the couple's relationship by increasing negative couple interactions and decreasing mutual coping efforts, even in the absence of having a child with ASD (55-57).

Another factor implicated in relationship satisfaction in couples raising a child with ASD is the psychological wellbeing of the parents (35, 40, 58). There is a high prevalence of mental health conditions in parents of children with ASD (43, 51, 59, 60). While psychological wellbeing can be affected by the stressful demands of raising a child with ASD (47), it is important to recognise the predisposition of relatives to mental health disorders and the broader autism phenotype (61-63), which may compound their challenges and affect their ability to cope.

A number of resilience factors have been identified in association with relationship satisfaction in couples raising a child with ASD. Resilience is the ability to withstand disruptive life challenges and emerge from such experiences stronger and more resourceful in managing future challenges (64). This may be achieved when couples make meaning out of adversity, retain a positive outlook and keep traditions that connect them to the wider community (64). In fact, if an individual perceives a situation as manageable and believe they have adequate resources to cope, a major stressor may not evolve into a crisis (65). Parents of children with ASD who demonstrate these qualities have been shown to experience greater relationship satisfaction (44, 58, 66, 67). Being religious and spiritual have also been positively associated with increased couple satisfaction and inversely associated with relationship conflict in parents of children with disabilities (68).

Family resilience frameworks identify the importance of economic and social resources when dealing with adversity (64). The impact of household socio-economic status (SES) on relationship satisfaction in couples raising a child with ASD is mixed (35, 59). The importance of social support as a positive coping resource for parents with a child with ASD has been consistently recognised in the literature (5, 25, 27, 35, 45, 67, 69). However, parents report that support from family and friends diminishes over time due to having a child with ASD (70). Therefore, the perception of a supportive partner is important (71, 72).

It is unclear what impact, if any, gender has on the experience of relationship satisfaction in couples. A meta-analysis using data from the general population found a small but statistically significant gender difference such that females showed slightly less relationship satisfaction (Hedges's *g* = 0.04). However, moderator analyses indicated that the differences were due to the inclusion of clinical samples, with the non-clinical samples showing no gender differences (73). A small number of studies sampling couples with a child with ASD have demonstrated significant gender differences in relationship satisfaction but the direction of these differences is inconsistent. One study showed that mothers experience less satisfaction (6), while another has shown that the reverse may be true (58). Additionally, evidence suggests that mothers and fathers differ with regards to levels of parenting-related stress (74-76), psychological health (46, 77), positive perceptions (77, 78) and coping responses (17, 76, 79, 80); all of which have been associated with relationship satisfaction (5, 40, 45, 81). Therefore, the relative contribution of risk factors for relationship satisfaction and their interaction effects may differ between genders, regardless of the overall outcomes.

Given the findings from research on the wider population, couple satisfaction has the potential to be a protective factor for families and help them cope with the challenges of raising a child with ASD (82). Furthermore, relationship satisfaction has been shown to impact on the wellbeing of children (83, 84). This highlights the importance of strengthening relationships in couples raising a child with ASD. Current knowledge needs to be extended through well-designed research that captures the complex transactional processes within couples with respect to broader ecological contexts. To facilitate this, the existing research needs to be collated, evaluated and synthesised. A recent scoping review (85) has provided preliminary insight into relationship adjustment, conflict and separation in couples of children and adolescents with ASD; however, the inclusion criteria and outcomes are broad. There remains a need for a systematic approach to reviewing research in this population with the specific outcome of relationship satisfaction. Furthermore, the current review extends upon the findings by proposing a theoretical framework for future research.

Research questions.

This review sought to answer two research questions:

1) Do couples raising a child with ASD experience lower relationship satisfaction when compared with couples raising children without ASD?
2) What are the factors associated with relationship satisfaction in couples raising a child with ASD?

2.3 Method

The PRISMA Statement was used to guide the methodology and reporting of this systematic review. It is comprised of a 27-item checklist developed for the purpose of improving the quality and consistency of systematic review reporting (86).

2.3.1 Eligibility criteria

The PICO Worksheet and Search Strategy Protocol (87) was used to guide a systematic search of the literature and outline study characteristics eligible for inclusion in this review. Criteria for study inclusion included: 1) peer review; 2) publication after 1980, in accordance with the initial inclusion of autism in the Diagnostic and Statistical Manual, third edition (88); and 3) English language (set as an inclusion criterion for screening rather than a search parameter to enable all relevant research to be identified). Literature reviews were initially included for the purpose of screening reference lists; however, these were excluded during the final selection of articles.

The population under study included parents who were raising one or more children with ASD under 18 years of age. The ASD diagnosis could be in accordance with DSM III, III-R, IV or V criteria, to accommodate the diagnostic changes that have occurred with each DSM release. Studies including parents of children with Rett Syndrome were excluded due to its removal from the autism spectrum in the DSM V (89).

The outcome under study was the experience of ‘relationship satisfaction’ to be inclusive of both married couples and the increasing number of couples choosing to cohabit without legal marital status (90). However, due to operational ambiguity, a number of synonymous terms including marital quality, satisfaction, adjustment, happiness and closeness were used in the search (12, 91).

2.3.2 Information sources

An electronic search was conducted in September 2015 to identify articles meeting the inclusion criteria. Thirteen databases were searched: CINAHL, PsycINFO, Scopus, Medline, Embase, Informit, Proquest, Sage Journals, AMED, Pubmed, OT Seeker, Google Scholar as well as the local University Library Catalogue. Search terms were identified from relevant literature then refined using database indexing. Relevant MeSH terms and subject headings included parents, spouses, caregivers, marriage, marital relations and pervasive developmental disorders. These were combined with free text terms and Boolean operators to develop a final search phrase. Three databases required a modified search phrase due to character limits or the use of a different search protocol. The search strategy for each database is presented in the electronic supplementary material 1.

2.3.3 Study selection

A checklist based on the selection criteria was used to select articles for inclusion at title, abstract and full text level. Retrieved titles were tabulated against predetermined inclusion criteria consistent with PICO. Titles meeting the criteria or judged as having insufficient information proceeded to an abstract screen. Ten percent of the abstracts screened were randomly selected for the assessment of inter-rater reliability by an independent researcher. Researcher agreement for inclusion was 100%. Full texts were then retrieved and screened and studies meeting all criteria were included in the review.

2.3.4 Data extraction

Data extraction was guided by the Cochrane for Systematic Reviews section 7.3 (92). A table was developed according to predefined guidelines to ensure consistent data extraction. Headings included: citation, publication status, source, country of origin, level of evidence, study design, research question/aim, outcome measures, study population, comparison group, analysis, outcomes, recommendations and study limitations.

2.3.5 Methodological quality

Each study was classified using a four-level hierarchy of evidence developed by the Australian Health and Medical Council (NHMRC; 93). Methodological evaluation was conducted using QualSyst (94). This tool is comprised of two scoring systems designed to critically appraise both quantitative and qualitative study designs. The scoring system is based on a 14 point checklist. Scores of >80% ranked as strong, 70-80 % as good, 50-69% as adequate. Scores below 50% were deemed poor and articles with such scores were excluded from the review.

2.3.6 Data analysis

A meta-analysis was conducted using the software program Comprehensive Meta-Analysis (95) to compare the levels of relationship satisfaction in couples raising a child with ASD with couples raising children without a disability. A random effects model was used as the study populations and methodologies were heterogeneous (96). Effect sizes were calculated using Hedges's g with effect size calculations being interpreted following Cohen's d convention: $d \leq 0.2$ as small; $d \geq 0.5$ as moderate; and $d \leq 0.8$ as large (97). The results were integrated with findings from additional studies using a narrative approach to explore, interpret and synthesise findings.

2.3.7 Risk of bias

Each study was individually assessed for the risk of selection, misclassification and confounding bias during the methodological evaluation using QualSyst (94) and reported in the results section. To reduce the impact of bias at the review level, a large number of databases were searched, a strict and consistent review protocol using pre-developed checklists was adhered to and interrater reliability was calculated. Publication bias was examined during the meta-analysis using the funnel plot and the classic fail-safe N test (96).

2.4 Results

2.4.1 Study selection

A total of 26 studies met the eligibility criteria for synthesis, of which 25 were quantitative and one was mixed method design. Of these, seven studies provided adequate data for inclusion in the meta-analysis. If the article was deemed suitable but provided insufficient data, attempts were made to contact the authors for further information. Figure 2-1 outlines the study selection process.

2.4.2 Study characteristics

Articles spanned 32 years of research from 1983 to 2015. Fourteen (54%) were published in the preceding 5 years (2010 - 2015). Evidence qualified for either NHMRC (98) level III (*n*=3) or IV (*n*=23). Study characteristics are described in Table 2-1.

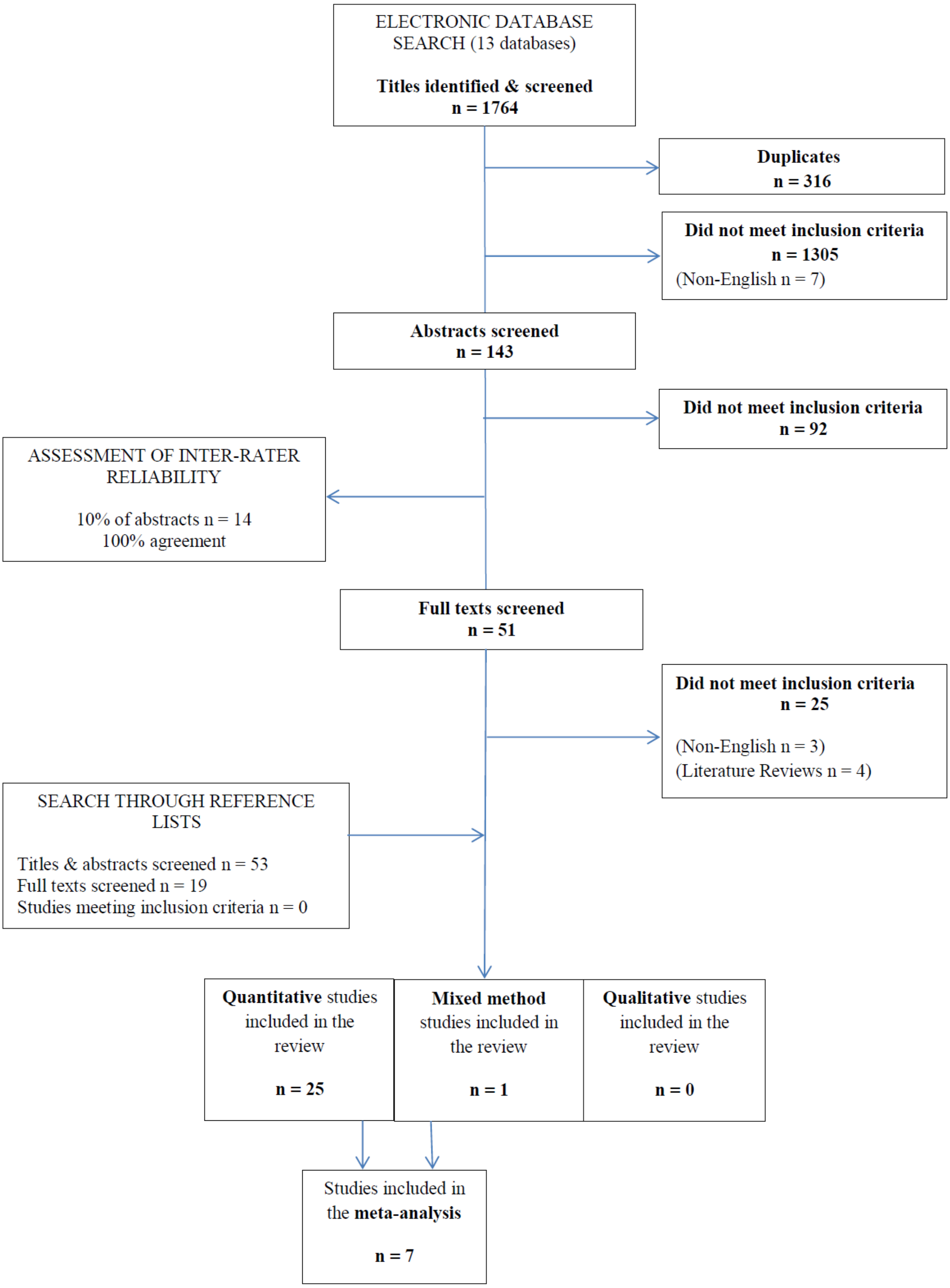

Figure 2-1. Flow chart of the study selection process.

Table 2-1. Summary of study characteristics and findings.

Author (date) Country Study design	Participant group: (n) Child diagnosis Child age: mean ±SD	Comparison group: (n) Child diagnosis Child age: mean ±SD	Outcome Measure	Levels of relationship satisfaction	Factors positively associated with relationship satisfaction	Factors negatively associated with relationship satisfaction	Non-significant findings
Benson & Kersh (2011) USA Longitudinal	96 mothers ASD 8.7±1.5 years	No comparison	DAS	26% scored in the "distressed" range at baseline Mean relationship adjustment increased over 2 years (p<.001)	Family SES (p<.01) Social support (p<.05) Prosocial behaviours (p<.01) Parenting efficacy (p<.001) Parent psychological wellbeing (p<.001) *(Cross-sectional)* Relationship adjustment predicted well-being after 2 years (p<.01) *(Longitudinal)*	Stressful life events (p<.01) Challenging behaviours (p<.01). Parent depressed mood (p<.05) *(Cross-sectional)* Relationship adjustment predicted depressed mood after 2 years (p<.05) *(Longitudinal)*	Relationship adjustment did not predict parenting efficacy over 2 years *(Longitudinal)*
Brobst et al (2009) USA Comparative Cross-sectional	50 parents (25 couples) ASD 6.6±2.7 years	40 parents (20 couples) No disability 6.8±3.2 years	RAS	Lower than comparison (p<.05) No gender difference	Spousal support (p<.01) Maternal commitment (p<.01) *(Bivariate)* Respect towards partner (p<.01) *(Multivariate)*	Number of challenging behaviours (fathers) (p<.01) Maternal parenting stress (p<.05) *(Bivariate)*	Intensity of challenging behaviours Number of challenging behaviours (mothers) ASD severity Paternal parenting stress Paternal commitment *(Bivariate)* Total parenting stress Level of special need Total social support *(Multivariate)*

Author (date) Country Study design	**Participant group: (n) Child diagnosis Child age:** mean ±SD	**Comparison group: (n) Child diagnosis Child age:** mean ±SD	**Outcome Measure**	**Levels of relationship satisfaction**	**Factors positively associated with relationship satisfaction**	**Factors negatively associated with relationship satisfaction**	**Non-significant findings**
Doron & Sharabany (2013) Israel Cross-sectional	55 parents ASD Age range: 4-17 years	No comparison	Modified from 'Yakutiel' (1995)	-	Social-familial support & satisfaction with it (p<.05)	Child age (p<.01)	ASD severity Professional support
Dunn et al (2001) USA Cross-sectional	58 parents ASD 7.5±3.3 years	No comparison	PSI - Spousal relationship subscale	-	Escape –avoidance coping (p= .00) [a] Decreased use of positive reappraisal (p= .00) [a] Decreased seeking of social support (p= .00) [a]	-	-
Ekas et al (2015) USA Cross-sectional	134 parents (67 couples) ASD 6.4±2.2 years	No comparison	CSI	No gender difference	Benefit finding (p<.001) Optimism (p<.05) Instrumental support (p<.05) Emotional support (p<.001) Partner support (p<.001)	-	Child gender Parent income Parent education Marital status Number of children with ASD Child age at diagnosis
Fisman et al (1989) Canada Comparative Cross-sectional	57 parents Autism 9.3±4.2 years	60 parents DS 9.1±4.2 years 121 parents No disability	WIQ	Mothers lower than comparison on identity & compatibility No significant difference for fathers	Parent education Additional children in the home (fathers)	Maternal depression (p<.001) Paternal depression (p<.00) Paternal stress (p<.05)	Parent age Income Employment status

Author (date) Country Study design	Participant group: (n) Child diagnosis Child age: mean ±SD	Comparison group: (n) Child diagnosis Child age: mean ±SD	Outcome Measure	Levels of relationship satisfaction	Factors positively associated with relationship satisfaction	Factors negatively associated with relationship satisfaction	Non-significant findings
		7.6±4.4 years		No gender difference			
Gau et al (2012) Taiwan Comparative Cross-sectional	302 parents (151 couples) Autism 7.8±2.9 years	226 parents No disability 7.9±2.9 years	DAS	Both parents lower than comparison in dyadic consensus Mothers lower than comparison in dyadic satisfaction & affection expression Mothers lower than fathers in dyadic satisfaction & affection expression	-	-	-
Higgins et al (2005) Australia Comparative Cross-sectional	52 parents ASD 10.8 years	Normative data	QMI	Lower than normative data in mean marital happiness (6.1±2.3 Vs 7.7±1.8)	-	-	-
Hock & Ahmedani (2012) USA Comparative Cross-sectional	1,427 parents ASD Age range: 2-17 years	80,496 parents No disability Age range: 2-17 years	Single survey question	Lower than comparison (p<.05)	-	ASD severity (p<.05).	-

Author (date) Country Study design	**Participant group: (n) Child diagnosis Child age:** mean ±SD	**Comparison group: (n) Child diagnosis Child age:** mean ±SD	**Outcome Measure**	**Levels of relationship satisfaction**	**Factors positively associated with relationship satisfaction**	**Factors negatively associated with relationship satisfaction**	**Non-significant findings**
Kaniel & Siman-Tov (2011) Israel Cross-sectional	176 parents (88 couples) ASD 10.3± 3.1 years	No comparison	QMS	Mothers higher than fathers	Maternal sense of coherence (p<.001) Maternal mental health (p<.01) Paternal mental health (p<.001)	Paternal appraisal of threat (p<.001) Maternal appraisal of threat (p<.05)	Paternal sense of coherence Appraisal of challenge
Koegel et al (1983) USA Comparative Cross-sectional	44 parents (22 couples) Autism 5.75 years	Normative data	DAS	Similar levels of happiness to normative married group (mean=119.7 Vs 114.8)	-	-	-
Kwok et al (2014) China Comparative Cross-sectional	73 mothers ASD Age range: 2-7 years	87 mothers ID Age range: 2-7 years	KMSS	Lower than comparison (p<.01)	-	Caregiving burden (p<.001) Time-dependence burden (p<.05) Physical burden (p<.001) Social burden (p<.001) Emotional burden (p<.001) Developmental burden (p<.001) Perceived stigma (p<.01)	Maternal education Maternal age Child gender Child age
Lee (2009) USA Comparative	48 parents (24 couples) HFASD Age range:	26 parents (13 couples) No disability Age range:	DAS	Lower than comparison in total score (p<.05) and	-	-	-

Author (date) Country Study design	**Participant group: (n) Child diagnosis Child age:** mean ±SD	**Comparison group: (n) Child diagnosis Child age:** mean ±SD	**Outcome Measure**	**Levels of relationship satisfaction**	**Factors positively associated with relationship satisfaction**	**Factors negatively associated with relationship satisfaction**	**Non-significant findings**
Cross-sectional	6-13years	6-13years		'general RS' (p<.01) Mothers higher than fathers on 'degree of consensus' (p<.05)			
Lickenbrock et al (2011) USA Longitudinal	49 mothers ASD 10.2± 4.3 years	No comparison	The Small Life Events Scale (30 day diary)	-	Positive affect (p<.01) Positive perceptions of child (p<.10)	Negative affect (p <.05)	Negative perceptions of child
McGrew & Keyes (2014) USA Longitudinal	78 parents *(base-line)* 64 parents *(follow-up)* ASD 4.7± 3.1 years	Normative data	DAS	Mean within distressed range at baseline (104.3) and after 12 months (101.2) No significant change over time	Social support: general (*Change in score over 12 months)*	Pile up demands (p<.05) Negative appraisal (p<.05) *(Change in scores over 12 months)*	Pile up demands Social support: general, provider, autism community Positive appraisal Negative appraisal Problem-focussed coping Emotion-focussed coping Avoidant coping *(Time 1 predictors of time 2 marital burden)* Social support: provider, ASD community Problem-focussed coping

Author (date) Country Study design	**Participant group: (n) Child diagnosis Child age:** mean ±SD	**Comparison group: (n) Child diagnosis Child age:** mean ±SD	**Outcome Measure**	**Levels of relationship satisfaction**	**Factors positively associated with relationship satisfaction**	**Factors negatively associated with relationship satisfaction**	**Non-significant findings**
							Avoidant coping Positive appraisal *(Change in scores over 12 months)*
Ramisch et al (2013) USA Mixed	22 parents (11 couples) ASD 7.5±2.4 years	20 parents (10 couples) No disability	KMSS Focal question	No significant difference	Communication (mothers and fathers) Working out differences (fathers) Love for each other (fathers) Common ideas about marriage (mothers and fathers) Couple time (mothers) Independence (mothers) Promote positive qualities (mothers) *(Qualitative)* Communication (mothers and fathers p<.05) Promote positive qualities (mothers p<.05)	-	ASD severity
Rodrigue et al (1990) Comparative Cross-sectional	20 mothers Autism 10.7	20 mothers DS 11.9 years 20 mothers	MAS	Lower than comparison (p<.01)	Male child	Female child	-

Author (date) Country Study design	Participant group: (n) Child diagnosis Child age: mean ±SD	Comparison group: (n) Child diagnosis Child age: mean ±SD	Outcome Measure	Levels of relationship satisfaction	Factors positively associated with relationship satisfaction	Factors negatively associated with relationship satisfaction	Non-significant findings
		No disability 3.8 years					
Rodrigue et al (1992) Comparative Cross-sectional	20 fathers Autism 10.8±4.8 years	20 fathers DS 11.9± 4.5 years 20 fathers No disability 3.8±1.9 years	MAS	No significant difference	-	-	-
Santamaria et al (2012) Italy Comparative Cross-sectional	36 parents ASD	24 parents DS 40 parents No disability	DAS	No significant difference between LFASD and HFASD samples LFASD sample lower than sample without a disability on total DAS (p<.009), dyadic consensus (p<.03) and couple satisfaction (p<.0001) LFASD sample lower than DS sample for total DAS (p<.04) and	-	Attributions of: Locus (LFASD p<.04; HFASD p<.001) Stability (LFASD p<.02; HFASD p<.001) Globality (LFASD p<.02; HFASD p<.001) Intention (LFASD p<.00; HFASD p<.001) Motivation (LFASD p<.001; HFASD p<.001) Blame (LFASD p<.001;HFASD p<.001)	-

Author (date) Country Study design	**Participant group: (n) Child diagnosis Child age:** mean ±SD	**Comparison group: (n) Child diagnosis Child age:** mean ±SD	**Outcome Measure**	**Levels of relationship satisfaction**	**Factors positively associated with relationship satisfaction**	**Factors negatively associated with relationship satisfaction**	**Non-significant findings**
				couple satisfaction (p<.008) HFASD sample lower than sample without a disability for couple satisfaction (p<.05) No significant difference between HFASD and DS samples			
Shtayermman (2013) USA Cross-sectional	253 parents ASD	No comparison	ENRICH	-	Parent idealistic distortion (p<.001)	Number of MDD symptoms in parent (p=.001) Number of GAD symptoms in parent (p=.001)	Number of children Parent age Parent education
Sikora et al (2013) USA Cross-sectional	136 families ASD Age range: 2-17.8 years	No comparison	FIQ-R 5th Scale	-	Externalising behaviours (p=.02) [a] Social relationships (p<.0001) [a] Negative feelings about parenting (p<.0001) [a] Impact on siblings (p=.004) [a] Financial impact (p=.009) [a]	Positive feelings about parenting (p<.0001) [a]	Internalising behaviours [a]

Author (date) Country Study design	**Participant group: (n) Child diagnosis Child age:** mean ±SD	**Comparison group: (n) Child diagnosis Child age:** mean ±SD	**Outcome Measure**	**Levels of relationship satisfaction**	**Factors positively associated with relationship satisfaction**	**Factors negatively associated with relationship satisfaction**	**Non-significant findings**
Siman-Tov & Kaniel (2011) Israel Cross-sectional	176 parents (88 couples) ASD 10.3± 3.1 years	No comparison	QMS	-	Maternal sense of coherence (p<.001) Paternal sense of coherence (p<.001)	Maternal internal locus of control (p<.01) Maternal parenting stress (p<.001) Paternal parenting stress (p<.05) ASD severity (fathers p<.01; mothers p<.05)	Social support
Stuart & McGrew (2009) USA Cross-sectional	78 parents ASD 4.8± 3.0 years	No comparison	DAS (reverse scored)	-	Negative appraisal (p<.001)[a] Passive avoidant coping (p= .001)[a] Pile up demands (p<.001)[a]	General social support (p<.001)[a]	ASD severity[a] ASD-specific social support[a]
Tunali & Power (2002) USA Comparative Cross-sectional	29 mothers ASD 9.7±2.4 years	29 mothers No disability 9.1±2.4 years	SMAT	No significant difference	-	-	-
Weitlauf et al (2014) USA Cross-sectional	70 mothers ASD 4.9±1.8 years	No comparison	DAS	-	-	Maternal depressive symptoms (p<.01)	Child age ASD severity Child intelligence Adaptive behaviours Challenging behaviours
Yamada et al (2007)	269 parents Autism	No comparison	IBM	-	Maternal psychological distress (associated	-	-

Author (date) Country Study design	**Participant group: (n) Child diagnosis Child age:** mean ±SD	**Comparison group: (n) Child diagnosis Child age:** mean ±SD	**Outcome Measure**	**Levels of relationship satisfaction**	**Factors positively associated with relationship satisfaction**	**Factors negatively associated with relationship satisfaction**	**Non-significant findings**
Japan Cross-sectional	9.3± 2.5 years Asperger's syndrome 10.3±2.4 years PDD-NOS 9.6±2.6 years				with 'control by spouse') (p<.01)		

Note: ASD = autism spectrum disorder, DAS = Dyadic Adjustment Scale (99) , RAS = Relationship Assessment Scale (100), PSI = Parenting Stress Index (101), CSI = Couple Satisfaction Index (102), DS = Down's syndrome, WIQ = Waring Intimacy Questionnaire (103), QMI = Quality Marriage Index (10), QMS = Quality of Marriage Scale (Olson 87), ID = intellectual disability, KMSS = Kansas Marital Satisfaction Scale (104), HFASD = high functioning autism spectrum disorder, MAS = Marital Adjustment Scale (105), LFASD = low functioning autism spectrum disorder, ENRICH = Evaluating and Nurturing Relationship Issues, Communication, Happiness (Flowers and Olson 93), MDD = major depressive disorder, GAD = generalised anxiety disorder, FIQ-R = Family Impact Questionnaire Revised (106), SMAT = Short Marital Adjustment Test (105), PDD-NOS = pervasive developmental disorder-not otherwise specified, IBM = Intimate Bond Measure (107).

[a] Factors are associated with negative impact on the relationship or relationship burden

2.4.3 Participants

All studies used purposive sampling procedures except for one which used a random digit dialling protocol (108). Across the studies, 3,808 parents of children with ASD (Range: 22 to 1,427) were sampled. Female participants approximated 72% of the sample. The children under study were less than 18 years of age with an ASD diagnosis. Two studies further categorised the children as having high functioning ASD (HFASD) or low functioning ASD (LFASD).

2.4.4 Outcomes

The following outcome terms were used: marital/relationship satisfaction, marital quality, marital adjustment, marital happiness, marital intimacy, marital impact, marital burden, relationship problems and marital distance/closeness. Outcomes measures included: a daily diary (n=1), interview questions (n=2), a single question from a larger study (n=1), a modified questionnaire (n=1), subscales from broader questionnaires (n=2) and self-report relationship satisfaction questionnaires (n=21). The most commonly used validated questionnaire was the Dyadic Adjustment Scale (n=8), but the diverse range included the Quality of Marriage Scale (n=2), Marital Adjustment Scale (n=2), Kansas Marital Satisfaction Scale (n=2), Quality of Marriage Index (n=1), Evaluating and Nurturing Relationship Issues, Communication, Happiness scale (n=1), Intimate Bond Measure (n=1), Relationship Assessment Scale (n= 1), the Waring Intimacy Questionnaire (n=1), Couple Satisfaction Index (n=1) and Short Marital Adjustment Test (n=1).

2.4.5 Risk of bias in individual studies

All but one study (which employed a random dialling protocol) were vulnerable to selection bias due to purposive recruitment strategies. Four employed analyses to attempt to control attrition or non-response bias (28, 45, 66, 67). All studies used self-report measures, potentially introducing social desirability and recall bias, with only a single study minimising the latter through the use of a daily diary (66). Inclusion of observational measures to supplement self-report would strengthen the reliability of data collected. Approximately half of the studies did not detail ASD diagnostic procedures sufficiently to judge the possibility of misclassification. Confounding bias was controlled to varying degrees through the application of multivariate analyses in most studies, with one minimising it through random sampling (108). The mixed method study (26) attempted to reduce interpreter bias in the qualitative component by using concept mapping methodology and hierarchical cluster analysis.

2.4.6 Methodological e valuation

In accordance with the NHMRC hierarchy of evidence (93), three studies met the criteria for level III and the remaining 23 studies were classified as level IV. Methodological quality of studies was assessed using QualSyst (94) and all studies met the minimum requirement of 50% or above for inclusion. Studies ranged in quality from good (n=3) to strong (n=23). Table 2-2 outlines the methodological evaluation of included studies

Table 2-2. Methodological evaluation of included studies.

Article	NHMRC Level of evidence [a]	QualSyst score (%)	Methodological Quality	Justification
Benson & Kersh (2001)	III	22/22 (100%)	Strong	Methods reliable and valid Adequate sample size Controlled for confounding
Brobst et al (2009)	IV	20/22 (91%)	Strong	Inadequate sample size ASD diagnosis not confirmed
Doron & Sharabany (2013)	IV	16/22 (73%)	Good	Partial reporting of variance Inadequate sample size Inadequate reporting of outcome measure Did not control for confounding
Dunn et al (2001)	IV	19/22 (86%)	Strong	Inadequate sample size Inadequate reporting of variance
Ekas et al (2015)	IV	22/22 (100%)	Strong	Methods reliable and valid Adequate sample size Controlled for confounding
Fisman (1989)	IV	20/22 (91%)	Strong	Inadequate sample size Partial reporting of results
Gau et al (2012)	IV	22/22 (100%)	Strong	Methods reliable and valid Adequate sample size Controlled for confounding
Higgins et al (2005)	IV	19/22 (86%)	Strong	Inadequate sample size Partial reporting of sample characteristics Partial reporting of outcome measure
Hock & Ahmedani (2012)	IV	20/22 (91%)	Strong	ASD diagnosis not confirmed Measure not validated (single item question)
Kaniel & Siman-Tov (2011)	IV	20/22 (91%)	Strong	Inadequate reporting of variance
Koegel et al (1983)	IV	17/22 (77%)	Good	Inadequate sample size Partial reporting of analytic methods Partial reporting of results Did not control for confounding
Kwok et al (2014)	IV	22/22 (100%)	Strong	Methods reliable and valid Adequate sample size Controlled for confounding
Lee (2009)	IV	21/22 (100%)	Strong	Inadequate sample size
Lickenbrock et al (2011)	III	21/22 (100%)	Strong	Inadequate sample size

Article	NHMRC Level of evidence [a]	QualSyst score (%)	Methodological Quality	Justification
McGrew & Keyes (2014)	III	22/22 (100%)	Strong	Methods reliable and valid Adequate sample size Controlled for confounding
Ramisch, (2013)	IV	Quantitative 19/22 (86%)	Strong	Inadequate sample size Did not control for confounding
		Qualitative 15/20 (75%)	Good	No reference to theoretical framework Partial reporting of verification procedures Did not report on reflexivity of account
Rodrigue et al (1990)	IV	21/22 (96%)	Strong	Inadequate sample size
Rodrigue et al (1992)	IV	21/22 (96%)	Strong	Inadequate sample size
Santamaria (2012)	IV	16/22 (73%)	Good	Inadequate reporting of recruitment method Inadequate sample size Partial reporting of sample characteristics Did not control for confounding
Shtayermman (2013)	IV	20/22 (91%)	Strong	Partial reporting of sample characteristics Partial reporting of outcome measure
Sikora (2013)	IV	22/22 (100%)	Strong	Methods reliable and valid Adequate sample size Controlled for confounding
Siman-Tov & Kaniel (2011)	IV	20/22 (91%)	Strong	Inadequate reporting of variance
Stuart (2009)	IV	21/22 (96%)	Strong	Partial reporting of analytic methods
Tunali (2002)	IV	20/22 (91%)	Strong	Inadequate sample size Partial reporting of results
Weitlauf (2014)	IV	19/22 (86%)	Strong	Partial reporting of sample characteristics Partial reporting of outcome measure
Yamada (2007)	IV	22/22 (100%)	Strong	Methods reliable and valid Adequate sample size Controlled for confounding

[a] NHMRC Evidence Hierarchy level: I = systematic reviews of level II studies; II = randomised controlled trials; III-1 = pseudorandomised controlled trials; III-2 = comparative studies with concurrent controls (non-randomised, experimental trials, cohort studies, case-control studies, interrupted time series with a control group); III-3 = comparative studies without concurrent controls (historical control studies, two or more single arm studies, interrupted time series without a parallel control group); IV = case series with either post-test or pre-test/post-test outcomes.

2.4.7 Study results

2.4.7.1 Levels of relationship satisfaction: Relationship satisfaction in parents of a child with ASD compared to parents of children without a disability.

Fourteen studies, with methodological quality ranging from good to strong, compared the relationship satisfaction of parents raising a child with ASD with parents raising children without a disability. Of these, seven contained data required for the meta-analysis yielding a total of ten subgroups (three studies reported mothers and fathers separately). Results showed that couples raising a child with ASD experienced, on average, less relationship satisfaction than couples raising children without a disability. A random effects model was used and heterogeneity was confirmed according to the I^2 value of 0.00. There was a low, tending towards moderate, effect size (Hedges's $g = 0.41$ [95% CI: 0.24 to 0.58]). The z-value of 4.74 with corresponding p-value < 0.001 suggests that the difference between groups was significant. Figure 2-2 provides the meta–analysis statistics and forest plot.

A second meta-analysis was run according to subgroups defined by gender. Five studies provided data for fathers, five provided data for mothers and two studies did not provide data according to gender. The effect sizes for mothers and fathers were similar (Hedges's $g = 0.39$ [95% CI: 0.12 – 0.66] and Hedges's $g = 0.30$ [95% CI: 0.02 – 0.59] respectively), both of which reached significance. For the subgroup of parents undefined by gender the effect size was higher, at Hedges's $g = 0.59$ (95% CI: 0.26 – 0.92). Results are shown in Figure 2-3.

Study name	Subgroup within study	Statistics for each study							Sample size	
		Hedges's g	Standard error	Variance	Lower limit	Upper limit	Z-Value	p-Value	ASD-Group	Control-Group
Rodrigue et al. (1992)	Father	0.056	0.310	0.096	-0.551	0.664	0.182	0.856	20	20
Santamaria et al. (2012)	Parents	0.653	0.233	0.055	0.195	1.110	2.795	0.005	36	40
Fisman et al. (1989)	Father	0.408	0.232	0.054	-0.047	0.863	1.756	0.079	27	59
Fisman et al. (1989)	Mother	0.391	0.222	0.049	-0.045	0.826	1.756	0.079	30	62
Brobst et al. (2009)	Father	0.467	0.299	0.089	-0.119	1.053	1.563	0.118	25	20
Brobst et al. (2009)	Mother	0.697	0.304	0.092	0.102	1.293	2.296	0.022	25	20
Lee et al. (2009)	Parents	0.519	0.245	0.060	0.040	0.999	2.122	0.034	48	26
Ramisch et al. (2013)	Father	0.099	0.420	0.176	-0.723	0.922	0.236	0.813	11	10
Ramisch et al. (2013)	Mother	0.700	0.442	0.196	-0.167	1.567	1.582	0.114	10	10
Tunali et al. (2002)	Mother	0.057	0.259	0.067	-0.451	0.565	0.220	0.826	29	29
		0.413	0.087	0.008	0.242	0.584	4.742	0.000		

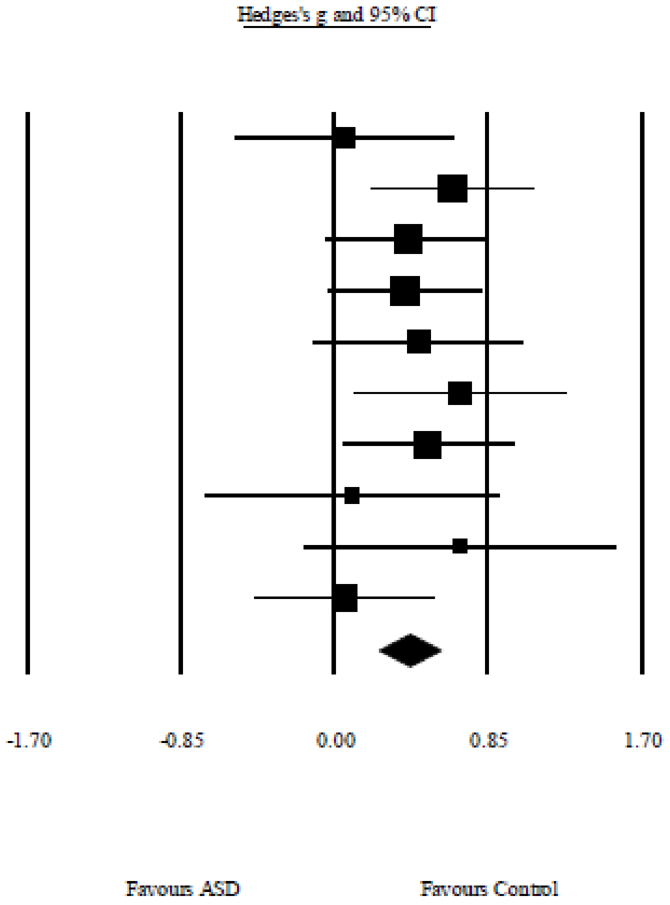

Figure 2-2. Meta-analysis of relationship satisfaction in couples with and without children with ASD.

Group by Subgroup within study	Study name	Subgroup within study	Statistics for each study							Sample size	
			Hedges's g	Standard error	Variance	Lower limit	Upper limit	Z-Value	p-Value	ASD-Group	Control-Group
Father	Rodrigue et al. (1992)	Father	0.056	0.310	0.096	-0.551	0.664	0.182	0.856	20	20
Father	Fisman et al. (1989)	Father	0.408	0.232	0.054	-0.047	0.863	1.756	0.079	27	59
Father	Brobst et al. (2009)	Father	0.467	0.299	0.089	-0.119	1.053	1.563	0.118	25	20
Father	Ramisch et al. (2013)	Father	0.099	0.420	0.176	-0.723	0.922	0.236	0.813	11	10
Father			0.304	0.148	0.022	0.015	0.594	2.060	0.039		
Mother	Fisman et al. (1989)	Mother	0.391	0.222	0.049	-0.045	0.826	1.756	0.079	30	62
Mother	Brobst et al. (2009)	Mother	0.697	0.304	0.092	0.102	1.293	2.296	0.022	25	20
Mother	Ramisch et al. (2013)	Mother	0.700	0.442	0.196	-0.167	1.567	1.582	0.114	10	10
Mother	Tunali et al. (2002)	Mother	0.057	0.259	0.067	-0.451	0.565	0.220	0.826	29	29
Mother			0.389	0.140	0.020	0.115	0.664	2.782	0.005		
Parents	Santamaria et al. (2012)	Parents	0.653	0.233	0.055	0.195	1.110	2.795	0.005	36	40
Parents	Lee et al. (2009)	Parents	0.519	0.245	0.060	0.040	0.999	2.122	0.034	48	26
Parents			0.589	0.169	0.029	0.258	0.920	3.488	0.000		
Overall			0.416	0.101	0.010	0.219	0.614	4.132	0.000		

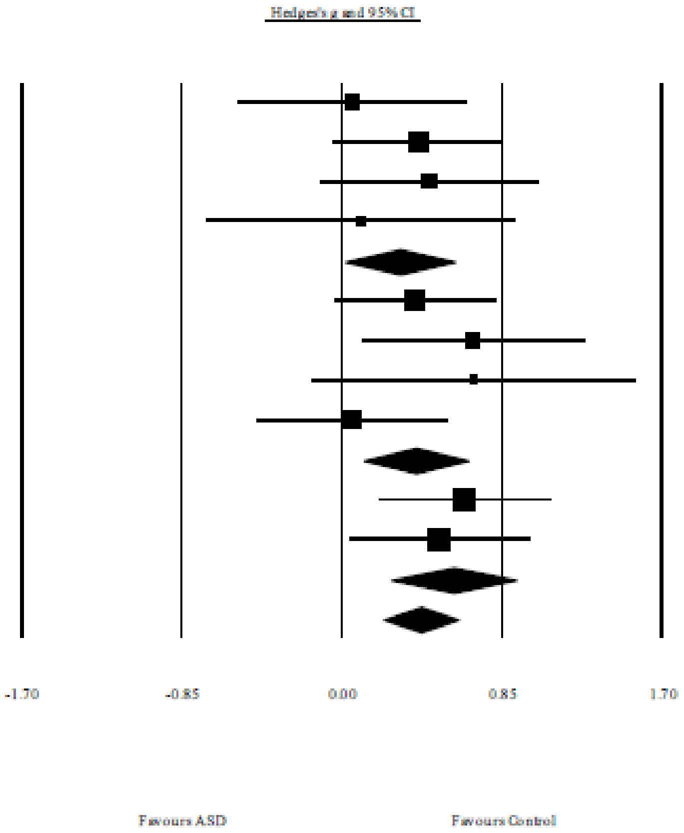

Figure 2-3. Meta-analysis of relationship satisfaction in couples with and without children with ASD: Subgroup analysis by rater.

Publication bias was tested through two analyses, the funnel plot and classic fail-safe N test. The funnel plot demonstrates that studies were distributed symmetrically about the combined effect size (supplementary electronic material 2). The classic fail-safe N test concluded that 45 studies showing no significant difference between groups would need to be included for the combined 2-tailed *p*-value to exceed 0.05. Together these tests show that the current analysis was unlikely to be affected by publication bias.

2.4.7.2 Levels of relationship satisfaction: Relationship satisfaction in parents of children with ASD compared to parents of children with other disabilities.

Five studies compared parents raising a child with ASD with parents raising children with other disabilities. One study showed that mothers raising a child with ASD experienced lower relationship satisfaction than mothers raising a child with an intellectual disability (18), while two studies demonstrated lower relationship satisfaction than mothers of a child with Down’s syndrome (DS; 19, 59). All of these studies were classified as strong quality level IV evidence. A fourth study of good methodological quality found that parents of children with LFASD, but not HFASD, scored lower than couples of children with DS, suggesting that relationship satisfaction may be impacted on by comorbid intellectual disability in the child with ASD (16). In contrast, no significant relationship was found between fathers of children with ASD and DS in two studies, a result which may be explained by gender differences or a type II error resulting from low sample sizes (59, 109).

2.4.7.3 Factors affecting relationship satisfaction

Child characteristics. Four studies examined the association between relationship satisfaction and child age or age at diagnosis (18, 25, 28, 67); however, only one found a significant relationship, such that parents with older children felt less closeness in their relationship (25). Three studies investigated child gender with mixed findings; two were of strong methodological quality and failed to find a significant association with relationship satisfaction (18, 67) whereas the third, of good quality evidence, found that mothers of girls reported less relationship satisfaction than mothers of boys with ASD (19). No association was found between relationship satisfaction and cognitive functioning in one study using standardised cognitive assessments (28). In support of this finding, no significant differences were found between parents raising a child with HFASD or LFASD (16); however, the method of cognitive assessment was not reported.

ASD symptom severity. Seven studies reported on symptom severity with mixed findings. Two studies found an inverse correlation with relationship satisfaction (4, 44), yet five others failed to find a significant relationship (5, 25-28). Furthermore, relationship satisfaction was not found to relate to the child's level of need (a composite of symptom severity and behaviour intensity; 5).

Challenging behaviours. Four studies examined the association between challenging behaviours and relationship satisfaction. One study found an inverse association between challenging behaviours and relationship satisfaction as reported by mothers, while pro-social behaviours were positively associated with relationship satisfaction (35). In particular, externalising behaviours were shown to have a greater impact on relationship satisfaction than internalising behaviours, which did not reach significance (36).The number of challenging behaviours related to relationship satisfaction for fathers only in another study; however, intensity of behaviour was not related significantly to relationship satisfaction for either parent (5). Another study of mothers also failed to find a significant difference between relationship satisfaction and challenging or adaptive child behaviours (28).

Socio-demographic and household characteristics. The impact of income, employment, education and number of children in the family on relationship satisfaction was investigated in six studies with mixed findings. One study found that high overall socioeconomic status (SES) positively correlated with relationship satisfaction (35); another found increased financial burden to be associated with increased relationship burden (36). Yet, two studies failed to find an association between relationship satisfaction and income (59, 67). One of these studies also failed to find an association with employment, but did find a positive association with parent education (59). Conversely, a further three studies failed to find a significant association between education and relationship satisfaction (18, 40, 67). Relationship satisfaction was not found to relate to relationship status (67), the total number of children in the home (40) nor to the number of children with ASD in the family (67). However, fathers who had additional children in the home reported greater levels of relationship satisfaction (59).

Parent characteristics. The parent characteristics investigated across nine studies included age and gender. Relationship satisfaction and parent age were not found to be significantly associated (18, 40, 59). Findings regarding gender differences were inconsistent. One study found that mothers perceived higher relationship satisfaction than fathers (58). More specifically, a second study found that mothers of a child with HFASD scored higher on the Dyadic Adjustment Scale subscale ‘degree of consensus’ (17). Conversely, another study found that mothers scored lower than fathers on ‘dyadic satisfaction’ and ‘affection expression’ but not overall relationship satisfaction (6). No significant difference in relationship satisfaction between the genders was found in four studies (5, 45, 59, 67).

Parent stress and psychological wellbeing. A significant negative association was found between relationship satisfaction and stressful life events (35), parenting burden (18), maternal parenting stress (5, 44) and paternal parenting stress (59). Accumulative stress was positively associated with relationship burden (27) and negatively predicted relationship adjustment 12 months following ASD diagnosis (45). Emotional stress in mothers of one child with ASD (but not two or more) was associated with the Intimate Bond Measure’s ‘control by spouse’ subscale, indicating that their partner’s authoritarian attitudes and behaviours increased their stress, but emotional stress was unrelated to perceived care from the partner (42). One study failed to find a significant association between relationship satisfaction and parenting stress on a multivariate level; however, maternal (but not paternal) parenting stress reached significance on a univariate level (5).

Parent psychological wellbeing has been positively associated with relationship satisfaction (58). Four studies revealed a significant negative relationship with depressed mood cross-sectionally (28, 35, 40, 59), one of which also found relationship satisfaction to negatively predict depression and positively predict psychological wellbeing two years later (35). One study examined the association of generalised anxiety disorder symptoms with relationship satisfaction and found a negative relationship between the two (40).

Parent personality, cognitive resources and coping strategies. Reviewed studies showed a positive correlation between relationship satisfaction and positive affect (66), maternal sense of coherence (44, 58), idealistic distortion (40) and parenting efficacy (35). A negative correlation was found with negative affect (66), dysfunctional attribution (locus, stability, globality, intention, motivation and blame; 16), maternal internal locus of control (44) and avoidant coping strategies (27, 81). Neither problem-focussed nor emotion-focussed coping were found to predict marital burden after twelve months (45). Optimism was identified as a significant positive factor in one study (67) but not in another (15).

Cognitive appraisal was investigated in seven studies with mixed findings. Negative appraisal was correlated with lower relationship satisfaction cross-sectionally (27, 36, 58) and longitudinally (45). However, no such correlation was found in another longitudinal study (66). An association between relationship satisfaction and positive appraisal was also reported cross-sectionally (36, 67) and longitudinally (66). Similarly, relationship burden has been associated with decreased positive appraisal (81). Yet, another three studies failed to find a significant association between positive appraisal and relationship satisfaction (27, 45, 58).

Relationship dissatisfaction in parents of a child with ASD was found to have a negative impact on social relationships (36). Cross-sectionally, general social support also positively correlated with relationship satisfaction in three studies (35, 67), negatively correlated with relationship burden (27, 81) and longitudinally predicted relationship satisfaction a year after ASD diagnosis (45). Specifically, partner support had a positive impact on relationship satisfaction (5, 67); however, no significant association was found for professional support (25, 45) or ASD-specific support (27, 45), suggesting that the type of support may influence outcomes.

2.4.7.4 Strategies to maintain relationship satisfaction.

Applying concept mapping methodology, one study explored strategies used by couples with children with ASD to maintain their relationships (26). Both mothers and fathers of children with ASD identified two common factors as integral to relationship success: communication and shared ideas about the relationship. Fathers uniquely attributed working out differences and love for each other as important, but mothers' responses were more action-focussed and included spending time alone and together without their child and encouraging positive qualities for the relationship.

2.5 Discussion

The overall finding of this systematic review and meta-analytic summary suggests that couples with a child with ASD are at risk of experiencing lower relationship satisfaction when compared with couples who have children without a disability. This finding was true for both mothers and fathers when analysed separately. However, care must be taken when drawing conclusions as the meta-analysis plots showed that seven out of ten studies displayed group differences with 95% confidence intervals crossing zero. This suggests that there may be a chance that random variations are responsible for the observed difference between ASD and control groups. However, the overall pattern is very consistent that relationship satisfaction favoured families without a child with ASD. Another area of concern was that while the methodological quality of studies included in the meta-analysis were good, none of them were population-based which limits the generalisability of the findings. Future research needs to include large scale population-based studies using well validated measures of relationship satisfaction and these studies should apply sensitivity analyses, in order to draw firm conclusions. The present review sets a foundation for that.

The studies included in the current review did not enable us to conclude whether raising a child with ASD impacted on couples' relationship satisfaction to a greater extent when compared with couples who have children with disabilities other than ASD (18, 19, 59). Two longitudinal studies included in the review attempted to capture change in relationship satisfaction over time. One demonstrated a significant increase in relationship satisfaction between the child's fifth and seventh year of schooling (35), while the other failed to uncover any significant changes over a one year period shortly after receiving the child's ASD diagnosis (45). The different lengths of time between baseline and follow-up could explain the seemingly contradictory findings. Moreover, one year is likely not long enough to detect any significant changes in relationship satisfaction. Additionally, data were collected at two different stages of the families' developmental trajectories. One study sampled couples within the first six months after their child received a diagnosis of ASD, a period recognised as tumultuous and often requiring intense support (22). The other study collected data between the child's fifth and seventh year of schooling, which could be argued as being a less intense period for families. However, an important limitation of both studies is that data were collected at only two time points, thereby restricting the ability to capture fluctuations in relationship satisfaction over time (110). Using four points of data collection over seven years, a study sampling couples of adolescent and adult children with ASD found a linear pattern of decline in relationship satisfaction (20). For children with ASD, the transition to adulthood is usually accompanied by the need to provide continued high levels of caregiving (22, 111). Conversely, children without ASD are typically gaining independence and may transition out of the home, allowing their parents to devote time to their relationship with an associated increase in relationship satisfaction and decreased risk of separation (21, 29). Thus, study results need to be considered with respect to the lifespan developmental trajectories of the child and family.

It is noteworthy that despite the focus on negative outcomes associated with raising a child with ASD, many couples succeed in maintaining relationship satisfaction. Parents have spoken of developing a common focus, solid partnership and ultimately a stronger relationship as a result of raising a child with ASD (26, 49, 69, 112, 113). A phenomenological study found that having a child with ASD acted as a crucible, forcing qualitative changes in the couple relationship, which ultimately resulted in deeper intimacy and commitment in the realisation that a strong couple relationship was better for the child (4). The researchers found that these changes occurred over time and at different rates for couples, confirming the need to investigate individual relationship trajectories.

The reviewed studies were mixed with regards to gender differences in relationship satisfaction in couples raising a child with ASD. Of the studies that measured gender differences, less than half reached significance and the direction of effects was inconsistent. That is, two studies found relationship satisfaction scores to be higher in mothers compared to fathers (17, 58), while the third found the opposite to be true (6). A number of factors need to be considered when interpreting these findings. Firstly, there are several methodological limitations, including sample sizes being too small to provide adequate statistical power. Secondly, outcomes depended on the specific concepts being measured in the studies. For example, two studies found gender differences in only one or two subscales of a relationship satisfaction measure but not in overall scores (6, 17). Thirdly, relationship trajectories may differ between genders. This was evidenced by a four year longitudinal study using general population-based data in which no gender differences were found in average levels of relationship satisfaction using growth curve intercepts; however, partners differed in the rate of linear change such that female partners showed stronger decline in relationship quality over time (114). Fourthly, it is plausible that the combinations of variables and pathways to relationship satisfaction differ according to caregiver gender. For example, impairments in sociability resulted in higher stress for mothers compared with fathers, whereas impairments in sensory and cognitive awareness have a greater impact on stress for fathers (115). Finally, the division of caregiving responsibilities may be a more salient predictor of relationship satisfaction than gender. For example, one study found that high relationship satisfaction was evidenced when parents of children with ASD were satisfied with the time their partner spent in child caregiving regardless of parent gender (116). Generally, however, greater caregiving duties are assumed by the mother of a child with ASD (70, 74, 79, 116), particularly when the child is young (116). Many mothers are dissatisfied with such a division of labour (79) and this may be reflected in their relationship satisfaction.

The reviewed studies provide insight into the factors associated with relationship satisfaction in couples raising a child with ASD, including challenging behaviours (5, 35, 36); caregiver stress (5, 35, 44); psychological wellbeing (28, 35, 40, 59); and cognitive appraisal and social support (5, 25, 27, 35, 45, 67). To interpret the findings against extant theoretical work of relationship satisfaction in families with a child with a disability and to encapsulate the dynamic processes involved in relationship satisfaction when raising a child with ASD, Figure 2-4 presents a theoretical framework adapted from the Model of Marital Quality and Psychosocial Wellbeing in the Context of Child Disability (117). In the model, arrows show potential pathways rather than causal relationships. Double arrows indicate a bidirectional relationship. Grey boxes reflect factors that may influence (and be influenced by) relationship satisfaction, whereas white boxes denote factors that may mediate relationship satisfaction. The pathways are numbered and the corresponding narrative passages are denoted by the same number in superscript.

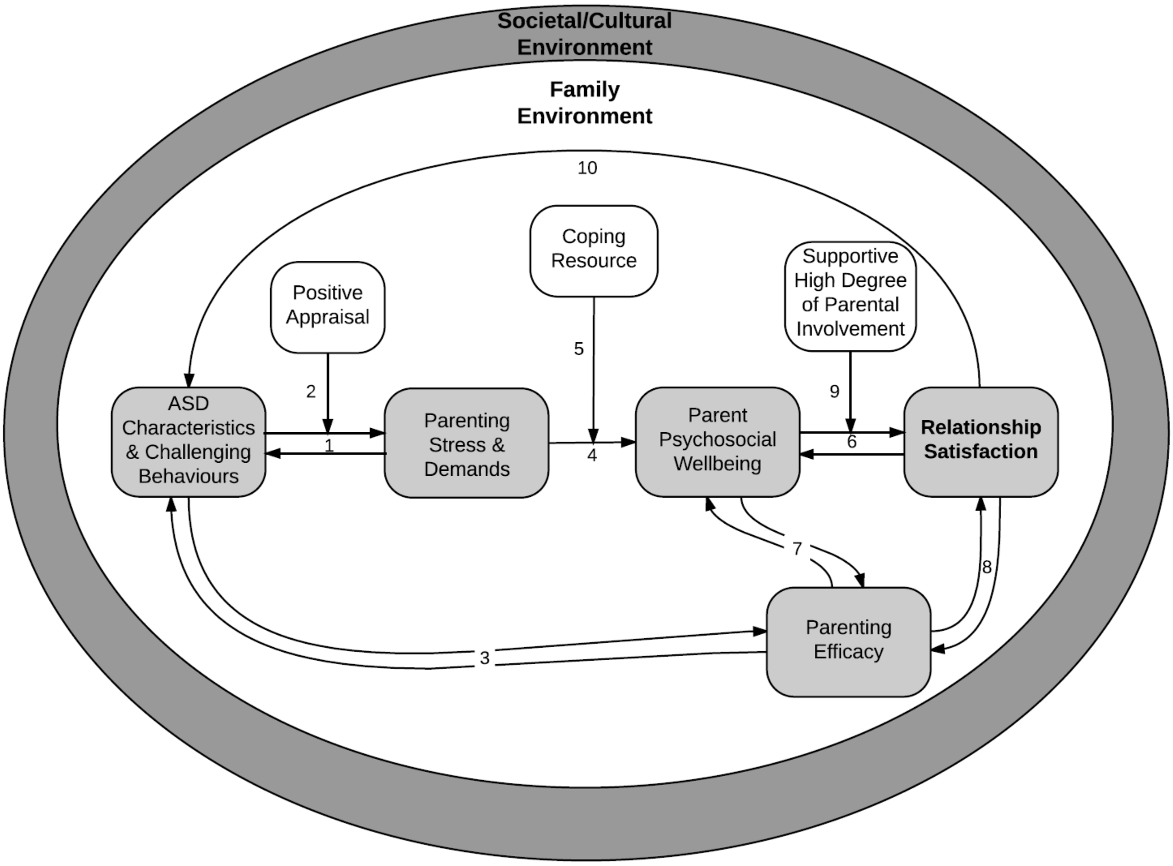

Figure 2-4. Model of Relationship Satisfaction in the Context of Child Autism Spectrum Disorder [Adapted from the Model of Marital Quality and Psychosocial Wellbeing in the Context of Child Disability, by Hartley et al (2011)].

ASD is associated with a number of *characteristics* that impact on the psychosocial wellbeing of the child. Although not a core symptom of ASD, the need to manage *challenging behaviours* was the most consistent child characteristic associated with relationship satisfaction in the reviewed studies (5, 35, 36). Challenging behaviours have also been found to co-vary with fluctuations in relationship satisfaction longitudinally (20). The need to manage challenging behaviours has been linked to *parenting stress and demands* in caregivers of children with ASD, both cross-sectionally and longitudinally through mutually escalating influences (48, 75, 118-120)[1]. However, this process may be buffered by positive appraisals of the stressful event[2]. Reviewed studies demonstrated that parents who perceived the challenges associated with raising a child with ASD as manageable and meaningful, and who held optimism about the future, were more likely to experience relationship satisfaction (36, 44, 58, 66, 67).

Challenging behaviours have also been linked to negative perceptions of *parenting efficacy* in caregivers of children with ASD (19, 36)[3]. Feelings of parenting efficacy rely on the ability to read, interpret and respond to a child's cues (121). A child with ASD may not respond to caregiver interactions as expected, resulting in caregivers feeling disempowered and doubting their capacity to parent (19, 122). The association between challenging behaviours and parenting efficacy may be bidirectional, as improvements in self-efficacy following a caregiver training workshop resulted in a decrease in the number of problem behaviours in children with Asperger's Syndrome (123).

Stress associated with parenting a child with ASD has been associated with the *psychosocial wellbeing* of caregivers (47, 70, 124)[4]. An Australian study found that over 90% of sampled parents felt, at some time, inept to deal with the behavioural challenges of their child with ASD and were consequently saddled with anger, frustration, loneliness and depression (119). Another study found that higher stress levels were evident in caregivers of children with ASD, with more parents meeting the diagnostic criteria for depression and anxiety than those parents who did not have a child with ASD (40). For many parents, anxiety stems from uncertainty around their child's future (69).

Social support has been shown to be an important *coping resource* for couples raising a child with ASD by reducing stress and improving both parent psychological wellbeing and relationship satisfaction (35, 44, 72, 125, 126)[5]. This has been robustly supported by studies of couples with children with developmental disabilities (65, 114). However, the value of social support may be dependent on its source. For example, family support appears to be a significant contributor to couple satisfaction, but not professional support (25) or ASD-specific support (27, 45). Despite the documented benefit of support from family and friends, caregivers of a child with ASD report far less support than families who do not have a child with a disability (51, 125, 127-129).Therefore, it is not surprising that many caregivers of a child with ASD consider their partner to be their most valued support system (15, 71, 79, 130), the perceived availability of which has been linked to reduced stress and improved relationship satisfaction (5, 67).

Parental psychosocial wellbeing has, in turn, been linked to *relationship satisfaction* in caregivers of a child with ASD (28, 35, 40, 59)[6]. Research from the general population shows that this relationship is likely to be bidirectional (131, 132). Furthermore, the psychological wellbeing of one partner can affect the other through couple interactions. For example, research has shown that an individual with depression is less likely to smile, make eye contact or engage in positive interactions with their partner and these dysfunctional interpersonal behaviours may lead to relationship dissatisfaction in the other partner (131, 133).

Perceptions of *parenting efficacy* and feeling competent as a parent have a bidirectional relationship with both parental *psychosocial wellbeing* and *relationship satisfaction*. Studies have evidenced a reciprocal association between the psychological status of caregivers of a child with ASD and parenting efficacy (35, 134, 135)[7] which has, in turn, been linked to relationship satisfaction (35, 36)[8]. Research from the wider population has demonstrated that fathers who experienced satisfaction in their relationship with their partner were more likely to have greater involvement in parenting (136). This greater involvement was linked to enhanced relationship satisfaction in the mother (137). A *high degree of parental involvement* is likely to mediate the relationship between parental psychosocial wellbeing and relationship satisfaction in couples with and without a child with ASD (121, 134)[9].

Coming full circle, relationship satisfaction may be a determinant of the wellbeing of a child with ASD[10]. There is ample literature supporting the influence of the couple relationship on child outcomes (83, 84). This finding is supported longitudinally, as relationship satisfaction has been shown to co-vary with fluctuations in challenging child behaviours (20). Drawing upon data from the wider population, one study found that externalising behaviours predicted relationship conflict; however, only couple conflict specific to the child predicted changes in externalising behaviour over time (138). Thus, we could speculate that tension within the couple relationship may arise from differences in opinions regarding the management of a child with ASD which, in turn, exacerbates challenging behaviours and a perpetual cycle ensues. This escalating process may be interrupted through intervention to strengthen the couple relationship, which may be a valuable adjunct to ASD interventions given that support in the co-parenting relationship has been documented to reduce externalising behaviours (139).

All of these processes need to be considered in context of the broader *family and societal/cultural environments*, as represented by the oval shapes in which the pathways are embedded (117). For example, not all caregiver stress arises from parenting; there are stressors arising from broader family and community contexts, such as work and finances (53, 54). Furthermore, parents may be genetically predisposed to psychiatric conditions, which may exacerbate parenting demands (61-63, 140). Relationships between other family members, availability of services and societal shifts in attitudes towards both disability and couple relationships are further examples of ecological factors that may impact on the processes occurring between the child with ASD and relationship satisfaction in the parents.

2.5.1 Non-significant findings

The non-significant findings of the review are worthy of discussion. Firstly, there was inadequate evidence to support an association between relationship satisfaction and SES variables such as caregiver education, employment and income in the reviewed studies. This is contrary to findings from a study sampling caregivers of adolescents and adults which found a positive association between relationship satisfaction and income (20). Additionally, greater income and employment status increased the likelihood of a child with ASD living in a two parent household (30). The importance of SES as a significant factor in relationship satisfaction has been supported by findings from the general population (141, 142). Therefore, the lack of significant findings in this review may be due to methodological limitations including an over representation of affluent families and clinically-based samples who have access to services.

Secondly, the majority of studies failed to find an association between ASD severity and relationship satisfaction. Again, this could be due to the limits of methodologies employed. For example, the studies investigated overall ASD symptom severity rather than investigate the severity of individual symptoms, such as communication and social impairments, on relationship satisfaction. Furthermore, the impact of the broad range of comorbid diagnoses has received little attention, yet they are highly prevalent (31, 32). Clearly, further research is warranted to better understand the impact of the severity of ASD characteristics on the couple relationship.

2.5.2 Limitations

Arguably, the most fundamental limitation of the reviewed studies is the lack of foundational paradigms which has led to inadequate study designs and methodologies. Many of the reviewed studies were grounded on poorly defined constructs leading to interchangeable terms that reflect a wider controversy in the field of relationship satisfaction. While some researchers believe distinctions between the terms are unnecessary due to strong correlations between them (9, 143), others argue that the lack of clarity around relationship constructs leads to the misinterpretation of research findings (91). Research could be strengthened with stronger theoretical underpinnings, such as family systems theories and resilience frameworks. Theories such as these are applicable to ASD research as they recognise that individuals live within the context of the whole family and that families evolve with distinct transitional periods. Furthermore, they emphasise the need to investigate both positive and negative processes, and acknowledge that no single model fits all (64, 144).

Relationship satisfaction is widely considered to be a continually evolving construct characterised by fluctuations in relationship appraisals that can only be captured through multiple waves of data collection (13, 110). Yet, the majority of studies reviewed were cross-sectional in design, capturing a static evaluation at a single time point. Furthermore, cross-sectional designs are unable to capture the direction of influence between two variables, which is likely reciprocal. Variables under study were often examined in isolation, with analyses that failed to account for interactional effects. Thus, so far, research has provided only superficial insight into what is clearly a complex and multidimensional construct. Recommendations for future research not only include longitudinal study of relationship satisfaction to encapsulate long term transactional processes, but also repeated measures over a shorter period of time to capture the subtle fluctuations in relationship satisfaction that occur on a daily basis.

Limitations with regard to recruitment and sampling have impeded the generalisability of findings. Individual study samples were relatively small, homogenous and purposively sampled. Families from low SES backgrounds were underrepresented and recruitment was predominantly from service providers, limiting the perspective of families not in receipt of services and therefore biasing results. Furthermore, respondents were largely female and given the potential for gender differences in relationship satisfaction experiences, mothers' reports cannot be assumed to be representative of the couple. Thus, larger scale research including samples representing a range of sociodemographic backgrounds would be beneficial, with increased efforts to recruit fathers.

Some important compounding variables were poorly controlled for in the reviewed studies, including the relationship quality prior to having a child, the length of the relationship and the developmental stage of the child and family. A strong relationship prior to having children or the diagnosis of the child has been identified by parents as a protective factor (70). Furthermore, due to declines in satisfaction over time, researchers need to give consideration to the effects of attrition resulting from couple separation.

There are two notable limitations at the review level. Firstly, the inclusion criterion of peer-reviewed articles created a potential for a publication bias. Significant results are more likely to be published than non-significant, negative or inconclusive results (145). Thus, the review may present unbalanced findings in favour of differences in relationship satisfaction between parents of a child with ASD and comparison groups. Inclusion of grey literature may balance the findings; however, close scrutiny is required to ensure its credibility. Publication bias was not found to have a significant impact on the meta-analysis results. Secondly, the review included studies conducted over the past four decades during which fluctuations in population-based trends have been reported (146) and ASD diagnostic procedures and interventions have changed (147). Therefore, comparisons between studies are problematic, as it is difficult to determine if changes are specific to relationship satisfaction in couples raising a child with ASD or reflective of broader societal shifts over time (117).

2.6 Conclusions and implications

The current systematic review and meta-analysis provides preliminary evidence that couples raising a child with ASD are, on average, less likely to experience relationship satisfaction than couples with children without a disability. However, couples adapt differently; many demonstrate resilience and are able to maintain high levels of relationship satisfaction. It is unclear why some couples adapt successfully and others do not, but a number of risk and protective factors have been associated with relationship satisfaction. A model has been adapted and introduced to capture the complex pathways that exist between the psychosocial wellbeing of a child with ASD and relationship satisfaction in their parents. This model provides a foundation for future research and should be tested and refined in response to findings. Theoretical underpinnings need strengthening to provide sound concepts, consistent terminology and appropriate study designs and methodology.

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Chapter 3 Secondary analysis of population-based data #1

Chapter 3 comprises a study investigating the impact of raising a child with ASD on the co-parenting relationship and the key factors associated with it. The study analysed relevant cross-sectional data from a West Australian population-based survey, which was designed primarily to determine the costs associated with raising a child with ASD. The 73-item survey garnered information on a broad range of sociodemographic, child and family factors. The survey also contained a question pertaining to the co-parenting relationship which was used as a proxy for relationship satisfaction given their strong positive association[1,2.] The findings supplemented the systematic review by providing insights into a local population of families raising a child with ASD. Together they set the scene, determining the need and direction of the research in this thesis.

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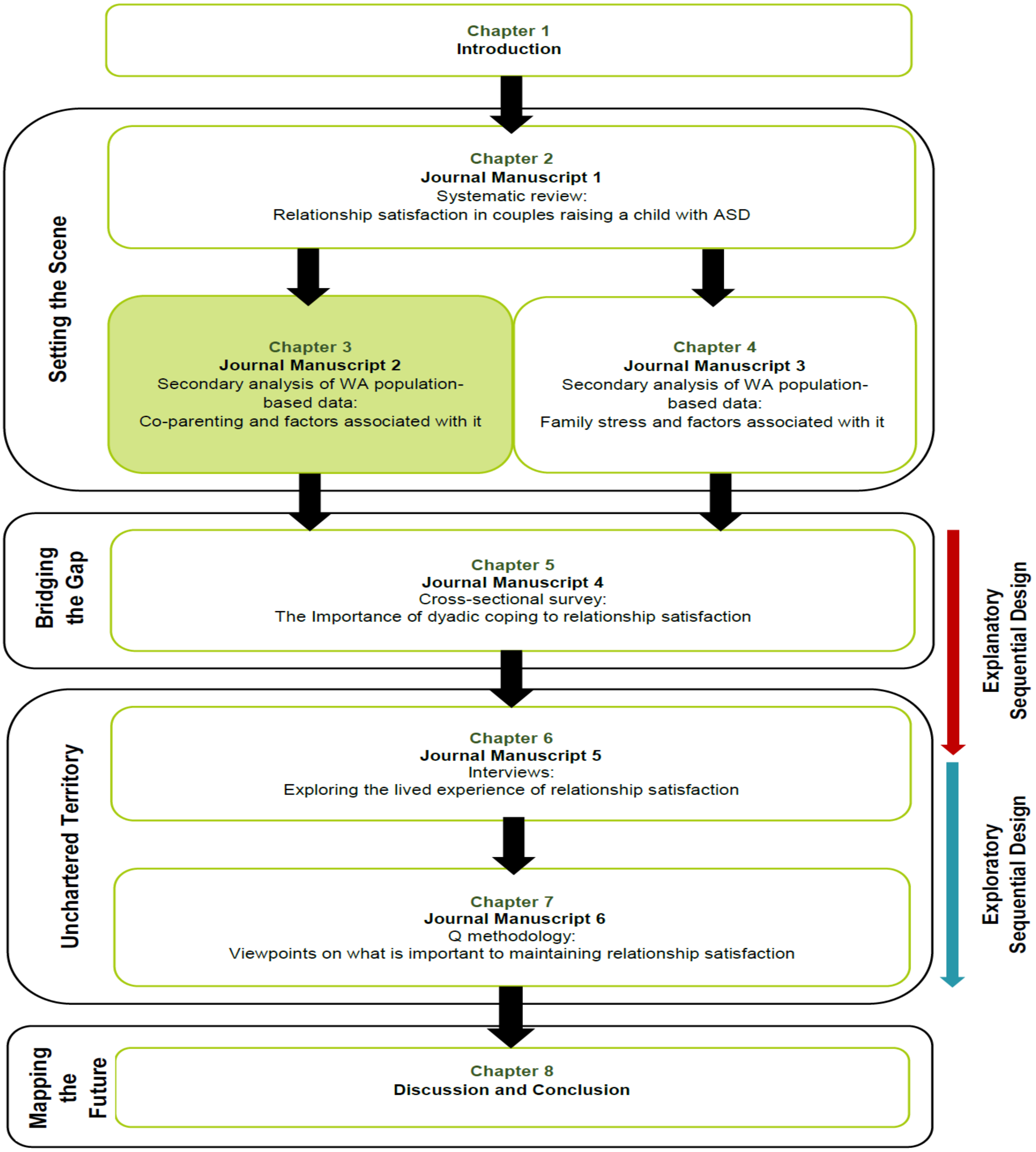

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Factors associated with negative co-parenting experiences in families of a child with autism spectrum disorder

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3.1 Abstract

Purpose: The purpose of this study was to identify key factors associated with negative co-parenting experiences in parents raising a child with autism spectrum disorder.

Methods: Questionnaires were sent to families with one or more children with a diagnosis of autism spectrum disorder. Parents of 142 children with autism spectrum disorder indicated that the diagnosis had a very negative impact on their co-parent relationship. A multivariate logistic regression model was run to analyse the association of these experiences with various demographic, family and community factors.

Results: Three factors were associated with negative co-parenting relationships: (1) family stress due to the child's diagnosis, (2) effects of the diagnosis on parents' relationship with their other children and (3) distance travelled to the nearest medical facility.

Conclusions: Findings highlight the need to further explore family dynamics, particularly the relationships between the co-parenting alliance, other family members and the extra-familial environment.

Keywords: ASD, family stress, parent alliance, siblings, travel distance.

3.2 Introduction

Autism spectrum disorder (ASD) can present multiple and unique challenges for caregivers. There is documented evidence of increased parenting stress (1-4), poor parent-child interactions (5) and low marital satisfaction (1, 6, 7) in these caregivers, compared to parents with children without ASD. These discrepancies have largely, but not exclusively, been attributed to the complex and pervasive characteristics and behaviours associated with ASD (3, 8-11). Yet, little research has investigated the co-parenting alliance in this population, despite its direct links to child adjustment in the broader populace (12, 13).

Co-parenting is the process by which parents support each other and coordinate childrearing responsibilities (14). Family systems theory not only conceptualises the co-parent alliance as a distinct family subsystem, it emphasises its importance as the executive system around which family processes evolve (15, 16). Through its links to both the marital and parent-child subsystems, the co-parenting alliance acts to bridge the two (14, 17-20). It is often erroneously considered synonymous with the marital relationship, but the two subsystems follow different trajectories; marital relationships ordinarily develop first and provide the foundations for co-parenting (21), and co-parenting alliances can continue to exist in the event of marital dissolution (22-24).

Much of the early co-parenting research has been in the context of divorced couples (24). Inter-parental cooperation after divorce has been established as a key predictor of adjustment in children (13, 25, 26). Given reports of high divorce rates in families with a child with ASD (27), a healthy co-parenting alliance may play a pivotal role in providing continuity and lessening the impact of family separation in this population.

More recently, co-parenting relationships have been explored in two parent family systems (18). Findings evidence a positive association between marital health and co-parenting quality (28, 29). A more germane finding, however, is the ability of the co-parenting alliance to mediate the relationship between the marital and parenting subsystems (18-20, 30-32). Not only do couples raising children with ASD report low levels of marital satisfaction (1, 6, 33), they are likely to experience reduced parenting efficacy (34, 35) and high levels of parenting stress (1, 6). The co-parenting relationship has been found to have a more proximal and powerful influence on the marital and parenting subsystems than they have on each other directly (36, 37), demonstrating the potential for sound co-parenting to act as a buffer or protective factor for both marital and child wellbeing (12, 36).

Although behavioural problems are not considered a core symptom of ASD, they are commonly cited as a source of excessive stress in parents (10, 11, 38). Child behaviour has been linked to co-parenting such that children experiencing cooperative parent relationships exhibit fewer behavioural problems and more prosocial behaviours (39-41). Conversely, unsupportive co-parenting has been correlated with greater child internalising and externalising problems and antisocial behaviour (39, 42). Furthermore, a recent study with parents raising a child with ASD found that co-parenting partially mediated the relationship between challenging behaviours and parent stress, such that parents of children with greater atypical behaviour reported lower parent related stress if they had a strong child-focussed parenting alliance (43).

Socio-demographic determinants of co-parenting have received limited attention from researchers and the available findings are mixed. Low socioeconomic status, as determined by the father's education and family income, has been associated with undermining co-parenting behaviour in new parents (44). Higher income, on the other hand, has been associated with more supportive co-parenting as perceived by non-resident, never married fathers (45). Furthermore, mothers of infants from dual earner families have demonstrated more supportive co-parenting than parents from single earner families (46). A positive correlation between levels of parent education and co-parenting quality has been found in married couples with young children (46, 47), as well as never married non-resident fathers (45). These fathers also perceived less supportive co-parenting if the mother of the child had lower education levels (45). However, negative correlations have also been found. For example, at-risk mothers (but not fathers) without a high school degree reported greater supportive co-parenting than college educated mothers of one-year old infants, although this difference did not remain significant upon follow up at age three and five (48). With regards to parent gender, some researchers have observed fathers to display more supportive co-parenting than mothers (46, 49), while others have identified mothers to be more cooperative in their relationship with their co-parent (18). As they age, mothers tend to engage in fewer intrusive co-parenting behaviours (46), while older fathers have been shown to exhibit less supportive co-parenting than their younger counterparts (49, 50).

The limited research investigating the influence of child characteristics on the co-parenting relationship has shown that as a child ages, intrusive co-parenting behaviour increases (46), while cooperative co-parenting behaviours decrease (18). For child gender, findings are more conflicting. Maritally distressed couples with infant boys have been shown to be more likely to engage in hostile-competitive co-parenting when compared to those with girls (51). Yet another study found that never married non-resident fathers perceived more supportive co-parenting when fathering boys (45). Additional research has failed to find significant relationships between child characteristics and co-parenting (52, 53). Interpretation of these results requires caution. Methodological differences make comparisons between studies problematic, and this may reflect the lack of consensus between scholars with regards to the co-parenting construct and its components (36). Moreover, methods of data collection varied between parent self-report (18, 52, 53) and researcher observations. For the latter, observation sessions varied from a single five minute interaction (44) to a one hour observation twice in a week (49, 50).

To date, the research literature exploring co-parenting of children with ASD is scant. However, there have been studies investigating the interconnected marital and parenting systems in this population, and they have revealed high levels of parenting stress and poor marital quality (1). The relationship between parent and child functioning is considered bidirectional and perpetuating, such that dysfunction in one subsystem can exacerbate difficulties in the other and this can escalate (54, 55). Drawing inference from a wider body of literature, the co-parenting alliance may have a mediating role in these dynamics, and influence child outcomes independent of the parent-child and marital subsystems (42, 56, 57). Consequently, interventions focussing on the co-parenting relationship may prove to be an effective adjunct to family-focussed therapy for children with ASD, regardless of marital status or quality. However, such interventions need to be informed by research and at present there is a wide gap in the literature. Thus, the aim of the current study was to identify key factors associated with negative co-parenting experiences in parents raising a child with ASD using a population-based approach.

3.3 Methods

3.3.1 Questionnaire development

Data for this cross-sectional study were obtained from a parent-report questionnaire developed primarily to investigate the costs associated with raising a child with ASD (58). However, the questionnaire also gathered information pertaining to family socio-demographics; the child’s diagnosis, developmental history, treatment history, education and child-care usage; and the family’s quality of life including the co-parenting relationship (for a copy of the full questionnaire refer to (58)). The questionnaire was informed by anecdotal reports from clinical experts and families, current research literature, and insurance reports. A pilot version was sent to a number of clinicians and service providers for comment prior to the development of the full version, which was pilot tested on three families with children with ASD.

The final questionnaire was comprised of 73 items, in a multiple-choice format. The last page of the questionnaire included a DSM-IV-TR/ICD-10 checklist (59). This contained 18 items covering the three main symptom domains. Respondents indicated the presence or absence of each symptom by answering with a “yes” or “no”. The internal consistency of these items is reported to be .84, with robust convergent validity with the Autism Spectrum Disorders-Diagnosis for Intellectually Disabled Adults ($r=.60$, $p<.01$) (59). An additional item was added to determine the presence of sensory difficulties. While not considered a core diagnostic symptom, sensory difficulties are commonly associated with ASD (60).

3.3.2 Participants and procedures

The questionnaire was distributed to 3,723 families with one or more children with ASD under the age of 18 who were registered with the Disabilities Services Commission (DSC) of Western Australia. Families with more than one child with ASD were provided with a questionnaire for each child, totalling 3,965 questionnaires. Five hundred and fifty seven questionnaires were returned giving a response rate of 14% return rate. Of these, only 496 questionnaires contained data relevant to the current study and were included in the analysis.

3.3.3 Analysis of non-respondents

Follow up contact was made six months following data collection for the purpose of a drop-out analysis. Telephone calls were made to 405 families randomly selected from the initial distribution list. During these calls, families who had not completed the original questionnaire were asked to complete an abbreviated version consisting of 20 of the original items. Subsequently, demographic variables from these non-respondents were compared with families who completed the original questionnaire using independent *t*-tests and chi-square tests.

3.3.4 Data management and statistical analyses

Data were managed and analysed using the SPSS Version 20.0 and SAS Version 9.2 software packages. Data were cleaned and managed using recommended guidelines (61). Descriptive statistics were then run to describe the demographic profile of the sample.

Parent responses to the question “How has your child’s diagnosis of ASD affected YOUR relationship with your partner/co-parent?” were used as the dependent variable (DV) for these analyses. Responses were given on a 5-point scale, where 1 = great negative impact, 2 = slight negative impact, 3 = no impact, 4 = slight positive impact, and 5 = great positive impact. These data were recoded into dichotomous variables, with responses of ‘great negative impact’ assigned to the response group and the remaining responses combined to serve as the reference category.

The independent variables (IVs) were derived from other questionnaire items. The large number of items was initially refined in accordance with relevant co-parenting literature, including peer reviewed research articles, and expert opinion gleaned through liaison with researchers experienced in the field of ASD. Univariate logistic regression analyses were then performed to identify the IVs that were significantly related to the DV. The significantly related IVs were selected for binary regression analysis run to address the study’s objective to identify factors associated with negative co-parenting experiences in parents raising a child with ASD. IVs were entered into the regression model using a backward stepwise procedure, as no priori assumptions on their relative importance existed.

3.3.5 Ethical approval

Ethical approval was obtained from the Curtin University Human Research Ethics Committee (HR 138/2012) and the internal ethical review board of the DSC in Western Australia. Questionnaire packs were sent to the DSC's clients with a cover letter from the Director General of DSC explaining the nature and purpose of the study. Completed and returned questionnaires were taken as consent to participate in the study.

3.4 Results

3.4.1 Descriptive profile of the sample

Of the 496 questionnaires there were 142 (29%) responses of "great negative impact". Figure 3-1 lists all of the response categories and the number and percentage of questionnaires in each.

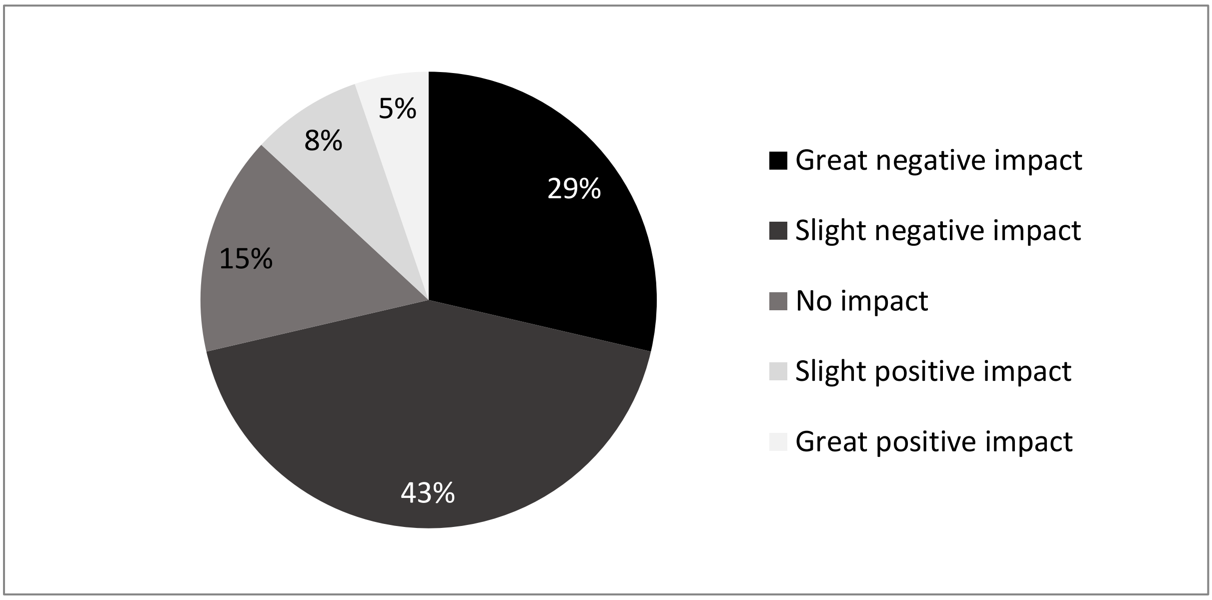

Figure 3-1. Percentage of responses in each response category for the question "How has your child's diagnosis of ASD affected YOUR relationship with your partner/co-parent?".

The vast majority of questionnaires were completed by the child's biological mother (80%). For the "great negative impact" sample, 69% were from a two-person household and 23% were single parents. For the reference group (n=354), two-person households were more common (90%), and single parent households less common (2%). The vast majority of respondents reported having more than one biological child (80-90%). The highest percentage of respondents in the reference group reported a household income of between $75,000 and $100,000 per annum (24%). In contrast, the "great negative impact" sample had an equally high percentage of respondents earning at the low end of the scale ($25,000 to $50,000 per annum) as those with a household income greater than $200,000 per annum (16%). The greatest percentage of the reference group resided 2-5km away from their child's medical centre (26%), whereas the greatest percentage of the "great negative impact" sample resided more than 30km (23%). Across the samples, children with ASD were predominantly boys (over 80%) averaging approximately 10 years of age. The most commonly reported diagnosis was autism for both the "great negative impact" and reference samples (56% and 48% respectively) and mental health comorbidities were present in 20% to 23% of the samples. Child and family characteristics are detailed in Table 3-1.

Table 3-1. Characteristics of the children with ASD and their families for the total sample and the sample of respondents reportiing a 'great negative impact' of raising a child with ASD on the co-parent relationship.

CHARACTERISTICS	**Total Sample**		**Great Negative Impact Sample**		**Other**	
CHILD	N=496	%100	N=142	%100	N=354	%100
Age (months) Mean (standard deviation)	122.1 (51.7)		116.4 (49.9)		122.1 (51.7)	
Gender						
Male	412	83.4	116	81.7	296	84.1
Female	82	16.6	26	18.3	56	15.9
Official ASD diagnosis						
Autism	247	50.1	79	56.0	168	47.7
HFA	126	25.6	32	22.7	94	26.7
AS	35	7.1	6	4.3	29	8.2
PDD-NOS	77	15.6	21	14.9	56	15.9
other	8	1.6	3	2.1	5	1.5
Presence of diagnosed psychological/mental health comorbidity						
Yes	103	21.0	32	22.9	71	20.2
No	388	79.0	108	77.1	280	79.8
PARENT						

Relationship to child diagnosed with ASD						
Biological Father	91	18.4	24	16.9	67	19.0
Biological Mother	395	80.0	116	81.7	279	79.3
Other	8	1.6	2	1.4	6	1.7
Household composition						
2 parent	410	84.4	98	71.0	312	89.7
Single parent	41	8.4	33	23.9	8	2.3
Extended family	3	0.6	0	0	3	0.9
2 parent & extended family	24	4.9	3	2.2	21	6.0
Single parent & extended family	5	1.0	4	2.9	1	0.3
Foster	3	0.6	0	0	3	0.9
Total number of *biological* children						
0	4	0.8	2	1.4	2	0.6
1	53	10.7	21	14.8	32	9.1
2	238	48.2	65	45.8	173	49.1
3	139	28.1	38	26.8	101	28.7
4	48	9.7	14	9.9	34	9.7
5	12	2.4	2	1.4	10	2.8
Father's highest level of education completed	68	14.1	24	17.8	44	12.6
Year 10	41	8.5	13	9.6	28	8.0
Year 12	93	19.3	22	16.3	71	20.4
TAFE	91	18.8	37	27.4	54	15.5
Apprenticeship	35	7.2	3	2.2	32	9.2
University – did not complete	82	17.0	18	13.3	64	18.4
Undergraduate	73	15.1	18	13.3	55	15.8
Postgraduate						
Mother's highest level of education completed	61	12.5	17	12.2	44	12.6
Year 10	61	12.5	18	12.9	43	12.3
Year 12	126	25.8	37	26.6	89	25.4
TAFE	12	2.5	5	3.6	7	2.0
Apprenticeship	43	8.8	13	9.4	30	8.6
University – did not complete	106	21.7	26	18.7	80	22.9
Undergraduate degree	80	16.4	23	16.5	57	16.3
Postgraduate degree						
Combined Household Income						
<$25000	34	7.1	21	15.1	13	3.8
$25 000 – 50 000	49	10.3	23	16.5	26	7.7
$50 000 – 75 000	62	13.0	19	13.7	43	12.7
$75 000 – 100 000	97	20.3	15	10.8	82	24.2
$100 000 – 125 000	56	11.7	13	9.4	43	12.7
$125 000 – 150 000	68	14.2	14	10.1	54	15.9
$150 000 – 200 000	55	11.5	12	8.6	43	12.7
>$200 000	57	11.9	22	15.8	35	10.3
Distance from medical facility						
<2kms	62	13.0	15	10.9	47	13.8
2-5kms	119	24.9	30	21.7	89	26.2
6-10kms	91	19.0	20	14.5	71	20.9
11-20kms	78	16.3	29	21.0	49	14.4
21-30kms	37	7.7	12	8.7	25	7.4
>30kms	91	19.0	32	23.2	59	17.4

3.4.2 Univariate logistic regression analyses

Univariate logistic regression analyses were carried out to determine which IVs were significantly related to the DV. Significant relationships were found between the DV (negative impact of a child with ASD on the co-parenting relationship) and the following IVs: 1) rating of family's overall stress due to the ASD diagnosis; 2) rating of the impact on the parent's relationship with siblings of the child with ASD; 3) effect on the employment status of the household; 4) combined annual household income; 5) rating of the level of social support; 6) difficulty finding a babysitter; 7) frequency of respite care; 8) access to child care for the child with ASD; 9) presence of a comorbid mental health condition; and 10) distance travelled to the child's medical facility. These IVs were entered into the multivariate regression model. Variables that did not reach significance were excluded from further analysis. The insignificant IVs included: 1) type of ASD; 2) symptom severity; 3) parent gender; 4) child age; 5) child gender; 6) household composition; and 7) total number of children.

3.4.3 Multivariate logistic regression analysis

The model was tested for goodness of fit against a constant only model and was found to be statistically significant ($\chi^2 = 126.39$, $df = 4$, $p < .001$). The included factors could explain 37% of the variability of the outcome (Nagelkerke's $R^2 = .37$). The prediction success of the overall model was 72.8%. The Wald criterion was used to identify statistically significant factors associated with negative co-parenting experiences in couples raising a child with ASD, and the Exp(B) was used to determine the strength of prediction (refer to Table 3-2).

The analysis revealed three factors that significantly contributed towards the experience of a negative co-parenting relationship. These included:

1. *Ratings of overall family strain/stress resulting from the child's ASD diagnosis*. Parent perceptions of increased family stress increased the odds ratio of experiencing a negative co-parenting relationship by a factor of 3.22;

2. *The effect of the child's diagnosis on the parent relationship with their other children.* A negative parent-sibling relationship increased the odds ratio of a negative co-parenting experience by a factor of 1.79;

3. *Distance to the nearest medical facility.* Greater distances travelled increased the odds ratio of a negative co-parenting experience by a factor of 1.21.

Table 3-2. Variables associated with a negative impact of a child with ASD on the co-parent relationship.

Negative impact on co-parenting relationship							
Independent Variables	*B*	SE	Wald	Sig.	Exp (B)	95% C.I. for Exp (B)	
						Lower	Upper
Family stress due to ASD	1.17	.15	58.84	<.001	3.22	2.39	4.33
Parent relationship with other children	.59	.15	14.80	<.001	1.79	1.33	2.42
Distance to medical facility	.19	.08	5.83	0.016	1.21	1.04	1.42

For the multivariate logistic regression analysis, no statistical significance was found for associations between the DV (negative impact of a child with ASD on the co-parenting relationship) and the following IVs: 1) effect on the employment status of the household; 2) combined annual household income; 3) rating of the level of social support; 4) difficulty finding a babysitter; 5) frequency of respite care; 6) access to child care for the child with ASD; and 7) presence of a comorbid mental health condition.

3.4.4 Analysis on non-respondents

Of the 405 families contacted on follow up, 146 completed the shortened version of the questionnaire for each of their children with ASD, totalling 171 children. Analysis showed that respondents were more likely to have a male child, have noticed atypicality earlier, have received an earlier formal diagnosis, be in a two-person household, and report higher treatment costs. However, the overall results did not reveal a statistically significant difference between the respondents and non-respondents (58), suggesting that the sample included in the study was representative of the larger population of families of children with ASD in Western Australia.

3.5 Discussion

3.5.1 Family stress

Parents that rated themselves as experiencing a negative co-parenting relationship were more likely to report increased family stress associated with having a child with ASD. This finding is supported by an earlier study whereby highly stressed parents of children with ASD reported having a poor co-parenting alliance (43). Similar findings have also been found for parents raising a child with intellectual disabilities (52), and children without a disability (14, 49). This outcome is particularly germane to the population of families raising children with ASD as their stress levels are acknowledged to exceed families of children without ASD, even if the child has another form of disability (1, 4, 6, 62-64). Social support has been shown to help alleviate this stress (14, 65-71), yet social networks are often compromised in families with a child with ASD (72-75). Consequently, the most valued support system for many parents is their partner (76-78). However, for many mothers this support is inadequate, particularly with respect to shared caregiving and disciplining (79). Therefore, by strengthening the co-parenting relationship, parents may feel supported, perceive less stress and be better equipped to manage the demands of raising a child with ASD (54, 80). These research findings highlight the importance of further research into relationships between co-parenting and the impact of ASD on family wellbeing.

3.5.2 Parent-sibling relationship

Negative co-parenting experiences were more likely to occur in families where raising a child with ASD negatively impacted on the parent’s relationship with their other children. The relationship between parents and siblings of the child with ASD has been largely unexplored in research, although qualitative reports reveal parent concern for reduced involvement with their other children due to the time demands of caring for a child with ASD (75). If co-parenting has been linked to the parent-child relationship in families of children with no known disability (17, 18, 81, 82), it is plausible that it also applies to the relationship between the parent and sibling of a child with ASD. With sound co-parenting, characterised by parent communication, shared goals, support and appreciation of their partner's involvement with the child (23, 83), parents may be better able to balance the needs of the family.

The present study found that 88% of families had more than one child, demonstrating the relevance of these findings for the vast majority of parents with a child with ASD, and the health professionals involved. This finding supports a strengths-based family-centred approach from health professionals that includes siblings of children with ASD in the therapeutic process to address their negative experiences and develop the parent-sibling relationship.

3.5.3 Travel distance to medical facilities

Another factor that was associated with negative co-parenting quality experienced by parents raising a child with ASD was the distance required to travel to the child's medical facilities. In this study, 19% of parents travelled more than 30 kilometres to their closest medical centre. This travel and the associated time demands would be expected to place a seemingly endless strain on the family due to the chronicity of ASD and the child's ongoing medical and therapy requirements (84). Many treatments are available to families with a child with ASD, and studies have shown that some families use as many as seven different treatments concurrently (85). The most widely used are speech therapy and occupational therapy (85-92), and it is not uncommon for parents to attend therapy sessions twice a week (88, 93). In addition to therapy, many children with ASD have associated conditions that require medical management, such as epilepsy, gastrointestinal problems, sleep disturbance and comorbid psychopathologies (84, 94). Furthermore, complementary and alternative therapies are accessed by 62-95% of families (86, 95-98), possibly due to the limitations of conventional interventions and lack of evidence for its efficacy (99, 100). The time invested in managing the treatment needs of a child with ASD are logically exacerbated by the distance required to travel. Moreover, the resulting time constraints may reduce the ability of the parents to nurture the parent-sibling relationship, which was found to be positively associated with co-parenting quality. Travel distance is a contextual factor in Australia that requires further exploration given the geographic expanse of the country and the impactions thereof on service delivery in rural and remote communities.

3.5.4 Other factors

Co-parenting relationships may, in fact, be an important component of a family-centred approach to the management of children with ASD. Parents may be more responsive to intervention focussed around the child rather than their individual parenting behaviours or marital relationship (18, 32). Consequently, parents may be more engaged, motivated and compliant with therapy (36). Furthermore, if reports of high divorce rates are accurate, a healthy co-parenting alliance may provide consistency and enhance child adjustment through the separation and beyond (13). For this reason, the study of co-parenting relationships in both cohabiting couples and separated families is endorsed. However, the validity of such research relies on the formulation of universal, well-defined co-parenting constructs and validated outcome measures. A multimodal approach to data collection is recommended, so that parent perceptions obtained through self-report measures are supplemented with objective observations of co-parenting behaviours. In this way, researchers will be better able to capture the complexity of co-parenting relationships in parents raising a child with ASD.

3.5.5 Limitations

There are several limitations to the research presented. Most notably, this study utilised data collected from a previous population based study (58) and the co-parenting alliance, as such, parental stress and the parent-sibling relationship were measured using a single questionnaire item. Therefore, generalisations must be made with caution and replication of the study using valid outcome measures is recommended. However, it is important to reiterate the purpose of this study as being exploratory, due to the lack of research literature to guide the generation of hypotheses. As such, the design does not allow for directionality of cause to be established. As such, the design does not allow for directionality of cause to be established. Secondly, the broad age range of the sample is a potential limitation; however, the univariate logistic regression analyses showed that child age did not significantly relate to negative co-parenting experiences in this study. Thirdly, the response rate of 14% observed in the present study is low (101). This may be because client contact details registered with the DSC are maintained sporadically and a number of records contained incomplete or inaccurate entries. Furthermore, for some families the questionnaire was only addressed to the father of the registered child due to a DSC database error. Consequently, mothers of separated couples may not have received the questionnaire and given that the vast majority of questionnaires were completed by the child's mother (80%), overlooking them would be expected to reduce the response rate. This is also supported by the finding that more respondents than non-respondents reported to be in two-parent household, indicating a potential underrepresentation of separated families. Thirdly, for some IVs the non-significant results may be due to a small sample size. For example, the presence of a mental health comorbidity was the final variable to be dropped from the multivariate model, possibly because the sample size was too small to adequately power the analysis (n=32). Similarly, the small number of respondents reporting a "very positive impact" prevented the analysis of factors associated with a positive co-parenting experience. However, the importance of exploring both positive and negative dimensions independently cannot be underestimated, as the factors associated with positive experiences do not necessarily mirror those associated with negative experiences (102-104). Parents who report that their child with ASD positively impacts upon their co-parenting relationship may be able to offer insight into the personal and relational strengths, strategies and resources they have found valuable. In doing so, they may offer hope to families who may be overwhelmed by the challenges they face.

3.6 Conclusions

This study provides a preliminary exploration of a neglected area of ASD research, namely, the impact of raising a child with ASD on the co-parenting alliance and lays the foundation for future research. Findings reveal that this impact is largely negative. Three factors were associated with negative co-parenting experiences. The first was family stress as a result of a child with ASD in the family. This outcome is perhaps not surprising, as studies have demonstrated a significant association between family stress and the parent alliance in families without a child with a disability, and families of children with ASD report higher levels of associated stress.

The second factor was a negative parent relationship with their other children. The interplay between the parent-sibling and co-parent relationship has, thus far, failed to capture the focus of researchers, and it undoubtedly deserves further attention. Lastly, negative co-parenting experiences were associated with greater distance of travel to medical facilities. This was another novel finding which may have particular relevance to the Australian populace and research in this context in warranted.

3.7 Declarations

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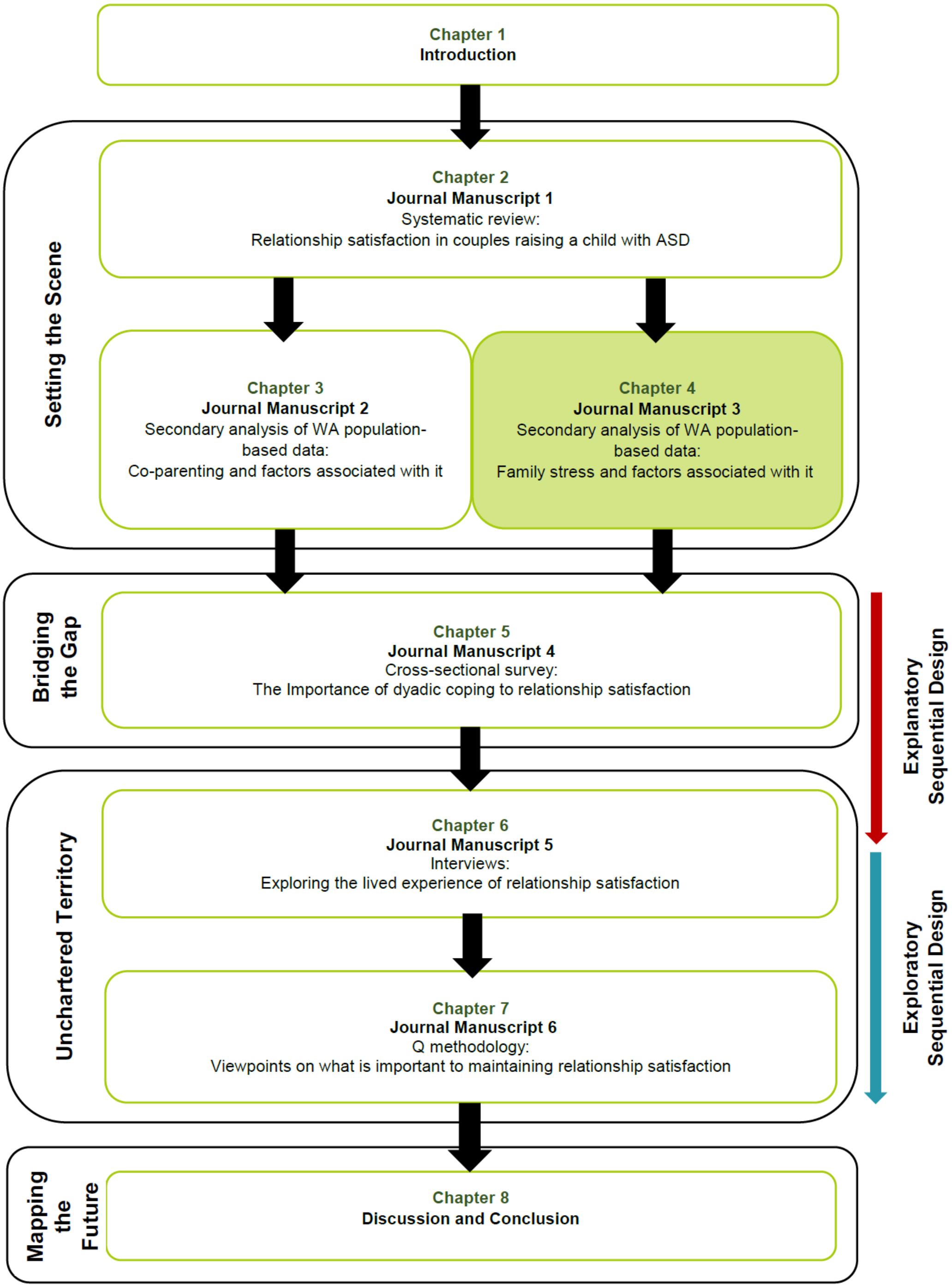
Chapter 4 Secondary analysis of population-based data #2

Chapter 4 outlines a study that investigated stress in families raising a child with ASD and examined the key factors associated with severe stress. The rationale for this study was derived from the findings from Chapter 2 and 3, which revealed stress as a significant factor associated with relationship satisfaction. West Australian, population-based data were obtained from a cross-sectional survey designed primarily to determine the costs associated with raising a child with ASD. The 73-item survey garnered information on a broad range of sociodemographic, child and family factors, as well as family stress. The findings from this study, together with those from Chapters 2 and 3, contributed to *setting the scene* for the thesis and determining the need and direction of the research.



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Factors associated with stress in families of a child with autism spectrum disorder

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4.1 Abstract

Purpose: The purpose of this study was to identify key factors associated with severe stress in families raising a child with autism spectrum disorder (ASD).

Methods: Questionnaires were mailed to families with one or more children with a diagnosis of ASD. Data from 543 surveys were analysed using univariate and multivariate logistic regression.

Results: Forty-four percent (n = 241) of the caregivers reported severe family stress associated with raising a child with ASD. Severe levels of family stress were associated with: 1) reduced ability to socialise; 2) not having accessed individual therapy; 3) negative co-parent relationships; and 4) high out of pockets costs due to the child's ASD. The specific ASD diagnosis, comorbid conditions, socio-demographic variables and social support were not associated with severe family stress.

Conclusion: The findings of the current study highlight the importance of a systemic approach to family stress whereby individual, family and ecological factors are investigated.

Keywords: ability to socialise, co-parent, cost, individual therapy, occupation.

4.2 Introduction

Raising a child with an autism spectrum disorder (ASD) can be rewarding; however, it can also place emotional, physical and financial challenges on the family (1). Families of children with ASD report higher levels of stress than families raising children without ASD (2-9). Many families report negative outcomes in terms of family cohesion and adaptability (1), quality of life, parenting efficacy (10-12), psychological health (13), and relationship satisfaction (1, 14). Despite these challenges, some families demonstrate resilience and adapt positively to raising a child with ASD (15, 16).

ASD is a life-long, multifaceted and pervasive condition characterised by impairments in social communication and interaction, and the presence of restricted, repetitive patterns of behaviour, interests or activities (17). Often, family life revolves around a child with ASD and such an intense focus on their needs often results in chronic stress and neglect of other aspects of family life (18). Challenges associated with raising a child with ASD can begin well before formal diagnosis and endure through the family lifespan (19). Furthermore, transitional periods, including, the time around diagnosis, entrance to school and transition to adulthood, that can be especially stressful for families (20). There are also additional stressors not specific to raising a child with ASD that can compound a family's experience of stress, including work, finances and other family issues (21, 22).

Empirical studies have largely focussed on the child and their ASD characteristics as the primary stressor in families. A number of these provide evidence to suggest that ASD severity is positively associated with caregiver stress (23-27). In particular, impairments in social skills appear to be salient stressors (28-30). However, behavioural challenges not central to the diagnosis, such as conduct and regulatory problems, have been implicated as greater predictors of stress than core ASD symptoms (31-35). Comorbid conditions are also common among children with ASD (17, 36-38), but their impact on family stress has been scarcely researched. The exception is intellectual disability, with current available evidence failing to reveal a significant relationship between cognitive functioning and stress (28, 39-41). The interpretation of findings and comparison of studies is complicated by methodological differences, heterogeneity in ASD presentation, and changing conceptualisations of ASD. Furthermore, most studies rely on self-report and the experience of stress may influence a caregiver's perception of symptom severity (19, 42). Regardless, it appears that high levels of stress can occur across the entire spectrum, including children traditionally considered 'higher functioning' (39, 40). It is likely that child characteristics explain only part of the stress experience in families and may be dependent upon contextual factors (19, 21, 41, 43). Thus, research needs to cast a wider net to capture the broad range of variables that affect these families.

Stress in families of a child with ASD may be related to socioeconomic factors. A diagnosis of ASD is usually associated with substantial lifetime costs to the family (4, 7, 44). Caregiving responsibilities sometimes require caregivers to take regular leave or resign from the workforce altogether (15, 45-47). Changes in employment status may affect household income making it more difficult to meet the costs of therapy, schooling and child care (15, 45). A recent Western Australian (WA) population-based study found that the median family cost of raising a child with ASD was AUD $34 900 per annum; 90% of the cost due to the loss of income from employment (48). It is commonplace for one caregiver to sacrifice his or her employment to accommodate caregiving responsibilities (15, 45-47) and for the co-parent to ameliorate the financial stress by increasing their working hours (15). As such, changing employment dynamics may compromise caregiving responsibilities and perpetuate family stress.

Another commonly reported stressor associated with raising a child with ASD is the family's limited ability to socialise (15, 46, 49). Family outings are often constrained by the child's behaviours, social stigma and the family's inability to have spontaneous social interactions (1, 15, 45). Equally challenging is finding family time without the child with ASD, due to the limited availability of child or respite care (45, 47). As a result, support systems may diminish (2, 6, 47) . Yet, previous studies underscore the importance of access to support systems in managing family stress (3, 50-53).

Many parents raising a child with ASD have reported that their partner is their most valued support (1, 54-56). One study found that the co-parenting alliance mediated the relationship between stress and child behaviours, such that caregivers of children with high functioning ASD experienced less stress when their co-parent relationship was strong (57).

A holistic understanding of stress in families with a child with ASD is vital if family-focussed ASD interventions are to be effective. Not only can family stress have a reciprocating impact on child outcomes directly (33, 58), it can create barriers to therapy such as reduced service engagement, therapy attendance, parental involvement and expectations for treatment, and can impair a caregiver’s ability to recognise positive changes in their child (19, 59-61). However, to date, family stress research has been limited to a narrow range of child and parenting variables, and has overlooked the contexts in which a child with ASD is embedded. Thus, this study sought to answer the following research question: What are the family and ecological factors associated with severe stress in families raising a child with ASD? It extends upon previous work by: 1/ using a large population-based sample, and 2/ studying family-centred variables pertaining to the social-ecological environment (including parent relationships with their partners and children without ASD, social participation and support); utilisation of family-directed intervention services (such as individual therapy and training for caregivers); and costs associated with raising a child with ASD (not just financial outlay but also the effect of lost income).

4.3 Method

4.3.1 Design

The current cross-sectional study collected data from a caregiver-report questionnaire developed primarily to investigate the costs associated with raising a child with ASD in the WA community (48). The questionnaire was comprised of 73 multiple-choice items which gathered information on the demographic profile of the family; the diagnostic process; the child’s symptoms, developmental history and treatment history; service utilisation; direct and indirect treatment costs; and family functioning and stress. Development of the questionnaire was informed by clinician and family reports, extant research literature and insurance reports. A pilot version of the questions and response formats was evaluated by a number of clinical psychologists, neuropsychologists, developmental psychologists, social workers, occupational therapists and other service providers. Their feedback informed the final version of the questionnaire which was piloted on three families with children with ASD. A copy of the full questionnaire can be found at http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0106552#pone.0106552.s001.

4.3.2 Participants and procedures

The questionnaire, packaged with a cover letter, information sheet and reply paid return envelope, was posted to 3,723 families with one or more children with ASD registered with the Disabilities Services Commission (DSC) of WA. Parents/guardians were asked to complete a separate questionnaire for each child with ASD, totalling 3,965 questionnaires. Five hundred and fifty-seven questionnaires were returned, resulting in a response rate of 14%. Of these, 543 contained sufficient data to be included in the analysis. This response rate is lower than that reported in similar ASD research (49, 62) and consequently carries a risk of response bias, which was investigated through an analysis of non-respondents.

4.3.3 Analysis of non-respondents

Six months after the initial distribution of questionnaires, a random sample of 405 families from the disability register were contacted. During telephone calls, families who had not completed the original questionnaire were asked to complete an abbreviated version consisting of 20 of the original items. These items included questions regarding the child’s gender, age, official ASD diagnosis, comorbidities and age at diagnosis; caregiver employment status; household composition; number of children with and without ASD in the family; ASD-related costs; the caregiver’s relationship with their co-parent and other children; and family stress. Subsequently, data from non-respondents were compared with those who completed the original questionnaire using independent *t*-tests and chi-square tests to determine if there were any differences between the two groups.

4.3.4 Statistical analyses

Data were managed and analysed using the SPSS Version 22.0 and SAS Version 9.2 software packages. Data were cleaned and managed using recommended guidelines (63). Descriptive statistics were run to describe the demographic profile of the sample. To address the research question in which the aim was to identify factors associated with *severe* levels of family stress, we chose to dichotomise the dependent variable and apply binary logistic regression. Our theoretical argument for this approach is that every family experiences stress to some extent and moderate stress levels are not necessarily maladaptive; it is the cumulative impact of sustained severe stress that can create a negative psychological response that interferes with family functioning (64, 65).

4.3.4.1 Dependent variable

Caregiver responses to the question “How would you rate your family's overall stress due to your child's ASD diagnosis?” were used as the dependent variable (DV) for the analyses. Responses to this question were given on a 6point scale, where 1 = no stress, 2 = mild stress, 3 = moderate stress, 4 = severe stress, 5 = very severe stress, 6 = worst possible stress. To reflect our aim to determine only the factors related to severe levels of stress, the categories were dichotomised such that responses of ‘severe’, ‘very severe’ and ‘worst possible stress’ were combined to create a variable labelled ‘severe stress’. The three remaining categories of ‘no stress’, ‘mild stress’ and ‘moderate stress’ were combined to serve as the reference category ‘low stress’ for the analyses.

4.3.4.2 Independent variables

The independent variables (IVs) included: 1) Socioeconomic status (SES) of the household ascertained using the Socio-economic Indexes for Areas (SEIFA), which assesses relative advantage and disadvantage of geographical areas in Australia in deciles (66). Decile 1 consists of the lowest 10% of households who represent the most disadvantaged, while decile 10 represents the highest 10% of household affluence. In the current study, residential postcodes reported by participants were matched to SEIFA deciles for analysis. Three categories of deciles (decile 1-5, decile 6-8 and decile 9-10) were created to determine whether stress in families varied as a function of their SEIFA index sub-group comparisons; 2) Total cost incurred by the family in order to raise the child with ASD, computed by summating the annual cost of treatment, treatment-related travel and loss of income due to reduced employment hours resulting from caregiving responsibilities. The cost of treatment was determined by totalling the reported out-of-pocket medical, therapeutic and complementary/alternative service costs. Treatment-related travel costs were calculated by multiplying the number of average visits per month by the distance to and from services reported by families. The resulting number of kilometres travelled was then multiplied by the cost per kilometre of running a small car (approximated at $0.65AUD by the Royal Automobile Club) and adjusted from a monthly to an annual estimate. To determine loss of income, the reported number of reduced working hours was converted to a proportion of full-time equivalent and multiplied by $48 864 (the median full-time income for 2010-2011 as reported by the Australian Taxation Office). For analysis, loss of income was divided into quartiles due to its skewed distribution (low quartile cost ≤ $22 033.60; mid 25-75 percentile cost = $22 033.61 – $52 808 and high quartile cost = > $52 808.01). This allowed the extreme ends of income loss to be compared against the median 50th percentile; 3) Household characteristics including household composition, total number of children and number of children with ASD; 4) Child characteristics such as age, gender, official ASD diagnosis (categorised according to DSM-IV(67) or 'other'), and presence of mental health, intellectual or medical comorbidities; 5) Caregiver characteristics including gender and whether they accessed therapy/counselling services or caregiver training (yes vs. no); 6) Relationship factors such as ratings of the co-parent relationship and the caregiver's relationship with their children without ASD (measured using a 5-point scale ranging from 'a great positive impact' to 'great negative impact' which were collapsed into a dichotomous variable to compare the 'positive impact' relative to the 'negative impact'); 7) Level of social support, measured through self-reported ratings on a 4-point scale ranging from "lots of social support" to 'no social support'; and 8) Impact on the caregiver's ability to socialise. This was measured through self-reported ratings on a 6-point scale. Due to low numbers, the categories of 'no impact', 'low impact' and 'moderate impact' were collapsed into a single variable labelled 'low impact' and the categories 'severe impact', 'very severe impact' and 'worst possible impact' were collapsed and labelled 'high impact'.

Univariate logistic regression analyses were conducted to identify the IVs that were significantly related to the caregiver's ratings of family stress. The significantly related IVs were entered into the logistic regression model using a backward stepwise procedure, as no a priori assumptions on their relative importance existed.

4.3.5 Ethical approval

Families of children with ASD registered with the DSC were sent questionnaire packs for the parent/guardian to complete. The pack included a cover letter from the Director General of DSC explaining the nature and purpose of the study and an information sheet explicitly outlining the voluntary nature of participation and the freedom of participants to withdraw at any time. It was stipulated on both the information sheet and the questionnaire itself that completion and return of the questionnaire would be taken as consent to participate. Ethical approval was obtained from the Curtin University Human Research Ethics Committee (HR 138/2012) and the internal ethical review board of the DSC in Western Australia.

4.4 Results

4.4.1 Descriptive profile of the sample

The majority of respondents reported experiencing ‘low stress’ (no, mild or moderate stress; n = 302, 55.6%), with the remaining 44.4% (n = 241) of families reporting ‘severe stress’ (severe, very severe or worst possible stress). See Figure 4-1.

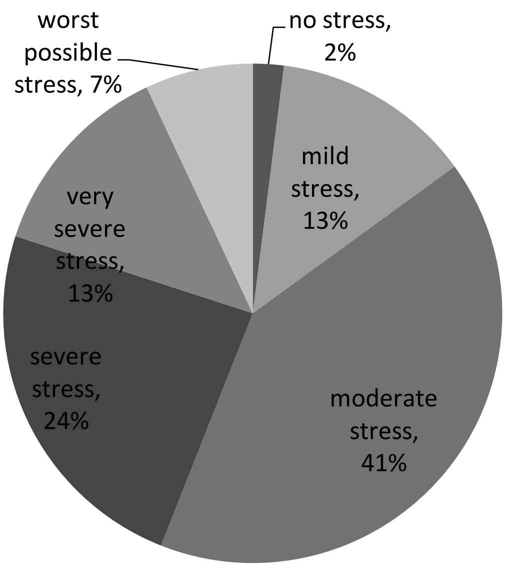

Figure 4-1. How would you rate your family's overall stress due to your child's ASD diagnosis?

Child and family characteristics are detailed in Table 4-1. A vast majority of the questionnaires were completed by the child’s biological mother (80%). More than 82% of the respondents were from a two-person household, 86.7% had more than one biological child and 29.7% had more than one child with ASD. Approximately 40% of families were in SEIFA decile 9 and 10, demonstrating high SES. The children with ASD were predominantly boys (over 80%) averaging 10 ± 4.2 years of age. The most commonly reported official ASD diagnosis was autism (50.9%) and mental health comorbidities were present in 21.6% of the sample.

Table 4-1. Demographic profile of the sample.

Demographic variables	**Total sample**		**Severely stressed families**		**Non-severely stressed families**	
	n	***%***	***n***	***%***	***n***	***%***
Child gender						
Male	449	83.0	194	81.2	255	84.4
Female	92	17.0	45	18.8	47	15.6
Respondent’s relationship to child						
Biological mother	436	80.6	192	80.3	244	80.8
Biological father	95	17.6	42	17.6	53	17.5
Other	10	1.8	5	2.1	5	1.7
ASD diagnosis						
Autism	274	50.9	142	59.9	132	43.9
High-functioning autism	138	25.7	47	19.8	91	30.2
Asperger syndrome	37	6.9	16	6.8	21	7.0
Pervasive developmental disorder-not otherwise specified	82	15.2	29	12.2	53	17.6
Other	7	1.3	3	1.3	4	1.3
How many biological children?						
0	4	0.7	4	1.7	0	0.0
1	68	12.6	34	14.2	34	11.3
2	256	47.3	110	46.0	146	48.3
3	147	27.2	59	24.7	88	29.1
4	51	9.4	25	10.5	26	8.6
5	15	2.8	7	2.9	8	2.7
How many children with ASD have one or more ASD sibling?						
0 (only child with ASD)	364	70.3	145	63.6	219	75.5
1 sibling	128	24.7	61	26.8	67	23.1
2 siblings	17	3.3	13	5.7	4	1.4
3 siblings	9	1.7	9	3.9	0	0.0
Presence of cognitive difficulties/intellectual disability						
Yes	148	27.6	81	34.0	67	22.4
No	389	72.4	157	66.0	232	77.6

Demographic variables	**Total sample**		**Severely stressed families**		**Non-severely stressed families**	
	n	**%**	***n***	**%**	***n***	**%**
Presence of other mental health/psychological conditions						
Yes	116	21.6	64	27.1	52	17.2
No	422	78.4	172	72.9	250	82.8
Presence of other medical conditions						
Yes	179	33.4	97	41.5	82	27.4
No	354	66.6	137	58.5	217	72.6
Household composition						
Two-parent	415	78.2	176	75.2	239	80.5
Single parent	75	14.1	39	16.7	36	12.1
Only extended family (e.g., grandparents)	4	0.7	1	0.4	3	1.0
Two-parent plus extended	24	4.5	9	3.8	15	5.1
Single parent plus extended	10	1.9	7	3.0	3	1
Foster situation	3	0.6	2	0.9	1	0.3
Socio-economic Indexes for Areas (SEIFA) categories						
Decile 1-5	146	27.5	66	27.6	80	27.3
Deciles 6-8	172	32.3	76	31.8	96	32.8
Deciles 9-10	214	40.2	97	40.6	117	39.9

4.4.2 Analysis of non-respondents

From the random sample of 405 participants, only 267 families were contactable, 203 of which had not completed the initial questionnaire. Of these, 146 completed the shortened version of the questionnaire for each of their children with ASD, totalling 171 children. With regard to the IVs included in the current study, respondents were significantly more likely to have a male child with ASD and report higher treatment costs associated with ASD. There were no significant differences found in caregiver ratings of family stress.

4.4.3 Univariate logistic regression analyses

Univariate logistic regression analyses were carried out to determine the IVs that were significantly related to caregiver perceptions of severe family stress due to ASD. Variables that did not reach significance included: 1) Official ASD diagnosis; 2) Caregiver gender; 3) Child age; 4) Child gender; 5) SES according to SEIFA deciles; and 6) Total number of children. Significant relationships were found between severe family stress and the following factors: 1) Impact of the child with ASD on their caregiver’s ability to socialise; 2) Whether caregivers accessed individualised therapy/counselling; 3) Impact of the ASD diagnosis on the co-parent relationship; 4) Total cost incurred by the family in order to raise the child with ASD ; 5) Household composition; 6) Presence of a comorbid mental health condition in the child with ASD; 7) Caregiver rating of their level of social support; and 8) Caregiver rating of the impact of having a child with ASD on their relationship with their children without ASD. These eight IVs were entered into the multivariate regression model. Only the first four were eventually used in the model, as the others did not significantly contribute towards the model.

4.4.4 Multivariate logistic regression analyses

The multivariate logistic model was tested for goodness of fit against a constant only model and found to be statistically significant ($\chi^2 = 5.064$, $df = 7$, $p < 0.001$). The included factors explained 61.5% of the variance of severe family stress, with a prediction success of 83.7%. In each regression analysis, the Wald criterion was used to identify statistically significant factors associated with the outcome, and the *Exp* (β) was used to determine the strength of prediction (Table 4-2).

Table 4-2. Factors associated with caregiver-perceived severe family stress due to their child's ASD diagnosis.

Variables in the model	Sample size (*n*)	Beta coefficient (β)	Standard Error (S.E.)	Wald	*p*	Odds Ratio Exp (β)	95% Confidence Interval for Exp (β)	
							Lower	Upper
Constant		-4.198	0.625	45.162	< 0.001			
1. Impact of child with ASD on parents' ability to socialise (high impact vs. moderate, low and no impact)	140 vs. 96	2.288	0.422	29.346	< 0.001	9.857	4.307	22.557
2. Access to individualised therapy/counselling (no vs. yes)	93 vs. 143	1.964	0.437	20.194	< 0.001	7.128	3.027	16.788
3. Impact of ASD diagnosis on relationship with co-parent/partner (negative vs. positive)	73 vs. 163	1.889	0.434	18.955	< 0.001	6.616	2.826	15.489
4. Annual cost associated with raising a child with ASD incurred by the family (annual travel + treatment in $ + loss of income)				12.902	0.002			
4.1. High cost[1] vs. Low cost	57 vs. 55	1.705	0.528	10.449	0.001	5.503	1.957	15.475
4.2. Mid-range[2] vs. Low cost[3]	124 vs. 55	2.119	0.628	11.397	0.001	8.319	2.432	28.462

Note. 1= 52,808.01+; 2 = 52,808.00 - 22,033.61; 3 = 22,033.60

The four IVs that contributed to severe family stress perceived by caregivers were:

1. Reduced ability of caregivers to socialise: Caregivers who reported a high impact (severe, very severe and worst possible impact) on their ability to socialise were 10 times more likely to also report severe stress, when compared with their counterparts who reported a less severe impact of ASD on socialisation (no, low and moderate);
2. Caregivers not having accessed individualised therapy/counselling: Primary caregivers who reported not having accessed individualised therapy/counselling, current or past, were 7 times more likely to report severe family stress than caregivers who did access individualised therapy;

3. Impact of ASD diagnosis on the co-parent relationship: Caregivers who reported a negative impact of ASD on their relationship with their partner/co-parent were 7 times more likely to be severely stressed when compared to their counterparts who reported a positive impact.
4. Annual cost associated with raising a child with ASD incurred by the family (annual travel + treatment in $ + loss of income):
    - Families who incurred high levels of annual costs were 8 times more likely to be severely stressed when compared with families who incurred low costs.
    - Families who incurred annual costs in the mid-range were in turn 6 times more likely to be severely stressed compared with families who incurred low costs.

4.5 Discussion

Research studies using validated measures have demonstrated that families of a child with ASD experience higher levels of stress than families with a child without a disability (2, 6, 68). Remarkably, the current study found that a majority of caregivers (56%) did not report severe levels of family stress. In fact, 2% of families reported experiencing no stress associated with raising a child with ASD. Similarly, an earlier study of families six months following their child's diagnosis of ASD found only moderate levels of family burden and concurrent stress (69). This finding could be the result of a self-selection bias whereby the family's stress influenced the likelihood of participation in the study; less-stressed families may have had more time and emotional resources to devote to research. Regardless, the diversity of family responses to potentially stressful situations is evident. Investigating such diversity should be a focus of future research with attempts made to explain resilience processes and identify protective factors that can be targeted through strength-based intervention approaches.

In the current study, families were more likely to be severely stressed if raising a child with ASD reduced the caregiver's ability to socialise. Caregivers of a child with ASD commonly report experiences of social isolation attributed to a number of factors including their child's functioning and behaviours; caregiving responsibilities; a negative community attitude; the inability to have spontaneous social interactions; and lack of suitable child care and respite (1, 15, 45, 47, 70). Yet, social support can play a vital protective role for families in times of stress (3, 25, 52, 71). Furthermore, the participation of caregivers in social activities is integral to the social participation of their child with ASD (72) and with it vital opportunities for social learning, development of peer relationships and quality of life (73-76). This is salient given that social difficulties comprise a core characteristic of ASD (17) and have been identified as a predictor of parenting stress (28, 29). This finding highlights the importance of collaborating with families to identify meaningful social activities and ways to overcome barriers to social participation as part of a comprehensive approach to managing stress.

Families were more likely to experience severe stress if the caregivers had not accessed individual therapy. Individual therapy or counselling may be a valuable resource for caregivers to help them cope with the challenges associated with raising a child with ASD by enabling them to tell their story; have their emotions validated; make sense of the situation; identify personal strengths and resources; and set explicit, realistic goals (77-79). Furthermore, therapy aimed at managing psychological conditions in caregivers may be beneficial given the higher rate of mental health problems in this population (27, 80, 81); a consequence of the stressors of raising a child with ASD (82, 83) as well as a genetic predisposition (84-86). In the current study, approximately 49% of caregivers who perceived severe family stress did not access individual therapy. Although speculative, it is plausible that the stressors experienced by caregivers, such as financial stress, time constraints and lack of support, created a barrier to access. However, with a dearth of research investigating mental health service use by caregivers, further study is warranted. Individual therapy for caregivers may serve as a valuable adjunct to family-centred ASD interventions on the premise that caregiver wellbeing can influence ASD symptomology and behavioural challenges (87, 88) and intervention outcomes (19, 89).

Another factor associated with severe levels of caregiver-perceived family stress was the negative impact of ASD on the co-parent relationship. This is consistent with findings from earlier research in families of children with ASD (57, 90); families of children with intellectual disability (91); and families of children without a disability (92, 93). A co-parent is often the most important source of informal support for caregivers raising a child with ASD and therefore a valuable protective resource (1, 55, 56, 94). Lack of support from a co-parent is associated with greater internalising, externalising and antisocial behaviour in children (95, 96), a documented source of stress for families (28, 33, 83). Conversely, a healthy co-parenting alliance mediates the relationship between parent stress and the experience of challenging behaviours in children (57). Furthermore, the co-parenting relationship is integral to both intact and separated families and may play a pivotal role in reducing family stress and facilitating positive child adjustment during and after the separation process (97-99). Thus, a strong co-parent relationship can act to stabilise families in times of stress and enhance the wellbeing of caregivers and children alike (100, 101).

We also found that families who incurred high ASD-related costs (including travel, treatment and loss of income) were eight times more likely to be severely stressed than those who incurred low ASD-related costs. ASD is a lifelong condition requiring ongoing therapeutic intervention and medical management of concomitant disorders such as epilepsy, sleep difficulties, gastrointestinal problems and psychological conditions (36, 102-104). Furthermore, research has shown that between 62% and 95% of families access complementary and alternative therapies (105-108). Altogether, families sometimes access up to seven forms of treatment concurrently (109) and the associated costs can accumulate. Moreover, highly stressed families utilise a greater number of services, perpetuating the cost-stress relationship (110). However, the greatest cost to families appears to be lost income, which has been found to constitute 90% of annual ASD-related costs (48). This is predominantly due to changes in employment status necessitated by the caregiving demands of a child with ASD (15, 45). Such changes not only have financial implications; paid employment has been positively associated with psychological wellbeing in mothers of children and adults with disabilities (111-114). Mothers have expressed dissatisfaction and resentment over the sacrifices made to their careers (56) which have led to feelings of isolation, lack of fulfilment and low self-esteem (115). Employment opportunities may play a protective role against stress in families by providing caregivers with opportunities to access social support and respite from caregiving (115). Together, these findings demonstrate the need for a multifaceted approach in managing finance-related stress that extends beyond financial assistance to facilitate participation in paid occupation for whom it is meaningful. These caregivers should be supported in identifying jobs consistent with their aspirations and abilities, and balancing work demands with caregiving (115). There is a need to address barriers to employment reported by caregivers, including the poor availability of suitable child care, lack of family-centred services and unsupportive work environments (114).

There were three findings of non-significance in the current study that are worthy of discussion. Firstly, the ASD diagnosis (according to DSM-IV categories) was not significantly associated with severe family stress, nor was the existence of comorbid psychological, cognitive or medical conditions. This may reflect the concerns that spurred recent changes in the DSM-5, being that distinctions between autistic disorder, Asperger’s syndrome and pervasive developmental disorder-not otherwise specified were inconsistent and likely a variation of the same underlying aetiology (116). The lack of significance for psychological comorbidities was surprising given previous findings that additional psychiatric disorders in adolescents and adults with ASD was associated with increased burden (117). Diagnostic challenges and methodological limitations were likely to have affected our results. However, the clinical implication of these findings is apparent; family-focussed stress interventions should not discriminate families based on specific ASD diagnostic labels or the presence of concomitant conditions.

The second non-significant finding was the relationship between severe family stress and socio-demographic variables, such as SES, caregiver and child gender, child age, household compositions and total number of children. One of the most researched of these variables is caregiver gender; however, findings are mixed. In support of the current finding, one study found no gender difference in levels of stress (35). Other studies have found a significant difference in stress perceptions between caregivers; however, the direction of this difference is not consistent. Some studies show greater stress levels reported by the father (118-120), while others have found mothers to have greater stress levels (56, 121). Some researchers have postulated that higher levels of stress may be more to do with caregiving roles than gender (45, 56, 120, 122). This highlights the potential for different stress experiences in family members based on their role in the family and supports an individualised approach to intervention. Furthermore, there are interaction effects that require further investigation. For example, there may not be a direct relationship between SES and stress, but SES may influence the impact of ASD-related costs (123), the ability to socialise (124) or the co-parent relationship (125).

Lastly, the lack of significance found for an association between severe stress and levels of social support and frequency of respite was surprising given that the extant research supports a link (53, 56, 126). Social resources are considered factors of resilience (127). However, it could be that global evaluations of support in this study did not allow for the relative importance of the various sources of support. For example, the findings are clear for an association between stress and support from a co-parent, but the value of support from families, friends, community groups and professionals were not assessed separately. Social support literature also emphasises the need to distinguish between quantity and quality of support (128), and actual and perceived support (129). Outcomes may have been different had this study made these distinctions. It is also important to note that while no significant direct relationships were found, social support and respite may have an indirect effect on family stress through other variables, such as the ability to socialise, engage in employment and costs to the family, and such interactions should be explored further.

4.5.1 Limitations

The findings of this study should be viewed cautiously due to several limitations. Most notably, the questionnaire was not validated and ratings of family stress, co-parenting and ability to socialise were collected using single questionnaire items. Due to the need to collect detailed data pertaining to the costs associated with raising a child with ASD, the inclusion of additional items had to be considered with respect to the impact of the length on the response rate. Consequently, compromises were made to the depth and detail of the secondary data collected, and generalisations must be made with caution. Replication of the study using valid outcome measures that capture the different dimensions of stress is recommended. The cross-sectional design of the study does not allow for causal relationships to be established, nor does it provide an understanding of stress as a multidimensional, transactional process that changes over time. Additionally, this study did not examine the dynamic interplay between the stressors and future research would benefit from more sophisticated modelling techniques to investigate the ways in which the variables interact to exacerbate or mitigate stress in families. A further limitation is the low response rate (14%) (130). This may be due to incomplete or inaccurate client contact details registered with the DSC. For example, a database error resulted in the questionnaire being addressed to the father of the registered child for some families. Consequently, mothers of separated couples may not have received the questionnaire, thereby reducing the response rate as the mothers were more likely to respond (80%). This is also supported by the finding that more respondents than non-respondents reported to be in a two-parent household, indicating a potential underrepresentation of separated families.

With regards to the sample, a majority of respondents were mothers whose perceptions may not be representative of the fathers or siblings. Consequently, the data collected may not provide a comprehensive depiction of family stress (118, 131-134). The sample was also over-represented by affluent families whose ability to access therapy and support may not be representative of the greater community. Another limitation is the broad age range of the sample; however, the univariate logistic regression analyses showed that child age did not significantly relate to severe levels of family stress in this study. Finally, the ASD diagnosis was not independently verified, creating a potential misclassification bias.

4.5.2 Implications for practice

The findings from the current study support the need for a multifaceted approach to managing stress in families that decentralises the child with ASD and considers the broader context in which the child is embedded. We found that raising a child with ASD can lead to family stress through various layers of the family system and therefore recommend family systems theories as the scaffolding for future research, policy development and service provision (135, 136). For example, at the individual level, family stress may be influenced by caregiver outcomes associated with individual therapy and engagement in meaningful occupations beyond caregiving (such as socialising and employment). At the sub-systemic level, strengthening the co-parenting relationship may act as a protective factor for the whole family. At the systemic level, stress in families may be ameliorated by minimising environmental barriers to social participation and employment, and addressing economic issues associated with raising a child with ASD. Working across these domains necessitates a transdisciplinary approach and there is a need for direct interventions together with advocacy to raise public awareness and drive policy change.

In practice, such a comprehensive approach presents challenges that may, counterproductively, exacerbate stress in families of children with ASD. Families may find themselves juggling multiple service providers and having to reconcile contradictory perspectives (137). The resulting costs, in terms of monetary, time and emotional resources (60, 82, 137, 138), may lead to financial strain and less time for socialising and employment; significant stressors found in this study. Practices that are family-centred may help reduce stress, improve psychological wellbeing and satisfaction with services (138, 139). Involving all family members in assessment and intervention is imperative to facilitate a rich understanding of the family's unique experiences and empower them to share responsibility for change (138). To do this, flexibility in service delivery is essential. For example, service providers need to offer appointments outside of work hours if work-force participation is a goal of stress management.

4.5.3 Conclusion

A majority of families reported low to moderate stress levels related to raising a child with ASD, challenging previous notions that raising a child with ASD equates to experiences of severe family stress. Family experiences are multifarious and further investigation of positive adaptation can enhance understanding of resilience factors. For those families who reported severe levels of stress, the experience was associated with four factors: 1) the restricted ability of caregivers to socialise; 2) caregivers not having accessed individual therapy; 3) a negative co-parent relationship; and 4) high ASD-related costs, recognising the contribution of travel cost and lost income to financial burden in addition to treatment costs. Interestingly, severe family stress was not directly associated with the studied child characteristics (age, gender, official ASD diagnosis) or demographic variables, such as household composition. The findings demonstrate the relevance of systemic approaches to stress research and interventions whereby the child is considered in context of the whole family system, as well as the broader social environment. A shift from child-centred to family-centred practices would facilitate a more comprehensive understanding of stress experiences and optimise outcomes in families raising a child with ASD.

4.6 Declarations

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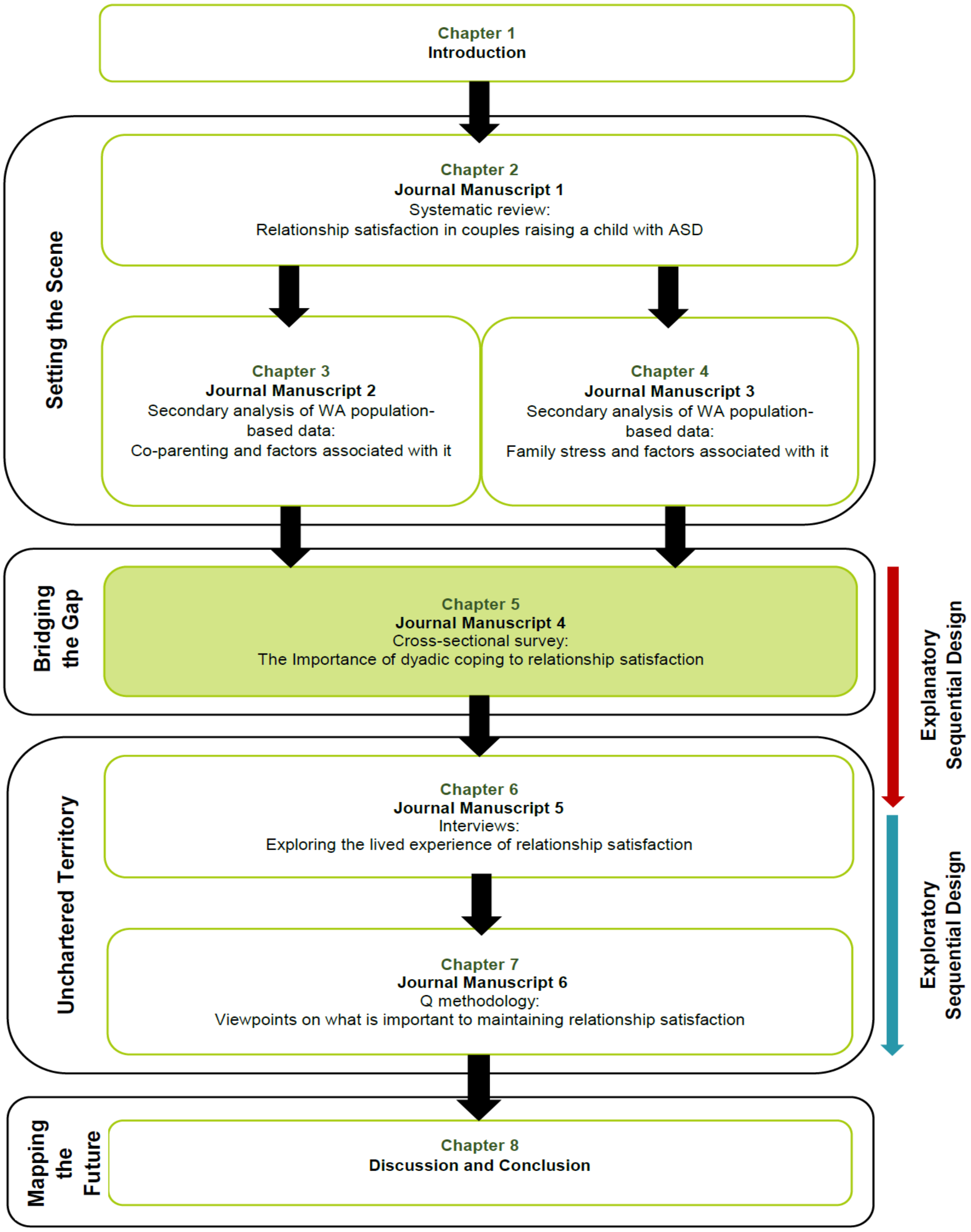
Chapter 5 Cross-sectional survey

Chapter 5 comprises a study developed to *bridge the gaps* identified in Chapters 2, 3 and 4. The main gaps highlighted were the failure to recognise positive couple adaptation to raising a child with ASD; lack of couple data and the consideration of each parent’s likely bidirectional influence on each other. Thus, the purpose of Chapter 5 was to investigate levels of relationship satisfaction in couples with a child with ASD and factors associated with a *satisfying* relationship, with emphasis on dyadic coping strategies as a way to manage stress and promote positive couple adaptation. This was achieved through the selection of appropriate analyses that accounted for the interdependent nature of couple data.



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Relationship satisfaction and dyadic coping in couples with a child with autism spectrum disorder

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5.1 Abstract

Dyadic coping strategies may play a pivotal role in relationship satisfaction and explain why some couples adapt positively to the challenges associated with raising a child with ASD and others do not. Survey data from 127 caregivers of a child with ASD were used in generalized estimating equation analyses to investigate the factors associated with relationship satisfaction, including socio-demographics, parenting stress and dyadic coping. Results showed that over two-thirds of the sample reported satisfaction, which was associated with low parenting stress, increased use of positive and decreased use of negative dyadic coping strategies. Positive dyadic coping was found to have a greater influence than negative dyadic coping, supporting a strengths-based approach to interventions promoting family resilience.

Keywords: ASD; marriage; parenting stress; partner support; resilience; strengths.

5.2 Introduction

Raising a child with autism spectrum disorder (ASD) can have a pervasive, dynamic and enduring impact on the entire family system (1-4), at the center of which is the couple relationship (5). Couples' responses to these challenges are diverse, yet research has focused predominantly on negative processes leading to conflict, relationship dissatisfaction and separation. Little attention has been given to positive outcomes despite evidence that relationship satisfaction may be a protective resource in families raising a child with ASD (6-8).

The transition to parenthood is commonly associated with decreased relationship satisfaction (9-11); however, couples appear to be at a greater risk if they have a child with ASD (12). Moreover, couples with a child with ASD typically show continued decline in satisfaction across the child's transition to adulthood (13) during which time couples without a child with ASD show an increase in satisfaction (10, 14). Despite this, there is evidence that a majority of couples raising a child with ASD maintain levels of satisfaction above that which is indicative of distress (15, 16). Furthermore, there are qualitative reports that raising a child with ASD can actually strengthen some relationships, demonstrating a great variability in couple adaptation (17-22).

It is not clear why some couples with a child with ASD adapt positively and others do not, although a broad range of factors have been implicated. A recent systematic review (12) investigated these factors and revealed inconsistent findings largely due to conceptual and methodological limitations. The strongest evidence highlighted challenging child behavior, parenting stress and psychological wellbeing as risk factors for relationship satisfaction, mediated by positive appraisal and social support. The authors acknowledged the interrelatedness of variables in a theoretical model. At the heart of the model is the child with ASD and associated parenting stress, which is exceptionally high in this population (23). This stress can constitute daily hassles and accumulate (24, 25), beginning before formal diagnosis and enduring throughout the family lifespan (2, 26). There are myriad sources of parenting stress (27), but challenging child behavior is, arguably, one of the strongest predictors (28-30) with mutually escalating effects (31). Parenting stress can negatively affect psychological wellbeing (15, 27, 32) and through it, relationship satisfaction (33). The child's behaviour can also impact on parent wellbeing and relationship satisfaction through the parent-child relationship and parenting efficacy (15, 34-36). For instance, a child with ASD may not always respond to interactions as expected, leaving parents feeling disempowered and ineffectual in their parenting capabilities (37). Positive appraisal and coping processes can buffer these effects. Caregivers who view their situation positively and are optimistic about the future are more likely to experience relationship satisfaction (34, 38, 39), as are those who report adequate social support (15, 25, 38). The model presented in the systematic review (12) embeds these transactions in broader ecological contexts which can influence stress, coping and relationship satisfaction. For example, there is need to consider additional life stressors unrelated to parenting (40, 41), genetic factors (42), societal attitudes (43), and availability of resources and access issues (4, 22). Reciprocally, relationship factors can influence caregiver and child outcomes (6, 13, 15) creating complex cyclical processes. Furthermore, there is evidence of cross-partner effects; the psychological adaptation of one partner affecting the other (36).

To expand on the relationship satisfaction model, factors intrinsic to the relationship and the effect of partners on each other require investigation. The systemic-transactional model (STM; 44, 45, 46) posits that couples share stress experiences and this process triggers a joint coping response (dyadic coping) promoting adaptation. If couples are able to provide each other with support and cope positively together, the deleterious effects of a stressor can be minimized; thereby fostering a sense of togetherness, mutual trust and satisfaction in the relationship.

According to the STM (44-46), dyadic coping can be categorized into four types: 1) *Supportive* dyadic coping occurs when one partner assists the other with coping efforts, with the secondary goal of reducing their own stress and maintaining the wellbeing of the relationship; 2) *Delegated* dyadic coping is when one partner explicitly asks the other to take over responsibilities to reduce their personal experience of stress; 3) *Common* dyadic coping is a joint coping process in which both partners work together to address a mutually experienced stressor; and 4) *Negative* dyadic coping includes unhelpful strategies such as hostility, ambivalence and insincerity*.* Supportive, delegated and common dyadic coping represent positive forms of coping.

There is substantial research supporting an association between relationship satisfaction and dyadic coping in both clinical and non-clinical populations. A meta-analysis (47) of 72 independent samples (totaling 17,856 participants) demonstrated a strong positive association regardless of gender, age, nationality, education or length of relationship ($r = 0.45$, $p < 0.001$, 95% CI [0. 41, 0.48]). When analyzed separately, a moderate to strong association was found for each dimension of dyadic coping; however, the strongest predictor was common dyadic coping. Dyadic coping dimensions were also aggregated into positive and negative and, while both reached significance (inverse), positive dyadic coping was found to be the stronger predictor. This suggests that efforts to strengthen positive dyadic coping may be more effectual than trying to reduce negative dyadic coping behaviors (Falconier, Jackson, Hilpert, & Bodenmann, 2015). Moderate to strong associations between mothers' and fathers' supportive dyadic coping and both their own and their partner's relationship satisfaction have also been found in couples raising a child with ASD (6). Additional research also demonstrates a link between relationship quality and partner support (38, 48).

The importance of studying relationship satisfaction is highlighted by growing evidence that it can protect families against the challenges associated with raising a child with ASD (6-8, 15, 39, 49). Furthermore, it can influence child development and couple interventions show promise for preventing childhood adjustment problems in the general population (50-53). For children with ASD, caregivers serve as "gatekeepers to their children's access to services" (54, p. 58) and with increasing use of parent-mediated interventions, support for caregivers is crucial (2, 55-58). One of the most important sources of caregiver support is their partner (7, 48, 59), making the relationship an important focus of research, yet it is unclear what factors are important to maintaining satisfaction in couples raisng a child with ASD.

The current study aims to investigate factors associated with relationship satisfaction in couples raising a child with ASD in the hope of identifying target variables for interventions aimed at improving relationship outcomes in this population, a gap in current research literature. We propose that dyadic coping strategies play a pivotal role in relationship satisfaction and may help explain why some couples adapt positively to the challenges of raising a child with ASD, whereas others do not. Based on the literature, the following hypotheses were postulated:

1. A majority of caregivers of a child with ASD will report satisfaction in their relationship with their partner.
2. Relationship satisfaction will have a significant inverse association with parenting stress in couples raising a child with ASD.
3. Relationship satisfaction will be positively associated with the positive dyadic coping dimensions of supportive dyadic coping, delegated dyadic coping and common dyadic coping and inversely associated with negative dyadic coping (e.g., being ambivalent, hostile or insincere) in couples raising a child with ASD.
4. Positive dyadic coping strategies will have a greater relative contribution to relationship satisfaction than negative dyadic coping strategies.

5.3 Methods

5.3.1 Participants and procedures

This study used a cross-sectional survey design. Participants were primarily recruited through the [name deleted to maintain the integrity of the review process] participant list, consisting of aprroxmately 250 families. This is a list of families with a child with ASD registered with the Disability Services Commission of [name deleted to maintain the integrity of the review process] who have indicated a willingness to be contacted regarding ASD research. Additional recruitment was carried out at university and community events targeted at the autism community and flyers were emailed to two parent support groups. Thus, the sample was largely community-based.

Each family was contacted by phone or email (depending on their documented preferred method of contact). To be eligible for the study, caregivers had to be cohabiting and be the primary caregivers of a child with ASD (0-18 years). Participants were offered the choice of completing the survey online, through a telephone interview or by completing a paper version which could be mailed to them.

An information sheet and consent form were forwarded with the survey, outlining study details and ethical procedures. Participants were informed that by submitting the survey online they were implicitly consenting to participation; however, remained free to withdraw at any stage without providing a reason. Both partners in a couple were encouraged to complete a survey independently. If caregivers had more than one child with ASD, they were asked to answer the questions with consistent reference to one child. To maintain confidentiality, each survey was individually coded and free of identifying information. Ethics approval was obtained through the Curtin University Human Research Ethics Committee (OTSW-05-2014).

5.3.2 Measures

The survey consisted of questions pertaining to socio-demographic and family characteristics and three validated questionnaires (described below). Prior to distribution to families, the survey was reviewed by clinicians and researchers in the field of ASD and piloted on caregivers with and without a child with ASD. Revisions were made in accordance with feedback.

5.3.2.1 Socio-demographic characteristics

The socio-demographic questionnaire collected information regarding child characteristics (i.e., gender, age, ASD diagnosis, presence of comorbid conditions); respondent’s gender and their relationship to the child; total number of children with and without ASD in the household; and residential postcode. Postcodes were used to determine the socio-economic status of couples using the Socio-Economic Indexes for Areas (SEIFA) developed by the Australian Bureau of Statistics. Each area in Australia is ranked according to relative advantage and disadvantage and assigned a percentile rank.

Additional questions gathered ratings of perceived levels of social support; frequency of respite use; parents’ ability to socialize; and the impact of raising a child with ASD on the caregiver’s relationship with their children without ASD. The format for these questions varied, but the majority were based on a five- or six-point rating scale.

5.3.2.2 Relationship satisfaction

The 32-item *Couple Satisfaction Index-32* (60) was used to measure the respondent's satisfaction with their relationship with their partner. It is a standardized, self-report scale using a variety of item response formats but mostly six-point scales. Examples of questions include: "To what extent has your relationship met your original expectations?" and "I have had second thoughts about this relationship recently". Responses are summed and total scores range from 0-161. Scores above 104.5 are taken to indicate relationship satisfaction. The authors have demonstrated strong construct and convergent validity and report good internal consistency (α = 0.94).

5.3.2.3 Parenting stress

The *Parental Stress Scale* (61) is a self-report scale reflecting positive and negative themes of parenting. Respondents rate their agreement with 18 statements on a five-point scale, ranging from 1 (strongly disagree) to 5 (strongly agree). Example questions include: "Having child(ren) gives me a more certain and optimistic view for the future" and "I feel overwhelmed by the responsibility of being a parent". Summed scores range from 18-90 with higher scores indicating higher levels of stress. The authors report satisfactory internal consistency (0.83) and test-retest reliability (0.81). Convergent validity with the Perceived Stress Scale (62) and Parent Stress Index (63) has been established. The Parental Stress Scale was selected as discriminant analysis showed it to be effective for mothers, fathers and respondents representing different family constellations, who are raising children with or without developmental and behavioral concerns (61). It is also brief and easy to administer and score.

5.3.2.4 Dyadic coping

To measure perceived coping within the couple relationship, the English version of the 37-item *Dyadic Coping Inventory* (64) was used. Respondents rated their own and their partner's coping behavior (15 items each) and common coping behaviors (7 items). The items are rated on a five-point scale ranging from 1 (very rarely) to 5 (very often) and sample questions include: "I tell my partner openly how I feel and that I would appreciate his/her support", "My partner provides support, but does so unwillingly and unmotivated” and “We try to cope with problems together and search for ascertained solutions”. The English version was validated on a US sample (n = 938; 65). Confirmatory factor analysis identified a five-factor structure each for dyadic coping by *oneself* and *one’s partner (*stress communication, delegated dyadic coping, emotion-focused supportive dyadic coping, problem-focused supportive dyadic coping and negative dyadic coping) and a two-factor structure for *common* dyadic coping (problem-focused common dyadic coping and emotion-focused common dyadic coping). Convergent and discriminant validity showed that Dyadic Coping Inventory scales were more correlated with the dyadic construct of relationship satisfaction than with individual coping constructs. Measurement invariance showed that observed score differences across gender and culture were due to true differences on the factor mean allowing meaningful comparison across the groups.

5.3.3 Data management and analysis

Data were collected via an online survey program (Qualtrics) and downloaded directly to the SPSS Version 22 software package before being cleaned and managed using recommended guidelines (66). All data were stored and handled ethically, according to the Australian Code for the Responsible Conduct of Research (67) and Curtin University guidelines. Validated questionnaires were scored and mean scores were calculated for each participant. Descriptive analyses were conducted to summarize the data and describe the sample. There were no missing data

Univariate (chi-square) and multivariate (generalized estimating equation [GEE]) analyses were conducted to identify factors associated with relationship satisfaction. The dependent variable (DV) was relationship satisfaction, recoded into binary categories of “satisfied” versus “dissatisfied” in accordance with the Couple Satisfaction Index cut-off score. Independent variables (IVs) included socio-demographic and family data, parenting stress and dyadic coping. Parenting stress was classified into categories of high stress (scores of 40 and below) and low stress (scores above 40). These categories were determined by examining the linearity of Parental Stress Scale quartiles; the cut-off score was selected between the first and second quartile consistent with a large increase in relationship satisfaction scores around that point. The Dyadic Coping Inventory was kept as a continuous variable. Univariate Chi-square tests were conducted to assess the associations between the IVs (including socio-demographic and family profile variables) and relationship satisfaction. When measuring associations between relationship satisfaction and IVs, only those IVs that approached significance (i.e., $p < 0.1$) were included in the multivariate GEE models. GEE was selected due to the violation of the assumption of independence, as responses from partners within the same family were expected to be correlated (68). The GEE model is similar to the Logistic regression model, except that it takes into account this internal correlational structure within the data. While the Chi-square (univariate) analyses are not strictly correct, because of this internal correlational structure, they give an approximate significance level which is used to guide inclusion of variables in the multivariate models. Results of the GEE model are presented in a manner similar to Logistic regression (Odds Ratios, their 95% confidence intervals and *p*-values). Two separate GEE models were developed using different Dyadic Coping Inventory scales. In the first model, the five coping factors for *oneself* and *one's partner* (stress communication, delegated dyadic coping, emotion-focused supportive dyadic coping, problem-focused supportive dyadic coping and negative dyadic coping) and the two factors for *common* dyadic coping (problem-focused common dyadic coping and emotion-focused common dyadic coping) were used to determine which dimensions of dyadic coping were associated with relationship satisfaction. In the second model, the Dyadic Coping Inventory aggregate scales for positive dyadic coping (comprising of supportive, delegated and common dyadic coping factors) and negative dyadic coping were entered to compare their relative contribution to relationship satisfaction. The DV and other IVs were kept the same for both models. A backward elimination strategy was used whereby all IVs were initially included in the model, then the least significant variable removed, one at a time, until all variables remaining in the model were associated with the outcome. When all significant main effects were identified, their pairwise interaction terms were tested for statistical significance (one at a time). The critical α-level was set at 0.05 in all tests. An odds ratio greater than 1 indicated a greater likelihood of satisfaction in the relationship.

Two Mann-Whitney *U* tests were conducted to identify group differences in median scores for relationship satisfaction, parental stress and dyadic coping. The first test compared respondents whose partner also participated with those whose partner did not participate. The second test compared gender differences within families where both partners participated in the study. Results are quoted as *p*-values from these tests, together with the median and interquartile ranges (IQR) for the outcomes.

5.4 Results

A total of 127 surveys were received from 83 families with a total of 142 children with ASD; in 44 families, both parents completed a survey (88 surveys) and in 39 families only one of the parents completed a survey.

5.4.1 Descriptive statistics

Biological mothers comprised 62% of the survey respondents, with 32% being biological fathers and 6% comprising stepfathers. Just over half (54%) of families had two children and 89% had just one child with ASD. In 80% of families the child with ASD was male and the mean age of the children with ASD was 129 ± 46 months. The primary diagnosis was autism in 44% of cases, and comorbid intellectual disability, mental health conditions and physical/medical conditions were present in 25%, 29% and 22% of children, respectively. SEIFA percentiles were recoded into quartiles; 44% of families lived in areas assigned to the highest quartile, suggesting high socio-economic advantage. Relationship satisfaction was reported in 65% of the survey respondents. Descriptive statistics are tabulated in Table 5-1.

Table 5-1. Sample characteristics.

	Sample *N* = 127	**Percentage**
Child gender		
Male	102	80.3
Female	25	19.7
Parent gender		
Male	48	37.8
Female	79	62.2
Relationship to child		
Biological father	41	32.0

Biological mother	80	62.5
Step father	7	5.5
Total number of children		
1	15	11.8
2	68	53.5
3	27	21.3
4 or more	17	13.4
Total number of children with ASD		
1	113	89.0
2 or more	14	10
ASD Diagnosis		
Autism	56	44.1
High-functioning autism	36	28.4
Asperger’s syndrome	22	17.3
Pervasive developmental disorder-not otherwise specified	13	10.2
Comorbid intellectual disability		
No	95	74.8
Yes	32	25.2
Comorbid psychological condition		
No	90	70.9
Yes	37	29.1
Comorbid physical or medical diagnosis		
No	99	78.0
Yes	28	22.0
SEIFA quartiles		
1 (0-25th percentile)	3	2.4
2 (26-50th percentile)	26	20.4
3 (51-75th percentile)	42	33.1
4 (76th-100th percentile)	56	44.1

5.4.2 Univariate analyses

The univariate (chi-square) analyses (based on N=127 responses) revealed significant associations between relationship satisfaction and the following IVs: (a) parent gender, $\chi2$ (df = 1) = 5.28, $p < 0.05$, (b) psychological comorbidity with ASD, χ^2 (df = 1) = 3.99, $p < 0.05$, (c) total number of children cared for, χ^2 (df = 1) = 4.45, $p < 0.05$, (d) the ability of caregivers to socialize, χ^2 (df = 3) = 7.38, $p < 0.1$, and (e) parental stress, χ^2 (df = 1) = 12.99, $p < 0.001$. These IVs were included in the multivariate GEE models.

5.4.3 Generalized estimating equation (GEE) analyses

Results from the GEE analyses are shown in Table 5-2. The *first* GEE analysis included the Dyadic Coping Inventory dimensions defined by the factor structures and other IVs identified for inclusion from the univariate analyses. No significant interaction effects were found (all *p*-values for interaction terms >0.2). The following factors reached significance for main effects:

1. *Parental stress* – caregivers raising a child with ASD who reported low levels of parental stress were 8.6 times more likely to experience relationship satisfaction than caregivers who reported high levels of parental stress.
2. *Problem-focused supportive dyadic coping* –relationship satisfaction increased by 2.3 for every unit increase in reported problem-focused supportive dyadic coping.
3. *Problem-focused common dyadic coping* – relationship satisfaction increased by 2.2 for every unit increase in reported problem-focused common dyadic coping.
4. *Emotion-focused common dyadic coping* – relationship satisfaction increased by 2.4 for every unit increase in reported emotion-focused common dyadic coping.
5. *Negative dyadic coping* – relationship satisfaction increased by 4.2 for every unit decrease in the reported use of negative dyadic coping.

No significant association was found between relationship satisfaction and either emotion-focused supportive dyadic coping or delegated dyadic coping.

Table 5-2. Results from the GEE model: Factors associated with relationship satisfaction in couples raising a child with ASD (using Dyadic Coping Inventory factors structures).

Variables in the model	**B**	***SE***	**Hypothesis Test**			***OR***	**95% Wald CI for *OR***	
			Wald Chi-square	***df***	***p*-value**		**Lower**	**Upper**
Low stress (Parental Stress Scale = 40 and below)	2.15	0.64	11.41	1	0.001	8.61	2.47	30.06
High Stress (Parental Stress Scale = 41 and above)	-	-	-	-	-	1	-	-
Problem-focused supportive dyadic coping	0.84	0.42	3.93	1	0.047	2.31	1.01	5.30
Problem-focused common dyadic coping	0.78	0.38	4.19	1	0.041	2.19	1.03	4.63
Emotion-focused common dyadic coping	0.86	0.29	8.56	1	0.003	2.36	1.33	4.18
Negative dyadic coping	-1.44	0.53	7.42	1	0.006	0.24	0.08	0.67

A *second* GEE analysis was conducted to determine the relative contribution of positive and negative dyadic coping strategies to relationship satisfaction (Table 5-3). The chi-square for positive dyadic coping on 1 *df* was 20.8 compared to negative coping, which was 5.6. The ORs for these variables were 22.1 and 3.7 for positive and negative coping, respectively (both statistically significant). There were no significant interaction effects (all interaction *p*-values >0.5).

Table 5-3. Results from a GEE model: Factors associated with relationship satisfaction in couples raising a child with ASD (using Dyadic Coping Inventory aggregate scores for positive and negative dyadic coping).

Variables in the model	**B**	***SE***	**Hypothesis Test**			***OR***	**95% Wald CI for *OR***	
			Wald Chi-square	***df***	***p*-value**		**Lower**	**Upper**
Low stress (Parental Stress Scale = 40 and below)	1.82	0.65	7.75	1	0.050	6.18	1.71	22.31
High Stress (Parental Stress Scale = 41 and above)	-	-	-	-	-	1	-	-
Positive dyadic coping	3.09	0.68	20.80	1	<0.001	22.06	5.84	83.38
Negative dyadic coping	-1.31	0.55	5.59	1	0.018	0.27	0.09	0.80

5.4.4 Analysis of differences between respondents whose partner participated and respondents whose partner did not participate.

Relationship satisfaction was significantly higher in respondents whose partner participated (*Median* = 3.97, *IQR* = 1.31), than in respondents whose partner did not participate (*Median* = 3.22, *IQR* = 1.53), U = 2,188.50, z = 2.47, p = 0.014, r = 0.22. There were no significant differences between groups on parental stress or dyadic coping scores.

5.4.5 Analysis of gender differences

Parenting stress was significantly higher in female respondents (*Median* = 2.67, *IQR* = 0.65) compared with their male counterparts (*Median* = 2.42, *IQR* = 1.89), U = 1,276.00, z = 2.57, p = 0.01, r = 0.27. There were no significant differences between genders in relationship satisfaction or dyadic coping.

5.5 Discussion

The purpose of the study was to investigate relationship satisfaction in couples raising a child with ASD and its associated factors, including socio-demographics, parenting stress and dyadic coping. Our first hypothesis was supported, with a majority (65%) of caregivers reporting relationship satisfaction. This is comparable to previous research; for example, three studies found between 73% and 84% of caregivers scored in the ‘non-distressed’ or satisfied range on validated questionnaires (15, 16, 21). Furthermore, qualitative studies have documented caregiver reports that raising a child with ASD strengthened their relationship by creating a common goal, working partnership, sense of unity and increased commitment (17-20, 22). These findings do not nullify the challenges experienced, but lend support to family resilience theories by demonstrating the potential for couples to maintain a satisfying relationship despite these challenges. Couples who demonstrate resilience are a valuable resource and qualitative exploration of how they maintain relationship satisfaction and cope together to manage stress would provide invaluable information to the field. Furthermore, narratives of success can help create hope, positivity and empowerment which are important factors in family adaptation (37, 38, 69-73).

Our second hypothesis was also supported as caregivers who perceived low levels of parenting stress were more likely to experience relationship satisfaction than those who reported high stress levels. This finding was expected given similar findings in extant research literature (7, 12, 15, 25, 49, 74, 75). According to the literature, parenting stress can spill over into the couple relationship in several ways. Firstly, it can trigger negative interactions and undermine communication and dyadic coping efforts (44, 76). A recent study using a 14-day diary found that days of high parenting stress were associated with increased negative and decreased positive couple interactions in caregivers of a child with ASD (77). Secondly, stress can compromise physical and psychological wellbeing, thereby reducing the energy and emotional resources available to invest positively in the relationship (44, 78). For example, caregivers of a child with ASD who are stressed are also likely to have depression (27); depression, in turn, has been associated with lower relationship satisfaction (15, 32). Finally, parenting demands can monopolize caregiver time (18, 21), leaving couples with fewer opportunities to nurture their relationship and maintain a sense of connectedness (44). However, these mechanisms assume the causal direction is from parenting stress to relationship satisfaction. Consideration should be given to the protective potential of relationships in lessening the stress associated with raising a child with ASD (6, 7, 15).

Hypothesis three was partially supported: relationship satisfaction was positively associated with two positive dyadic coping dimensions (supportive and common, but not delegated, dyadic coping) and inversely associated with negative dyadic coping. For s*upportive* dyadic coping, only problem-focused strategies, not emotion-focused strategies, reached significance. This suggests that practical support, such as provision of information and help with concrete tasks, was more important than support with managing emotions. This is consistent with findings from a qualitative study, whereby caregivers of a child with ASD reported that preparation and circumvention of anticipated problems were key coping strategies, while they tended to withhold expression of emotion to keep their composure (79). Interestingly, *delegated* dyadic coping was not significantly associated with relationship satisfaction. Delegated dyadic coping is also a problem-oriented response, but it differs from problem-focused supportive coping in that assistance is explicitly requested (44). Thus, it could be hypothesized that the significance of practical partner support to relationship satisfaction may be lost when a partner has to ask for help; however, such a claim needs further substantiation. Certainly, it suggests that consideration should be given to the contexts in which partner support is provided and qualitative designs may elicit richer information on which to build interventions.

For *common* dyadic coping, both problem-focused and emotion-focused strategies reached significance. According to a meta-analysis, common dyadic coping is a stronger predictor of relationship satisfaction than other coping dimensions (47). Common dyadic coping is more than just partner support; it involves coordinated efforts to manage stress experienced by the couple and this fosters a sense of togetherness and confidence in the relationship as a resource during adversity (44). During interviews, caregivers raising a child with ASD recognized the importance of couple-centered factors, such as team work, common goals and beliefs, shared responsibilities and time together as a couple (18, 20, 21). Furthermore, similar findings can be drawn from literature on co-parenting, which is defined as coordinated support between caregivers specific to shared childrearing responsibilities (80). Positive co-parenting can be a protective factor for couples from diverse family types (81, 82).

Negative dyadic coping was inversely associated with relationship satisfaction, as hypothesized. Negative dyadic coping occurs when a partner provides support, but does so with hostility, ambivalence or without authenticity (44, 45). Unlike positive dimensions of dyadic coping, which are believed to restore homeostasis in stressful circumstances, negative dyadic coping can undermine a couple’s adjustment to stress and taint partners’ perceptions of each other and their relationship (47).

Our fourth hypothesis was supported. When positive dyadic coping dimensions were aggregated to form a single variable, it was found to have a greater relative influence on relationship satisfaction than negative dyadic coping. This finding is consistent with results from a meta-analysis of studies on the general population (47). Additionally, research shows that the ratio of positive to negative interactions can predict relationship outcomes (83). For example, one study found that satisfied couples had two to three times more positive than negative interactions, while dissatisfied couples engaged in equal or greater amounts of negative interactions (84). Similarly, the positive-to-negative ratio of parent interactions can influence child behavior (85). These findings support strengths-based interventions that focus on positive couple attributes to compensate for negativity.

5.5.1 Limitations

The study results need to be considered with regards to a number of limitations. The cross-sectional design prevents causal inference and does not capture the changing nature of relationships over time. Moreover, the single point of data collection occurred at different stages of the family lifespan for each couple. This limits comparisons as there are key transitional periods associated with specific challenges, such as the time around diagnosis, entry into school and transition to adulthood (26). It is recommended that future research collect data across three or more time points to capture the longitudinal transactions between relationship satisfaction, stress and coping. In hindsight, we should have collected information pertaining to time since diagnosis and length of relationship. Future research should consider including these variables.

The small sample size presents another limitation, especially when considering the lack of independence within couples in the GEE analysis, as some of the non-significant findings may have resulted from insufficient statistical power. The sample was purposively recruited from a list of families who had expressed interest in participating in research, creating a potential self-selection bias toward well-adjusted couples who had the time and energy to participate. There was also an overrepresentation of high SES families, limiting the generalizability to families with fewer financial resources whose stress and coping experiences may differ. Finally, social desirability bias may have resulted from the self-report measures of this sensitive topic; participants may have portrayed their relationship favorably and under-reported dissatisfaction.

5.5.2 Implications for practice

Family-centered approaches to supporting children with ASD are widely considered best practice (86-89), but such practices cannot be fully realized without consideration of the entire family system with the inter-parent relationship as the nucleus (5). Early intervention to prevent couple distress is vital, as the diagnostic period and navigating services can be especially challenging for families (4, 26). Strengthening the couple relationship can promote family resilience and prepare the critical foundations for long-term therapeutic caregiving. A key tenet of family-centered practice is parent involvement in therapy, but it can also exacerbate caregiver burden (54, 90) and successful implementation may be dependent on parental coping and positive adaptation (2, 55, 56). Thus, parent education and training could benefit from incorporating couple-focused features in a more systemic way; there is emerging evidence that couple-focused interventions can be just as effective as parenting-focused interventions in promoting positive child adjustment in children with behavioral challenges (52).

Our research highlighted the potential for dyadic coping as a target variable for couple interventions for families raising a child with ASD. Its relevance is supported by evidence from the general population that dyadic coping interventions not only improve relationship satisfaction (91-95), but can have a positive impact on psychological health (96, 97), personal happiness (98), life satisfaction (97) and parenting and child behaviors (52, 99). A comprehensive evaluation of such interventions on child, parent and family outcomes in families raising a child with ASD is warranted.

The study findings contribute to a growing body of research informing a strengths-based approach to working with families with a child with ASD. Caregivers are often overwhelmed with challenges and have identified the need for professionals to provide a sense of optimism (57). This study is a source of positivity, demonstrating that relationship satisfaction is possible and may be achieved by strengthening the positive ways couples cope together. This information should be filtered down to caregivers, as the intense focus on the needs of a child with ASD often results in neglect to other areas of family life (100). Clinicians can promote the value of the couple relationship in a family-centered approach and help caregivers identify meaningful ways to support each other and work as a team to raise their family. A focus on couple strengths can help create a positive environment, empower caregivers and increase their resourcefulness in managing challenges that arise.

5.6 References

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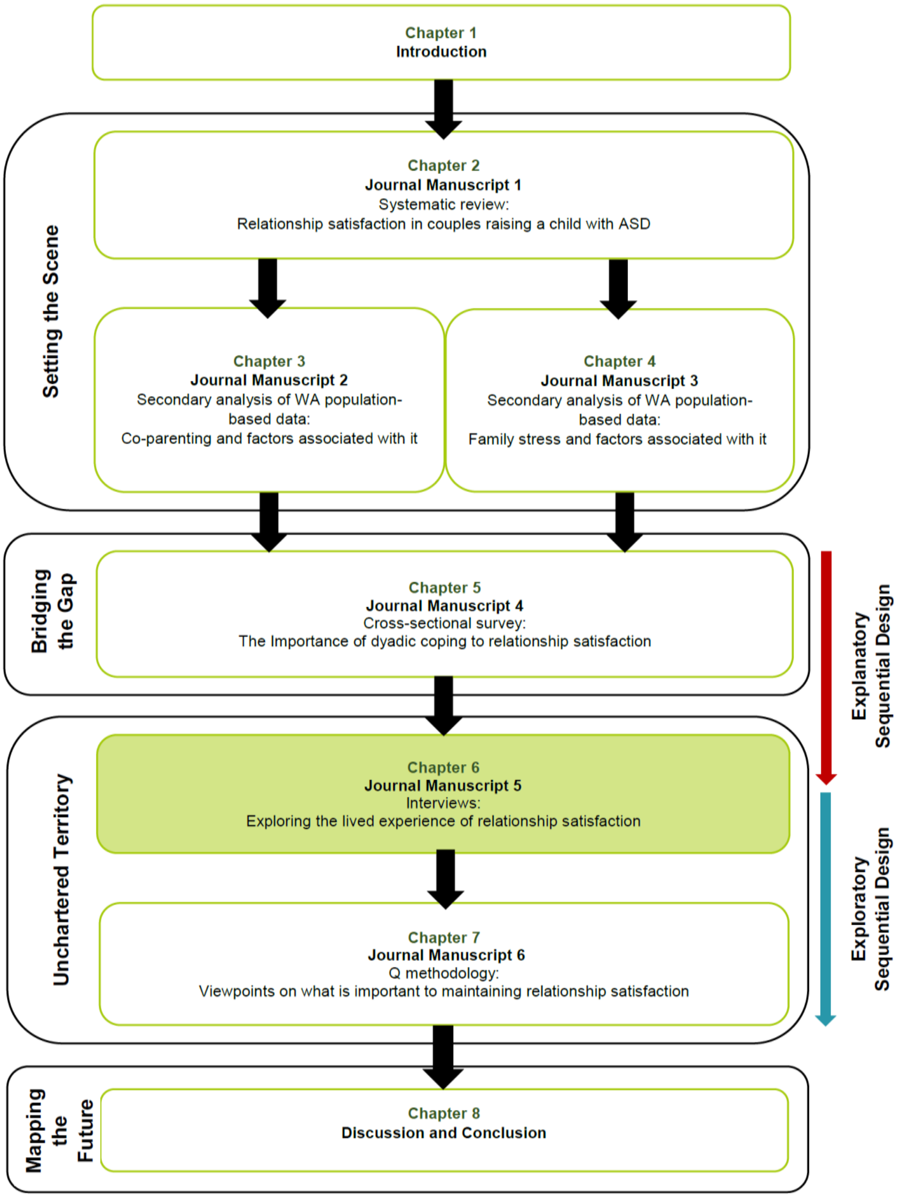
Chapter 6 Interviews

Chapter 6 outlines an interview study that expands on the findings from Chapter 5. Phenomenology was used to approach and analyse the lived experience of relationship satisfaction in eleven couples raising a child with ASD.



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“We are in this together”: Experiences of relationship satisfaction in couples raising a child with autism spectrum disorder

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6.1 Abstract

Couple relationships play an integral role in family adjustment when a child has ASD. Using phenomenology, data from eleven couple interviews were analysed to gain an understanding of the lived experiences of relationship satisfaction when raising a child with ASD. The overall essence of “We are in this together” reflected the attitude that a strong partnership was beneficial in maintaining relationship satisfaction. This essence was captured in three main themes: 1) Shared beliefs, 2) Teamwork and 3) Shared experiences which closely paralleled the Walsh family resilience framework. Couples can be supported in these areas to strengthen their relationship to serve as a source of resilience for families with a child with ASD.

Keywords: acceptance; communication; dyadic coping; positivity; resilience; teamwork

6.2 Introduction

The couple relationship remains the keystone of family functioning in modern times (1-3) and may play an important role in the adjustment of families of children with ASD. Yet, little is understood about the contexts in which couples maintain relationship satisfaction and promote family resilience.

ASD is a lifelong neurodevelopmental condition characterised by impairments in social communication and interaction, and restricted, repetitive patterns of behaviour, interests or activities (4). Comorbid developmental, intellectual, psychological and medical conditions are common (4-9). Although ASD symptoms and associated challenging behaviours may abate over time (10-12), the child often requires support and intensive caregiving into adulthood (13, 14).

Parents of a child with ASD experience greater levels of stress and decreased self-efficacy, psychological and physical wellbeing, and relationship satisfaction than parents of children without ASD (15-20). One of the most documented stressors is the need to manage challenging behaviours associated with ASD (21-28) and these can place families at risk of stigmatisation and social isolation (29-32). Additionally, caregivers face challenges selecting, accessing and coordinating medical, therapy and educational services (33, 34). Best practice emphasises early and intense multi-modal intervention with high levels of parental involvement (35-42). Consequently, the caregiving needs of a child with ASD can monopolise parent time and energy and result in neglect to other areas of family life. For example, parents often express concern for the wellbeing of their children without ASD, reduced quality time with their partner, reduced participation in leisure activities, and changes to employment that can affect availability of social support and cause financial strain (30, 32, 33, 38, 43-47). It is plausible that the constellation of all of the above mentioned factors are interrelated and lead to a circular loop of diminished relationship satisfaction over time (15).

Despite reported challenges, many couples adapt positively to raising a child with ASD (15, 48-50) and some even assert that the experience strengthened their relationship (32, 51-53). This is consistent with family resilience theories, which postulate that adverse circumstances can lead to personal and relational transformations through the discovery of untapped resources and strengths (54). For example, qualitative studies report on personal growth amongst caregivers including the strengthening of empathic responding, tolerance, selflessness, humility, assertiveness, determination, perseverance and unconditional love (32, 52, 53, 55, 56). Some couples attempt to make meaning out of their situation and reprioritise areas of importance (35, 55, 57-59). Thus, parenting challenges may create opportunities to work together for the benefit of the family, ultimately bringing them closer over time (51).

Traditionally, effective intra-couple communication was considered one of the most important positive dimensions of relationship satisfaction and has been a key element of couple interventions (60). However, researchers postulate that communication is more effective when stress experienced by the couple is better managed. Consequently, recent research has focussed on the impact of dyadic coping (61). Dyadic coping describes the efforts made by a couple in managing stress that affects their relationship, and might include strategies such as helping each other with practical tasks, joint problem solving or relaxing together (62). There is emerging evidence that interventions aimed at strengthening dyadic coping increase relationship satisfaction in the general population (61, 63, 64). Such interventions may also be relevant to couples with a child with ASD, as a recent study found that satisfied couples were more likely to engage in positive rather than negative dyadic coping strategies than dissatisfied couples (50). Consistent with this finding, another study found that mothers and fathers supportive dyadic coping related to their own and their partner’s relationship satisfaction (65). Partner support and joint coping strategies may be especially pertinent in couples with children with ASD due to the social isolation and associated decrease in support experienced (46, 56).

To date, ASD research has overwhelmingly focussed on the impact of raising a child with ASD on the parents, overlooking the potentially protective role of the couple relationship and its influence on the family. The challenges faced by families have been well documented; however, some families appear to emerge from this adversity strengthened and more resourceful when viewed through the family resilience framework lens (66, 67). This framework offers a useful perspective in interpreting how families surmount challenges and positively adjust even in the midst of overwhelming stress (67). It describes vital family processes within three domains of family functioning: belief systems, patterns of family organisation and communication processes (68). As the nucleus of the family, the couple relationship is integral to these family processes and may be the key to family resilience as studies show that relationship satisfaction is associated with improved child behaviours, reduced stress and positive adjustment in families raising a child with ASD (69-71). Yet, few researchers have focussed their efforts on resilient couples and used their experiences to inform meaningful family-centred practice. Thus, the current study aimed to explore experiences of couples raising a child with ASD who self-report satisfaction in their relationship with their partner.

6.3 Methods

6.3.1 Research design

To address the study's aim, a phenomenological approach was used to elucidate a comprehensive understanding of relationship satisfaction in couples raising a child with ASD and how it can be maintained. It was designed to explore and give meaning to a preceding cross-sectional survey which collected data on socio-demographics, parenting stress, dyadic coping and relationship satisfaction (72).

6.3.2 Sampling and recruitment

To be eligible for this study, couples were required to be: 1) Cohabiting; 2) Primary caregivers of a child with ASD 18 years of age or under; and 3) Satisfied in their relationship with their spouse/partner. Couples were purposively recruited from the sample that participated in the preceding survey using a screening process. The Couple Satisfaction Index (CSI; 73) - which constituted part of the survey - was used to identify couples experiencing relationship satisfaction in accordance with the CSI test score cut-off of 104.5. The CSI is a 32-item standardised, self-report questionnaire that measures the respondent's satisfaction with their relationship with their partner.

6.3.3 Participants

A total of 31 couples met the inclusion criteria and were contacted by telephone and invited to an interview. Eleven of these couples agreed to be interviewed and consented to their interview data being used for the current study. Of the eleven couples interviewed, nine were legally married. Relationships ranged in length from 6 to 25 years. The majority of interviewees were the biological parents of a child with ASD, with three being a step-father. Two families had two children with ASD, the other nine had one child with an ASD diagnosis. The 13 children with ASD ranged from 7 to 18 years and all but two were male. Nine were reported to be ‘high functioning’ and five had comorbid psychological, cognitive or medical diagnoses. A detailed description of the participants is provided in Table 6-1.

Table 6-1. Participant characteristics.

Couple	Marital status	Length of marriage/ cohabitation	Relationship to the child/children with ASD	Total number of children living with the couple	Number of children with ASD living at home	Characteristics of child/children with ASD			
						Gender	Age (years)	Official ASD Diagnosis	Comorbid conditions
Mr and Ms A	Married	17	Biological parents	1	1	Female	8	Autistic disorder	N/A
Mr and Ms B	Married	6	Biological mother Step father	1	1	Female	12	High functioning autism	N/A
Mr and Ms C	Married	25	Biological parents	2	1	Male	18	High functioning autism	N/A
Mr and Ms D	Married	13	Biological parents	1	1	Male	10	Autistic disorder	N/A
Mr and Ms E	Married	14	Biological parents	2	1	Male	11	High functioning autism	N/A
Mr and Ms F	Married	21	Biological parents	2	1	Male	10	Autistic disorder	Sensory processing disorder Asthma Allergies
Mr and Ms G	Married	12	Biological parents	4	2	Male	10	High functioning autism	N/A
			Biological mother Step father			Male	16	Asperger’s Syndrome	N/A

Mr and Ms H	Married	10	Biological parents	2	1	Male	7	High functioning autism	Coeliac disease
Mr and Ms I	Cohabiting	17	Biological parents	4	2	Male	7	Autistic Disorder	Cerebral palsy Global developmental delay Asthma Epilepsy
			Biological parents			Male	15	High functioning autism	
Mr and Ms J	Cohabiting	18	Biological parents	2	1	Male	12	High functioning autism	Hearing impairment
Mr and Ms K	Married	8	Biological mother Step father	2	1	Male	15	High functioning autism	ADHD

6.3.4 Data collection

In-depth face-to-face interviews were used to gain access to the lived relationship experiences of couples raising a child with ASD who reported satisfaction in their relationship. The interview was semi-structured with a minimum number of broad, open ended questions to facilitate guided storytelling (74). The interview guide was informed by findings from a systematic review (15) and cross-sectional survey disseminated in an earlier study (50). Questions can be viewed in Table 6-2. Additional open-ended prompts were used where necessary to elicit greater detail and depth. The interview guide was piloted with a mother of a child with ASD who met the criteria for inclusion but whose partner did not want to participate. The researcher reflected on this interview to refine interview skills, but no changes to the questions were deemed necessary.

Table 6-2. Outline of the semi-structured interview guide.

Question
1. Would you please tell me about [your child with autism]? 2. How has raising a child with autism impacted on your lives? 3. Specifically, how has having a child with autism affected your relationship as a couple? 4. Describe the ways in which you maintain satisfaction in your relationship. 5. Is there anything you would like to add that would help me to understand your experience as a couple raising a child with autism?

Interviews took place over a three-month period. Couples nominated the time and place of their preference; eight interviews were conducted at the family home, two via teleconference and one in a meeting room at the university. Interviews were between 1 and 1 ½ hours in duration and were audiotaped to supplement hand written notes to facilitate accuracy, trustworthiness and authenticity of data (74). All but one of the interviews were conducted by the first author (a PhD student with an occupational therapy background working with families of children with disabilities). In a single case, the couple was known to the researcher so a colleague from the university with similar skills and background conducted the interview to minimise bias.

Interviews were conducted until the information collected became repetitious and the research team decided that further recruitment would not add sufficient meaning to justify the costs and effort of continued data collection, in accordance with the principles of saturation (75). The first author anonymised transcripts prior to analysis.

To fulfil ethical requirements, participants were provided with an information and consent form prior to the interview. At the time of the interview, the interviewer reiterated the study details, participant rights and invited questions before gaining written consent. All participants agreed to be audiotaped. The study received ethics approval from Curtin University Human Research Ethics Committee (OTSW-05-2014).

6.3.5 Data management and analysis

Data were analysed using inductive thematic analysis (76). Interviews were transcribed verbatim by either the first author or a research assistant (employed under an agreement of confidentiality). In cases where transcription was completed by the research assistant, the first author reviewed the recording with the transcription to confirm accuracy. Being directly involved in the transcription process enabled the researcher to have prolonged immersion in the data and attain a depth of understanding to aid the analytic process (77). Transcriptions were imported to Nvivo 11 software (78) where they were stored and managed. Descriptions were read repeatedly and excerpts that provided an understanding of the phenomenon were identified and assigned codes that reflected the meaning (79). Statements that were similarly coded were grouped together in categories (nodes). The coding structure was refined in consultation with the last author, examined for patterns and organised around central themes. These final themes were then reviewed and refined in discussion with the research team. Finally, the themes were used to create an exhaustive description that represented the ‘essence’ of the phenomenon according to common participant experiences, taking into account the contexts that influenced their experience (79). The audio recordings were frequently referenced during the analytic and writing process to make use of cues such as intonation, volume and pausing in interpreting information (74).

A number of strategies were used to improve trustworthiness of data. Detailed notes were recorded immediately following each interview and the audio recording was checked to ensure the information was accurately recorded and described the phenomenon adequately. Interview data were used together with questionnaire data (gathered during the preceding survey), as well as field notes gathered by the interviewer, thus achieving data triangulation (80). Additionally, investigator triangulation was achieved by consultation with multiple researchers during the analytical phase (80). Following analysis, each couple was contacted to review the themes and confirm that they authentically reflected their experiences in a process of member checking (74). The researcher engaged in reflexive journaling to identify and reflect on how held beliefs, assumptions and experiences influenced data collection and analysis. Peer debriefing was also conducted during fortnightly research meetings with three experienced researchers to promote reasoned methodological choices and credibility of data analysis (74). These procedures have all been recorded to provide an audit trail.

6.4 Findings

The overall essence that emerged from the data was captured with the quote, “We are in this together”. Couples expressed the belief that raising a family was a long-term commitment and acknowledged the importance of a solid partnership in achieving this. Ms A summarised: “We both went into it thinking we are both a part of this, we both want to make it work and help [our child] any way we can. We will do a better job of that together”.

The shared experiences of raising a child with ASD brought them closer and they valued mutual support, stating: “No-one knows exactly what it has been like except the two of us”. One couple expressed that the lack of understanding and support from others led them to quickly realise that they had to take full responsibility for their child’s wellbeing and could only rely on each other. Couples affectionately described their partnership as: “…partners in crime” or “…soldiers in the trenches”. Several caregivers explicitly stated that they did not feel they could raise a child with ASD alone and consequently did whatever it took to make the relationship work.

Three essential themes supported this essence: 1) Shared beliefs; 2) Teamwork, and 3) Shared experiences. Each theme had three subthemes as described in Figure 6-1.

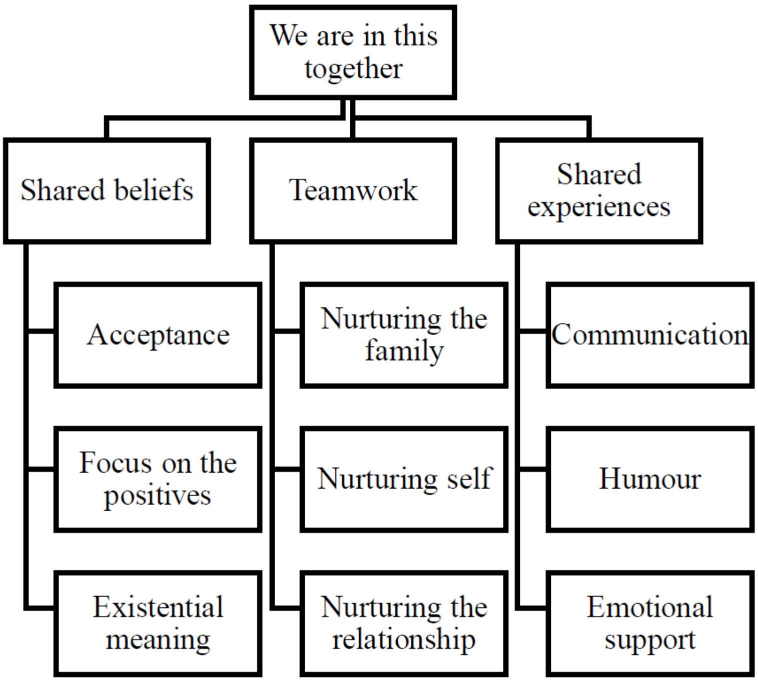

Figure 6-1. Overview of the overall essence, themes and their subthemes.

6.4.1 Shared beliefs

6.4.1.1 Acceptance.

Couples asserted the importance of acceptance in adjusting positively to raising a child with ASD and maintaining relationship satisfaction. Mr A described: "An important part of this [raising a child with ASD together] is acceptance. It is the way it is. That's all". Similarly, Ms G stated: "One of our biggest strengths as a couple is that we have accepted that this is our family and it will be what it is". With acceptance, caregivers were able to make sense of their situation and comprehend it as manageable, reprioritise goals and maintain realistic family expectations. The process involved accepting that some situations could not be changed and instead acting upon the things that were changeable. Couples reported the importance of accepting challenges as they arose and adapting accordingly. As Mr F said, “You just do it. You do what you need to do”. Mr A noted the importance of not getting caught up in notions about what ‘should be’ or wishing for things to be different:

> The acceptance means we are not highly focussed on results. So, we don’t have the expectations that our child is supposed to reach certain milestones at certain times…and in terms of our personal circumstances we accept that we can’t do x, y, z…the trap is when you get caught up in desire and become frustrated.

Without acceptance, couples may not be able to effectively support each other to move forward and overcome challenges. Ms D gave an example of this, reflecting on friends with a child with a disability who were struggling with their relationship. She posited that their lack of acceptance led to self-pity, blame and, consequently, the inability to work in partnership effectively.

6.4.1.2 Focus on the positives.

Most couples mentioned the importance of being positive to adapting as a couple raising a child with ASD and this quality was reflected in their narratives. For example, even when discussing challenges and stressors, couples would contextualise them positively with follow up statements such as: “…but we are making progress” (Mr E) and “…but it’s not that bad, it could be worse” (Ms G). A positive perspective entailed optimism for the future, a focus on progress, emphasis on good qualities, making the most of life and practicing gratitude. Mr A provided an example:

> I’ll offer a story. It’s like you are planning a trip to Paris and you end up in Moscow, and it’s like ‘wait a second, this is not what I was expecting!’ But hey, you make the most of it. Moscow’s got its own sights to see.

6.4.1.3 Existential meaning.

Some couples made existential references to explain their experiences, thereby providing hope and belief in their ability to surmount all the challenges they faced as a couple. For example, Ms H stated: “Nothing happens without a reason and nothing gets put in front of you that you can’t deal with. That would have to be core belief of our marriage, I think”. For one couple (Mr and Ms C), religious faith was instrumental in maintaining their relationship:

> There was no one who had the knowledge or the expertise or even the compassion to step out and help. If we were trying to work something out and I was trying to get counsel, there was no one. No one that I had met that actually had the ability to help me clarify or to see what was going on, so I’d be praying like crazy! And that’s the truth. The spiritual part of our lives has been a huge part in developing our relationship because without that we wouldn’t have stayed together.

6.4.2 Teamwork

Each couple discussed the importance of working together as a team to raise their family. In fact, some couples felt that raising a child with ASD strengthened their ability to work together and this brought them closer. They learnt to rely on each other and became each other’s most important source of support. For example, “We both know that without one of us here the household wouldn’t run” (Mr I) and “If one of us falls in a heap, the other one is hanging on, keeping things floating” (Ms J).

Couples differed in the way their ‘team’ operated; for instance, some couples fulfilled traditional gender roles whereby the mother was the primary caregiver and the father was the wage earner, while others had less differentiated roles and shared employment and caregiving equitably. Regardless of the role distinction, couples expressed having a mutual understanding and appreciation of each other’s roles and felt satisfied that, overall, family responsibilities were shared within their partnership.

> There is no real sense of ‘this is your job, that’s my job’. That doesn’t just refer to [the child] but things that need doing around the house. There are things I might do that Ms A doesn’t and vice versa, but I think the load is pretty well shared (Mr A).

Couples reflected that through teamwork, they could better achieve common goals, which included nurturing the family, the self and the relationship.

6.4.2.1 Nurturing the family.

Working in partnership to nurture the family was an important part of relationship satisfaction. Couples reported that they were both actively involved in raising their child with ASD. Some couples made an effort to attend appointments together, finding it “less daunting” (Ms A) and valuing the support in managing the children. However, circumstances did not always permit this, in which case caregivers actively kept each other involved by communicating outcomes and sharing the goal setting and decision making. Ms F explained:

Mr F comes along if it’s a big appointment with a big specialist. I can’t handle driving in the city, never mind managing the children as well. So that becomes a family thing, we all go. But if it’s a local appointment – and there just seems to be an endless stream of appointments – it’s always me that has to go but I still want Mr F to feel involved and not cut off.

Mr and Ms F gave a further example of how they were both involved in the medical management of their child with ASD:

We made a joint decision that we’re going to give him this medication. We had a lot of discussion about it. We both did our own research and then we talked about, you know, the various findings (Ms F) and – [Mr F interjects] the side-effects. Like, with the current one he’s on, one of the side-effects is obesity. We’ve noticed that there’s significant weight-gain with him. As I have always done the cooking, it’s my responsibility to try to make sure his diet is as balanced as can be, given that he eats all the time! (Mr F). Yeah, and it’s my responsibility too, because I’m here all day at home schooling him so if you were planning the main meal and I was stuffing him full of junk food during the day it wouldn’t work. So, we are working together towards the same goals (Ms F).

Many couples placed significant value on spending time together as a family to create a sense of belonging, connectedness and a semblance of what they considered to be ‘normal’ in family life. This required a level of adaptability to balance things that had to be done with things they enjoyed, and accommodating for the often-restricting needs of their child with ASD. A quote from Ms J captured this:

We do things together, but things we can involve the kids in. Like, Mr J likes watching the baseball so all four of us went and watched our local club play the other weekend. Now, if you asked me what kind of activity I would like to do on a Friday night, I probably wouldn’t pick a baseball game! But I got to sit there and chill out for a bit and the kids enjoyed going and Mr J enjoys going and it’s our club…We also eat at the table; we all sit at the table for our tea every night. I think we try and maintain that connectedness between the four of us, that’s just one of the ways we keep all the people together.

Several couples expressed the importance of parental solidarity in their relationship. For example, Mr and Ms F stated:

We do try to keep a united front with each other because [the children] could so easily divide and conquer - you know? Play us off against each other. Also, they don’t get conflicting messages. If we do have a problem with each other and our parenting styles or skills, we try to keep that conversation until after they’ve gone to bed. But, you know, if I disagree with the way Mr F handled something, I won’t undermine his authority in front of the children. But after they’ve gone to bed I will say something. (Ms F).

6.4.2.2 Nurturing self.

Couples recognised that an important aspect of being in a satisfying relationship was nurturing the self: “We are a couple but we are still individuals within the relationship and everyone needs to have some ‘me’ time” (Mr H). By working as a team, couples could provide opportunities for self-nurturing. For example, one partner would assume caregiving responsibilities to allow the other to relax or pursue their own interests. This not only aided their management of stress and improved quality of life, but promoted feelings of being valued by their partner and consequently a fondness and appreciation for each other. Ms E explained:

One thing we do to stay close is…I like to go for a run and if I don’t I go crazy. So, when there’s crap everywhere and I really should be staying home, Mr E gives me half an hour to go for a run. That makes me feel close to him because I think ‘well, that’s pretty nice of him’.

6.4.2.3 Nurturing the relationship.

Couples stated the need to prioritise the relationship and perceived it as a joint responsibility that required effort. Mr I captured this by saying: “As much as the therapy and the specialists and the medical appointments are important, your relationship is also important. If you are wanting to stay married, you need to work on it”. To nurture their relationship, couples ensured they spent quality time together without the children. For some couples, this involved scheduled time or formalised events, such as date nights. However, not all couples had the means (or desire) to do this and found alternate ways to enjoy time together. Most couples stated they simply enjoyed being in each other’s presence, be it watching television, reading, gardening or having a drink on the porch together. For example, Ms E described the stress around going out and leaving their child in the care of others and went on to say: “…so we didn’t do date nights. But just sitting on the couch when [the child] was in bed was enough, you know? We didn’t need to go out.”

Maintaining intimacy was also a priority for several couples: “…and sex! We actually quite enjoy our love life…it’s something which we work on and try to take time to get that intimacy” (Mr I).

6.4.3 Shared experiences

Couples voiced that they were united by shared experiences and mutual understanding; they both knew what it was like to raise their child with ASD and they were aware of the compromises and effort each other made. These shared experiences provided grounds for appreciation of each other and promoted positive couple interactions – such as communication, humour and emotional support.

6.4.3.1 Communication.

In order to work effectively as a team to raise a family, couples spoke of the need to practice open and honest communication. However, effective communication was not limited to coordinating parenting responsibilities; couples proclaimed that they felt comfortable in sharing their feelings and opinions about almost anything. Mr C explained: “We are always talking about everything, because if you don’t communicate, you make assumptions.” Mr A stated that communication was necessary for effective problem solving: “It’s in the talking discourse that the knowledge about what to do arises.” Several couples felt that learning to listen was vital to effective communication, as was remaining calm: “In the heat of the moment you can’t achieve anything, you have to walk away for a bit, calm down and then talk about it” (Ms D).

6.4.3.2 Humour.

“You’ve got to have a sense of humour” (Mr D). Couples expressed the importance of being able to share jokes with each other and laugh at themselves and the situations they found themselves in. Ms I described it as a coping strategy: “If you don’t laugh, you cry!”. Often, the humour related to their specific circumstances so that only their partner would appreciate it; for example, quirks the children have or do. Ms I explained: “We can laugh at each other’s jokes without having to explain the situation or whatever. We both just look at each other and know what we are laughing about.” One parent appreciated the freedom to be honest in their humour with their partner without judgment and the need to be politically correct.

6.4.3.3 Emotional support.

Couples stated that they looked out for each other and made themselves available to their partner when they needed it, even if they could only afford five minutes. This often involved merely being listened to, as Ms H described: “All he has to say at the end [of my rant] is a little bit of validation and I still love you and don’t worry…a verbal hug.”

When the need for emotional support was communicated, partners would ask what they could do, or simply take over tasks to give their partner time and space to manage their distress. Ms J captured this with her description:

So, if Mr J’s having a really flat ‘I’m at the end of my tether’ kind of time then I recognise that…or if he sees that I’m ready to throw someone against the wall, he’ll say ‘Look, mum’s feeling really tired, let’s leave her alone for a bit’…so one of us will take responsibility for the kids and it’s like putting an emotional or mental buffer around the other person. You don’t let the kids go in and cause an upset, or if the phone rings you answer it, or if dinner needs to be put on you put on dinner. So, give the other person a bit of time and space to come back to reality.

Being emotionally supportive and empathic involved avoiding taking things personally. Couples understood each other's need to vent or take time out without making it a personal reflection on them.

6.5 Discussion

The purpose of this study was to gain insight into the relational experiences of couples raising a child with ASD who report relationship satisfaction, acknowledging them as an important source of resilience for families. The overall essence of "we are in this together" encapsulated three main themes: 1) Shared beliefs, 2) Teamwork, and 3) Shared experiences, which closely paralleled the three interactive domains of the family resilience framework (66, 81). Resilience is the capacity to withstand and recover from disruptive life challenges to emerge strengthened and more resourceful in facing future challenges (67). Even relatively low levels of resilience can buffer against stress associated with raising a child with ASD (82, 83). The couples interviewed not only managed the challenges but also demonstrated personal and relational transformation. The three domains of the family resilience framework (66, 81) are discussed below with reference to the themes extracted from the data.

6.5.1 Belief systems

An important component of a resilient family structure is shared beliefs as they govern family functioning; shape relationship expectations and interactional patterns; and influence adjustment to challenging situations (67). All of the interviewed couples shared the belief that raising a family was a joint responsibility and challenges were best overcome if they worked as a team. Together, couples gave meaning to their situation and contextualised it as comprehensible and manageable. This sense of coherence can act as a protective factor, buffering stress and enhancing quality of life, wellbeing and relationship quality (84-87). By making sense of their situation, couples were able to focus on strengths and mobilise resources for change (66). However, raising a child with a disability can impact on parents' sense of coherence (88). Therefore, providing clear and consistent information about ASD, treatment options and available support can help parents comprehend their situation and reduce stress (86).

Making meaning from life’s challenges requires acceptance and for the interviewed couples this involved recognising aspects of their lives that were outside of their control and learning to live with the uncontrollable through positive reframing. This enabled them to become action-focussed and prioritise situations that were amenable to change. Positive thinking was also believed to contribute to relationship satisfaction in the couples, a finding supported in other ASD studies (15, 49, 89). This is because positivity creates feelings of optimistic expectations in couples about their lives together and makes it harder for negative events to disrupt their equilibrium (90). Hope can be a source of energy, motivating couples to search for solutions, surmount challenges and seize opportunities (66). In fact, one study of caregivers of a child with ASD found that positive cognitions can mediate the effect of caregiver burden on their resourcefulness (91). Couples can be supported to examine their own belief systems, affirm strengths and envisage a better future. There is preliminary evidence for the effectiveness of positive thinking training in caregivers of children with ASD (92) and future research would benefit from evaluating its effects on caregiver outcomes such as relationship satisfaction.

Spirituality has been identified as a resilience factor in a number of studies (54, 55, 93, 94) and some of the interviewed couples confirmed its role in maintaining relationship satisfaction. Spirituality does not necessarily involve religious associations; spiritual nourishment may come from personal connection with nature, music or the arts. In fact, anything that provides meaning and purpose beyond ourselves and immediate circumstances can be perceived as spiritual experiences (66).

6.5.2 Organisational processes

According to the family resilience framework, resilience can be fostered through organisational processes, such as flexibility, connectedness, shared leadership, mutual support and teamwork (54). Teamwork emerged as a key theme for couples in maintaining relationship satisfaction by facilitating connectedness in their mutual commitment to the family, their relationship and themselves; a finding supported in other studies (51, 52, 55). Couples showed flexibility in making changes to meet the needs of their child with ASD. For example, couples prioritised the need to spend time together and in situations where it was difficult leaving their child in the care of a babysitter, they found alternate ways to get this time. There was also recognition that while family cohesiveness was important, so was the need to respect individual differences, separateness and boundaries (66) and couples enacted this by supporting each other to nurture the self.

6.5.3 Communication and problem-solving processes

Family resilience can be fostered through communication processes that clarify ambiguity, encourage open emotional expression and empathic responses, and enable collaborative problem solving (66). Couples explicitly stated that in the absence of clear communication assumptions are borne which can cause unnecessary stress and conflict in the relationship and that solutions to problems are usually identified through discussion. Couples felt that communication was fundamental to working as a team to raise their child with ASD; however, it went beyond that to encompass the expression of feelings and concerns, and being listened to, validated and supported emotionally. The partner’s response to the communication was also important, for example, if one partner communicated needing space, the other would respond by allowing them space, which reinforced the communication as successful and made the partner feel closer to them. Open communication also meant that couples felt free to share jokes, and they were connected by humorous moments that only they could jointly understand.

6.5.4 Strengths, limitations and future research

By virtue of design, the findings cannot be generalised to other couples with a child with ASD. Paradoxically, this is also a strength of the study as individual differences are recognised. The interviewed couples had experiences with common, as well as unique, characteristics and this highlights the need for a non-prescriptive approach to intervention that accounts for different perspectives and circumstances.

Another limitation is the potential for premature cessation of data collection; some researchers argue that the concept of saturation is arbitrary and may never truly occur (75). Thus, it is plausible that eleven interviews, capturing the narratives of 22 parents, were not enough to gain an exhaustive account of experiences and further data collection may have revealed new information. Bias may also have been introduced as a result of assumptions built on the researchers' knowledge and experience. It is believed that the fewer the preconceived notions, the less chance of bias (74). However, the nature of the research project was such that the first author was already familiar with the phenomenon under study through background research, clinical experience working with families with ASD and shared experiences of a married parent of a child with ASD. To address this, the first author journaled her reflections and debriefed regularly with the other researchers.

The decision to interview partners together may have limited full disclosure; however, it was believed this impact would be minimal given the strengths-based approach. Another limitation of this method is that one partner may assume responsibility and do all the talking. The interviewer was aware of this potential and endeavoured to involve both partners by directing questions accordingly. Overall, the potential for the presence of these limitations was outweighed by the benefits of observing couple dynamics.

6.5.5 Implications for practice

A child with ASD can have a pervasive, long term, reciprocal impact on the family, thus, family-centred approaches are considered best practice (41, 42, 95-98). To authentically achieve this, attention ought to be given to the couple relationship as the core of the family system. The present study shows that shared beliefs, teamwork and shared experiences are integral to relationship satisfaction, which is a promising finding as they are variables amenable to change. This is also consistent with the understanding that dynamics within couples are stronger predictors of relationship satisfaction than demographic variables (60). Thus, relationship satisfaction is potentially achievable for most if not all couples raising a child with ASD with appropriate support, despite experiencing adversity.

Many couples may experience the negative impact of raising a child with ASD by the time of diagnosis (13, 33) making early relationship intervention imperative. However, intervention should not be restricted to families in distress; instead, a strengths-based approach targeting key processes for resilience can promote positive family adjustment, empower families, bring hope, reduce family vulnerabilities and equip families with the ability to effectively manage future challenges as they may arise over the course of the family life span (68, 87).

Professionals can support families with a child with ASD through therapeutic interactions, education and referral to relevant services. Raising awareness of the importance of the couple relationship to the entire family and highlighting the possibilities for satisfaction, is fundamental. Couples can be supported to prioritise their relationship as a goal alongside other therapy goals and identify strengths and ways to fortify their relationship. Clinicians can encourage both parents to be ‘in it together’ by sharing responsibilities, goal setting and problem solving together. This can be facilitated through service delivery, for example, offering appointments outside of work hours, home visits or provision of child minding at clinics so that both parents can be present. It is important that professionals are aware of the resources available to families, such as respite and couple therapy programmes and provide this information as necessary. Through the therapeutic relationship, clinicians can also model and encourage acceptance, positive reframing and open communication.

Families with a child with ASD would benefit from relationship education and enrichment programmes as an adjunct to other parenting- and child-focussed intervention. Involving parents in therapy improves outcomes, but their capacity for involvement depends upon their stress and coping (19, 36, 38, 39, 99). Strengthening the couple relationship and dyadic coping strategies can enhance parental wellbeing, parenting efficacy and maximise the effectiveness of child-centred interventions; in fact, there is emerging evidence that couple-focused interventions can be just as effective as parenting-focused interventions in promoting positive child adjustment in children with behavioural challenges (100).

There is a need for intervention approaches that focus on strengths, not just in the individual but within the couple as a source of family resilience. Raising a child with ASD places couples at a greater risk for relationship dissatisfaction (15) but with greater attention to factors such as shared beliefs, teamwork, and shared experiences couple relationships can be enriched and families better equipped to manage challenges as they arise throughout their child’s development.

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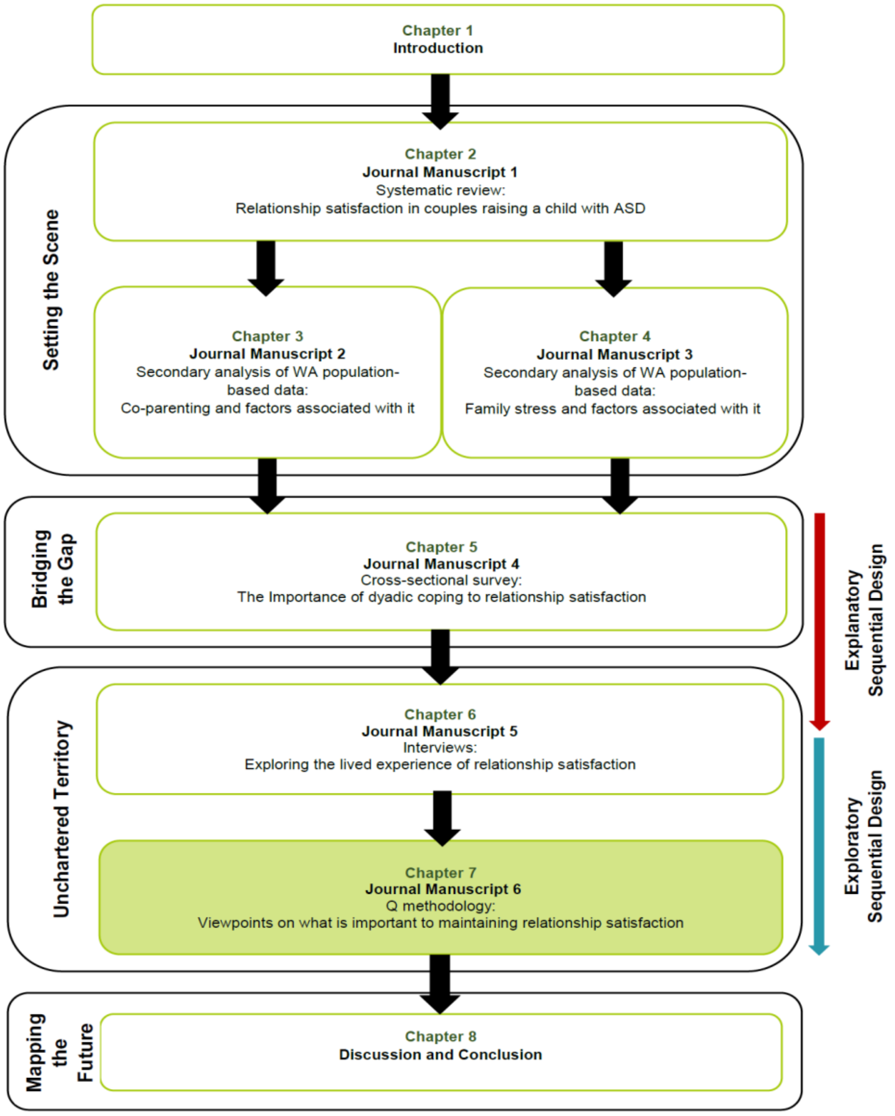
Chapter 7 Q-methodology

Chapter 7 progresses from Chapter 6 using an exploratory sequential design; interview data were used in the development of a study that applied Q-methodology to explore the viewpoints of caregivers raising a child with ASD regarding factors important to maintaining relationship satisfaction.



The following is an original manuscript:

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Viewpoints on what is important to maintain relationship satisfaction in couples raising a child with autism spectrum disorder

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7.1 Abstract

Despite the challenges experienced in raising a child with ASD, many caregivers maintain satisfying couple relationships. However, it is not yet clear why some couples adapt positively, while others do not. This study used Q-methodology to explore the viewpoints on the factors important to maintain relationship satisfaction from the perspective of those experiencing it. Data from 43 caregivers were analysed using by-person varimax rotation factor analysis. Results revealed two key viewpoints, one highlighting the importance of building trust through effective communication, the other highlighting the importance of building a strong partnership by sharing responsibilities and working as a team to raise a child with ASD. Findings confirm the importance of addressing couple communication and other coping strategies in family-centred evaluations and interventions.

Keywords: communication; coping; factor analysis, marital satisfaction; partner support; Q-methodology.

7.2 Introduction

Couples raising a child with ASD report both challenging and rewarding experiences, impacting on their relationship in various ways (1-4). Parenting can place strain on any relationship (5-7); however, couples raising a child with ASD are at a greater risk of poor relationship satisfaction (3). This risk is sustained over the child's transition to adulthood (8); a time when other parents typically report an upturn in relationship satisfaction (6, 9). Despite this risk, many couples report maintaining a stable, strong, and satisfying relationship with their partner (4, 10-12).

A broad range of factors have been posited to influencing relationship satisfaction in couples raising a child with ASD. A systematic review found the most consistent risk factors to be challenging child behaviour, parental stress, and poor psychological wellbeing, and it acknowledged the interrelatedness of these variables in a theoretical model (3). The model also proposed two protective factors supported by the review findings: positive appraisal and social support. The impact of a stressful event can be buffered through positive appraisal and several studies have demonstrated that parents who perceive the challenges associated with ASD as manageable and meaningful, and who held optimism about the future, were more likely to experience relationship satisfaction (3, 13-17). Psychological support can also reduce stress, improve psychological wellbeing, and contribute to relationship satisfaction (13, 17-21). However, the value of psychological support may vary according to its source. For example, support from a partner has been shown to be particularly important to couples raising a child with ASD (3, 19, 22). Expanding upon the concept of partner support, a recent study investigated dyadic coping in couples raising a child with ASD and found that satisfied couples were more likely to engage in positive dyadic coping than dissatisfied couples (10). Dyadic coping is conceptualised as more than merely partner support; it also involves coping strategies used jointly by couples in response to a common stressor, and such strategies include relaxing together or collaborative problem solving (23).

There are two studies that provide preliminary insight into the ways in which couples maintain relationship satisfaction when raising a child with ASD. The first applied concept mapping methodology and found that both mothers and fathers identified two factors integral to marital success: communication and shared ideas about the relationship (24). More recently, a phenomenological study of couples who reported relationship satisfaction revealed an overall essence of togetherness, encapsulated in three main themes of 1) shared beliefs (including acceptance, focus on the positives and existential meaning), 2) teamwork (to nurture the family, self and relationship), and 3) shared experiences (including communication, humour and emotional support) (12). This study adopted a strengths-based approach to investigate if key processes for resilience can promote positive family adjustment, empower families, bring hope, reduce family vulnerabilities and equip families with the ability to effectively manage future challenges (25). To extend upon these findings, this study sought to answer the following research question: What factors are *most* important to maintaining relationship satisfaction in couples raising a child with ASD? This question is important as relationship satisfaction in couples can be a valuable protective resource for families managing the challenges associated with ASD (14, 17, 18, 26-28). Furthermore, the couple relationship can influence child outcomes which is especially pertinent as parents are increasingly expected to be involved in interventions (29-32). Thus, relationship satisfaction is a vital component of any ASD intervention delivery, but there is a paucity of research in this area.

7.3 Methods

To answer the research question, Q-methodology was adopted to systematically understand and compare participants' subjective views (33) on factors important to maintaining relationship satisfaction. It involved participants rank ordering a set of statements (Q-set) relative to one another so that they could be analysed and considered holistically as key factors, or viewpoints, common to a group of participants (34). Q-methodology has previously been successfully used in ASD research and with parents of children with a disability (35-38). Five distinct phases were followed: 1) developing the 'concourse', 2) identifying the Q-sort statements, 3) administering the Q-sort, 4) factor analysis, and 5) interpretation of factors.

7.3.1 Developing the concourse

The concourse is the overall set of statements about the topic in question and it lays the foundation for the development of the sample of statements to be rank ordered

(39). For this study, a wide range of perspectives on maintaining relationship satisfaction were gathered from in-depth semi-structured interviews with couples raising a child with ASD who reported being satisfied in their relationship (12) and integrating findings from a systematic review about relationship satisfaction in couples raising a child with ASD (3).

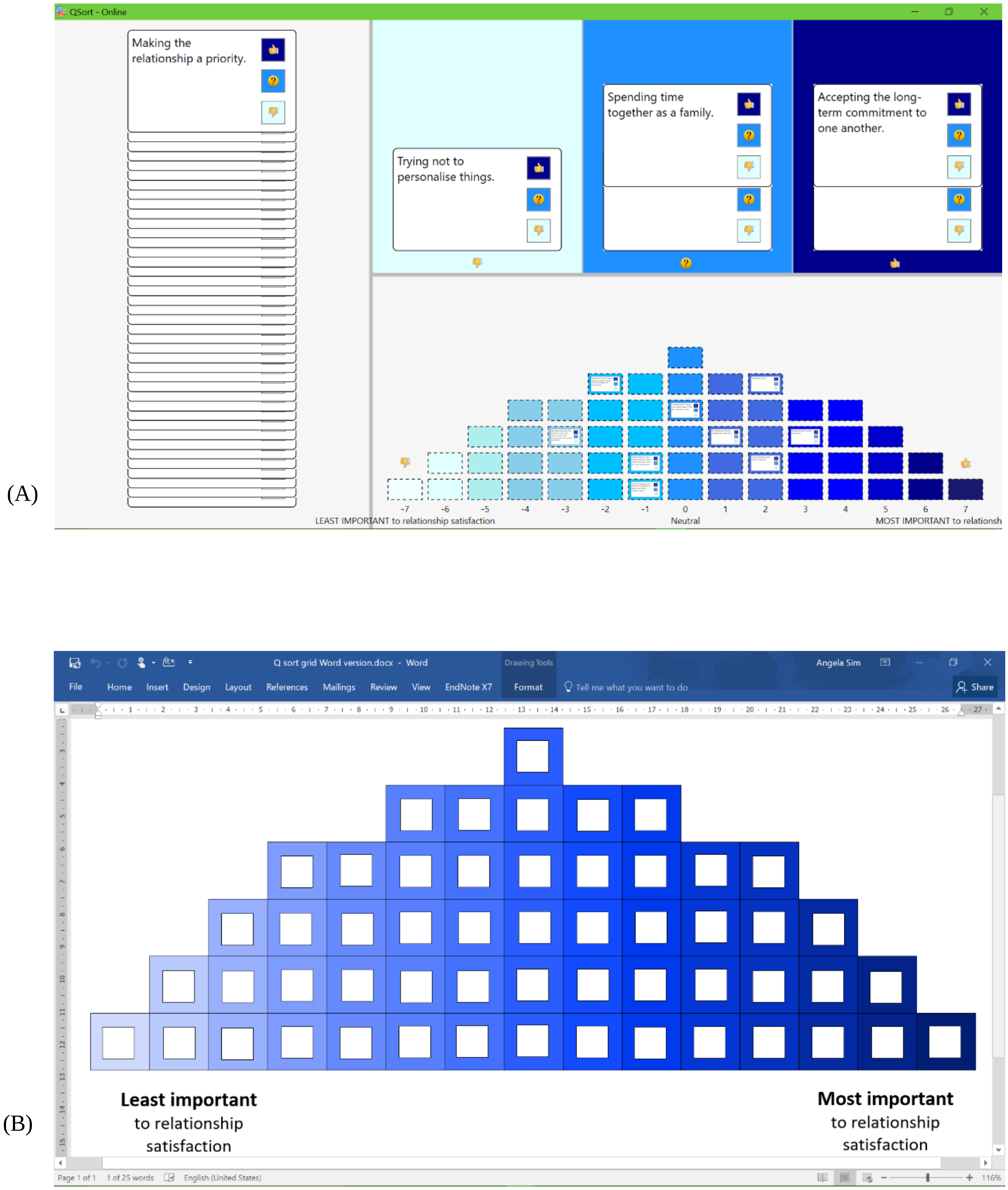
7.3.2 Identifying the Q-sort statements

By integrating participant statements from the expansive interview data and findings from the systematic review, ninety statements were developed which were considered broadly representative of the concourse. These statements were then pilot tested by a sample of four individuals in a cohabiting relationship and raising a child with ASD. The purpose of the piloting was to reduce the number of statements by eliminating irrelevant or repetitive statements and to rephrase as necessary for increased clarity and understanding. To check if the content related to the topic were comprehensively covered, the pilot participants were asked if any they felt there were any important statements missing. No missing content were identified. This process resulted in a total of 54 statements, which were refined and checked for readability in consultation with four of the authors who are experts in the field.

7.3.3 Administering the Q-sort

Participants were purposively recruited from the Curtin Autism Research Group participant list, a list of more than 300 families with a child with ASD who agreed to be contacted about ASD research. They were contacted via telephone or email, depending upon their preferred method of contact listed and caregivers were invited to participate if they met three inclusion criteria: 1) being primary caregivers for a child with ASD; 2) living with the child with ASD; and 3) cohabiting with their partner. Upon expressing interest, potential participants were sent an information letter and instructions for completing the Q-sort. Participants were given the option of completing the Q-sort using online software developed for the Curtin Autism Research Group at Curtin University in Western Australia (40) or by filling in a Microsoft Word document version emailed or posted (with responses either handwritten or typed). Participants were required to give informed consent using a forced response function before being able to proceed with the online Q-sort. Written consent was obtained from those doing the Word document version. All data were de-identified during the data collection process and stored securely. Ethics approval was obtained from Curtin University Human Research Ethics Committee in Western Australia (OTSW-05-2014).

After giving informed consent, participants were asked to carefully read the 54 statements and then sort them according to their relative importance to maintaining relationship satisfaction. This was done by placing each statement in one of the 54 squares on a normally distributed sorting grid, which were arranged in columns scaled from least important (-6) to most important (+6) as shown in Figure 7-1. Participants were advised that their subjective viewpoint was being sought and there were no right or wrong answers. Before submitting the completed Q-sort, participants had the opportunity to rearrange statements until they were satisfied with their placement relative to one another. Upon submission of the completed Q-sort, participants were asked to complete a series of survey questions, including providing an explanation for their choice of statements as most important and if there were any statements that they felt were important to maintaining relationship satisfaction that were missing. Demographic information was then collected about the participant (gender, length of cohabitation, number of children with and without an ASD diagnosis, relationship to child with ASD) and the child with ASD (gender, age, official ASD diagnosis, presence of comorbid conditions). Finally, the Couple Satisfaction Index-32 (CSI; 41) was used to screen the participants' satisfaction with their relationship with their partner. The CSI is a standardised 32-item self-report scale with mostly a six-point response format. Responses were summed with total scores ranging from 0-161, with 104.5 being the minimum cut-off score for relationship satisfaction. It has demonstrated strong construct and convergent validity and report good internal consistency ($\alpha = 0.94$). Given that this study adopted a strengths-based approach, only participants who were satisfied in their relationship were included. As such, only Q-sorts of participants who scored above the cut-off for relationship satisfaction were included in the analysis.



Making the relationship a priority.

Trying not to personalise things.

Spending time together as a family.

Accepting the long-term commitment to one another.

Figure 7-1. Q-sort online and Word document versions of the sorting grid. (A) Screen shot of participant sorting statements onto the grid using the online program. (B) Example of the Q-sort grid normal distribution.

7.3.4 Factor analysis

The Q-factor analytical process involves identifying factors that have correlations with a large magnitude between participants, thus reducing the subjective views down to a few factors that represent a shared viewpoint (34). A total of 43 completed Q-sorts were analysed using the PQMethod 2.35 software package (42). Q-sorts completed on the document version were entered into the online software program so that all sorts could be exported directly into PQMethod. Factors were initially extracted using principle component analysis, resulting in eight unrotated factor matrices (the default number in PQMethod). To determine the number of factors to be retained, four criteria were consulted. The first, the Kaiser-Guttman criterion, states that factors considered for extraction should have an eigenvalue of 1.00 or more (43, 44). All eight factors met this criterion. Humphry's rule was the second criterion applied, where the multiplication of the two highest loadings for each factor should be greater than twice the standard error, which was calculated to be 0.28 (34). All eight factors complied with this rule. The third criterion required the acceptance of factors with at least two significantly loading Q-sorts (34). Factors 1, 2, 4, 5, 7 and 8 met this criterion. Lastly, a scree plot test was performed whereby the eigenvalues were plotted and visually examined for factors displayed prior to the plot plateauing (Figure 7-2). Results supported the retention of two or three factors.

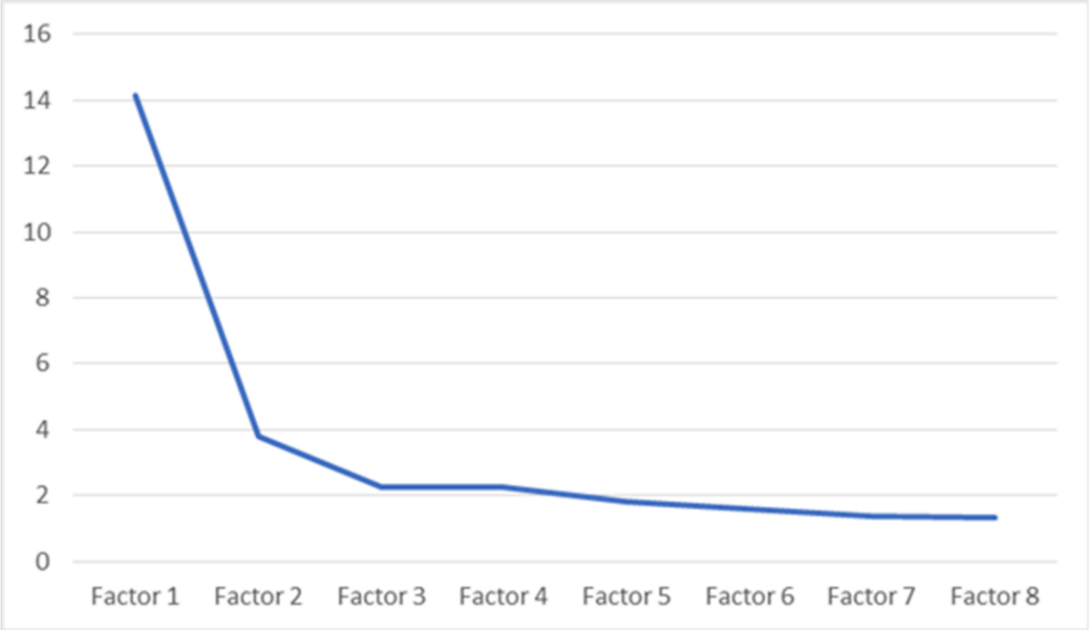


Figure 7-2. Scree plot of factor eigenvalues.

Based on the findings after applying the above criteria, two by-person varimax rotation factor analyses were conducted, one for two factors and the other for three factors. This process produced an overall rotated solution that maximised the amount of study variance explained and ensured each Q-sort had a high factor loading in relation to only one factor (34). Both sets of results were examined and it was determined that a two-factor solution gave the greatest meaning to the research question, explaining 41% of the common variance. Factor arrays were then created to define and contrast the two rotated factors. A factor array is the configuration of a Q-sort that represents the viewpoint of a particular factor (34).

7.3.5 Interpretation of factors

Interpreting the factors involves generating viewpoints, which were labelled in consultation with experts in the field. The viewpoints were studied with regard to defining features, similarities and differences in the factors considered important to maintaining relationship satisfaction. A crib sheet was developed to assist in a holistic factor interpretation by promoting engagement with every item in a factor (34). Consensus statements (those that are agreed upon - that is, not ranked as significantly different) and distinguishing statements (those that are ranked as significantly different - that is, not agreed upon) were also consulted to compare the viewpoints and make a sensible description of them.

7.4 Results

Participant characteristics are presented in Table 7-1. The two factors included in this analysis were defined by 42 participants (98%) with a single Q-sort not loading significantly on either factor. See Table 7-2 for the factor loadings. A list of each statement and the corresponding rankings and z-scores across each factor can be seen in Table 7-3.

Table 7-1. Participant characteristics.

Demographic Information	**Sample (*n* = 43)**	**Percentage (%)**
Parent gender		
Male	17	40
Female	26	60

Demographic Information	**Sample (*n* = 43)**	**Percentage (%)**
Marital Status		
Married	42	98
Cohabiting	1	2
Length of marriage/cohabitation (years)		
Mean(SD)	18(5)	N/A
Median	19	N/A
Range	10-32	N/A
Couple Satisfaction Index-32 Scores		
Mean(SD)	135(14)	N/A
Median	137	N/A
Range	105-158	N/A
Relationship to child with ASD		
Biological father	16	37
Biological mother	26	60
Step father	1	2
Total number of children		
1	2	5
2	29	67
3	7	16
4	5	12
Total number of children with ASD		
1	38	88
2	4	9
3	1	2
Gender of Child with ASD		
Male	36	84
Female	7	16
Age of Child with ASD (years)		
Mean (SD)	13(4)	N/A
Median	12	N/A
ASD Diagnosis		
Autism	18	42
High-functioning autism	13	30
Asperger's syndrome	9	21
Pervasive developmental disorder-not otherwise specified	3	7
Comorbid intellectual disability		
No	37	86
Yes	6	14
Comorbid psychological condition		
No	36	84

Demographic Information	**Sample (*n* = 43)**	**Percentage (%)**
Yes	7	16
Comorbid physical or medical diagnosis		
No	30	70
Yes	13	30
Q-sort completion time (minutes)		
Mean(SD)	21(11)	N/A
Median	16	N/A
Range	5-60	N/A

Note. Some families had more than one child with ASD, however they were asked to report on only one child; N/A = not applicable.

Table 7-2. Factor loadings (bold numbers indicate Q-sorts loading highly on each factor).

Characteristics: Gender, marital status, length of cohabitation (years)	**Factor 1**	**Factor 2**
Female, married, 10	**0.40**	0.30
Female, married, 32	**0.40**	0.18
Male, married, 22	**0.53**	0.33
Female, married, 12	**0.68**	0.38
Female, married, 22	**0.76**	0.16
Male, married, 13	**0.65**	0.39
Female, married, 15	**0.65**	0.12
Male, married, 20	**0.58**	0.50
Female, cohabiting, 19	**0.54**	0.42
Female, married, 22	**0.86**	-0.06
Female, married, 10	**0.41**	0.05
Male, married, 23	**0.49**	0.36
Male, married, 21	**0.52**	0.18
Male, married, 15	**0.86**	0.08
Male, married, 15	**0.53**	0.39
Female, married, 11	**0.72**	-0.24
Male, married, 13	**0.70**	0.18
Female, married, 15	**0.49**	0.28
Female, married, 12	**0.60**	0.35
Female, married, 26	**0.29**	0.19
Female, married, 20	**0.48**	0.38
Male, married, 19	**0.70**	0.28
Female, married, 19	0.25	**0.58**

Characteristics: Gender, marital status, length of cohabitation (years)		**Factor 1**	**Factor 2**
Male, married, 25		0.11	**0.28**
Female, married, 25		0.36	**0.47**
Female, married, 19		0.33	**0.60**
Female, married, 22		0.20	**0.40**
Female, married, 12		0.27	**0.66**
Female, married, 22		0.46	**-0.53**
Female, married, 25		0.32	**0.35**
Female, married, 18		-0.20	**0.80**
Female, married, 25		0.14	**0.53**
Male, married, 22		0.13	**-0.59**
Male, married, 18		0.36	**0.63**
Male, married, 22		0.33	**0.39**
Male, married, 17		0.39	**0.42**
Female, married, 25		0.47	**0.58**
Male, married, 11		0.49	**0.49**
Male, married, 12		0.33	**0.54**
Male, married, 10		0.06	**0.75**
Female, married, 23		0.37	**0.52**
Female, married, 16		0.45	**0.54**
Female, married, 13		0.09	0.06
Explained variance (%)		23	18
Number of defining variables		22	20
Factor score correlations	**Factor 1**	0.51	1.00
	Factor 2	1.00	0.51

Table 7-3. Q-set statements, factor arrays of viewpoints, rankings and z-scores.

	Viewpoints	
Statements	1 ranking (z-score)	2 ranking (z-score)
1. Following cultural traditions.[a]	-6 (-2.29)*	-6 (-2.62)
2. Being friends.	6 (2.19)**	5 (1.24)
3. Putting the child/children’s needs first.	2 (0.45)**	-4 (-0.86)
4. Sharing your feelings with each other.	5 (1.69)**	-1 (-0.17)
5. Being able to resolve conflict.	5 (1.55)**	-1 (-0.24)
6. Sharing the household responsibilities.	3 (0.71)**	-2 (-0.49)

Statements	Viewpoints 1 ranking (z-score)	 2 ranking (z-score)
7. Maintaining stability in the family environment.	5 (1.49)**	0 (0.00)
8. Having open and honest communication.	6 (1.80)**	3 (0.87)
9. Focusing on the positives.	3 (0.74)**	-2 (-0.37)
10. Following religious practices.[b]	-6 (-2.46)	-6 (-2.54)
11. Providing practical help to one another.	4 (0.96)**	-2 (-0.27)
12. Making an effort to socialise	-4 (-0.88)**	-6 (-1.93)
13. Being thankful of what you have.	2 (0.63)**	-3 (-0.74)
14. Having financial stability.	3 (0.86)**	-3 (-0.50)
15. Maintaining social networks.	-2 (-0.36)**	-5 (-1.34)
16. Dealing with challenges as they arise.	4 (1.06)**	-2 (-0.24)
17. Accepting that all relationships have ups and downs.	1 (0.27)**	-3 (-0.64)
18. Focusing on personal growth.	-3 (-0.73)**	-5 (-1.30)
19. Spending time together without the children.[a]	2 (0.36)*	2 (0.68)
20. Working through challenges together.[b]	4 (0.98)	4 (1.07)
21. Trying to make things better.	-1 (-0.20)**	-4 (-1.22)
22. Accessing individual, couple or family therapy.[a]	-5 (-1.31)*	-5 (-1.70)
23. Loving each other.[b]	6 (1.83)	6 (1.98)
24. Having common interests.[b]	-3 (-0.76)	-3 (-0.68)
25. Having realistic expectations about the way life is.[b]	1 (0.11)	-1 (-0.10)
26. Understanding each other’s strengths and limitations.	3 (0.64)**	-1 (-0.16)
27. Looking after yourself.[b]	-1 (-0.32)	0 (-0.08)
28. Appreciating each other’s sense of humour.	0 (-0.11)**	2 (0.69)
29. Working towards the same family goals.	2 (0.31)**	3 (0.78)
30. Having confidence in your parenting ability.[b]	-1 (-0.20)	0 (-0.07)
31. Working as a team.[a]	4 (0.96)*	5 (1.31)
32. Maintaining intimacy.	1 (0.23)**	4 (1.02)
33. Making meaning of your situation based on personal beliefs.	-6 (-1.91)**	-4 (-0.93)
34. Having professional support for your child/children with autism.	1 (0.10)**	-2 (-0.30)
35. Balancing the needs of all of your children, your partner and yourself	0 (0.08)**	2 (0.72)
36. Together taking ownership of the family’s welfare.	-1 (-0.26)**	2 (0.64)

Statements	Viewpoints 1 ranking (z-score)	 2 ranking (z-score)
37. Appreciating the small things in life.[b]	0 (-0.02)	1 (0.05)
38. Helping each other to put challenges in perspective.	-1 (-0.43)**	1 (0.06)
39. Making sure each other feels appreciated.[b]	1 (0.23)	1 (0.44)
40. Making the relationship a priority.	0 (-0.03)**	6 (1.32)
41. Being optimistic about the future.[b]	-1 (-0.29)	0 (0.01)
42. Acknowledging each other's opinions.	0 (-0.06)**	4 (0.93)
43. Being able to do things that you enjoy doing, not just things that you have to do	-3 (-0.56)**	1 (0.30)
44. Thinking about how things could be done differently when they don't go as planned.	-5 (-1.26)**	-1 (-0.22)
45. Acknowledging how difficult it would be to raise your child/children alone.[b]	-4 (-1.04)	-4 (-1.15)
46. Managing stress.	-2 (-0.32)**	2 (0.65)
47. Accepting the family situation for what it is.	-4 (-0.95)**	0 (0.03)
48. Prioritising the family over other areas of life (for example, work).	-2 (-0.42)**	3 (0.72)
49. Recognising that your partner is the only person who truly understands the family situation.	-4 (-0.99)**	1 (0.60)
50. Accepting the long-term commitment to one another.	-2 (-0.43)**	4 (1.18)
51. Spending time together as a family.	2 (0.36)**	3 (0.83)
52. Sharing the parenting responsibilities.	-3 (-0.54)**	5 (1.19)
53. Trying not to personalise things.	-5 (-1.41)**	0 (-0.08)
54. Enjoying each other's company.	0 (0.02)**	6 (1.58)

Note: *Distinguishing statements significant at p<0.05. **Distinguishing statements significant at p<0.01. [a]Consensus statements non-significant at p>0.01. [b]Consensus statements non-significant at p>0.05.

7.4.1 Viewpoint 1: Building trust.

Viewpoint 1 was defined by 22 caregivers and explained 23% of the variance (Table 7-4). This viewpoint recognised the importance of love and friendship to maintaining relationship satisfaction (statement 23: rank +6; statement 2: rank +6) characterised by open and honest communication that included the sharing of feelings and being able to resolve conflict (statement 8: rank +6; statement 4: rank +5; statement 5:

rank +5). This helped to maintain stability in the family environment which was also highly valued (statement 7: rank +5). This viewpoint was captured in the open-ended response: “Having open and honest communication and being able to talk like friends and not have conflict are so important! They are foundations to any relationship”.

Table 7-4. Viewpoint 1: Building trust.

Statements		Viewpoint	
		1	2
2	Being friends	**6**	5
8	Having open and honest communication	**6**	3
23	Loving each other	**6**	6
4	Sharing your feelings with each other	**5**	-1
5	Being able to resolve conflict	**5**	-1
7	Maintaining stability in the family environment	**5**	0
22	Accessing individual, couple or family therapy	**-5**	-5
44	Thinking about how things could be done differently when they don’t go as planned	**-5**	-1
53	Trying not to personalise things	**-5**	0
1	Following cultural traditions	**-6**	-6
10	Following religious practices	**-6**	-6
33	Making meaning of your situation based on personal beliefs	**-6**	-4

7.4.2 Viewpoint 2: Building partnerships.

Viewpoint 2 was defined by 20 caregivers and explained 18% of the variance (Table 7-5). As with viewpoint 1, this group of parents also prioritised love and friendship as most important to maintaining relationship satisfaction (statement 23 rank +6; statement 2: rank +5), but in Viewpoint 2, love and friendship laid the foundation of a long-term commitment to a partnership which was both prioritised and enjoyed (statement 50: rank +4, statement 40, rank +6; statement 54: rank +6). This partnership was exemplified by teamwork in which parenting responsibilities were shared and respect was paid to each other’s opinions (statement 31: rank +5, statement 52: rank +5; statement 42: rank +4). This viewpoint was articulated in the open-ended responses: “Being friends and loving each other is the best foundation for dealing with ASD as a team on a day-to-day basis” and “It is not fair to load one person with the humdrum day to day jobs; equity is necessary for each person to feel valued”.

Table 7-5. Viewpoint 2: Building partnerships.

Statements		Viewpoint	
		1	**2**
23	Loving each other	6	**6**
40	Making the relationship a priority	0	**6**
54	Enjoying each other’s company	0	**6**
2	Being friends	6	**5**
31	Working as a team	4	**5**
52	Sharing the parenting responsibilities	-2	**5**
15	Maintaining social networks	-2	**-5**
18	Focusing on personal growth	-3	**-5**
22	Accessing individual, couple or family therapy	-5	**-5**
1	Following cultural traditions	-6	**-6**
10	Following religious practices	-6	**-6**
12	Making an effort to socialise	-4	**-6**

7.4.3 Similarities between the viewpoints

There were 15 consensus statements for which there were no statistically significant differences across both viewpoints. Both groups of parents agreed that loving each other was the most important characteristic of relationship satisfaction (23). They also both agreed that working as a team to negotiate challenges (31, 20), spending time together without the child/children (19) and making sure each other felt appreciated (39) were of importance to relationship satisfaction. Of slightly less importance were having realistic expectations, appreciating the small things in life and holding optimism for the future (25, 37, 41), as were looking after yourself, parenting self-efficacy and having common interests (27, 30, 24). Both groups of parents also shared agreement on characteristics of (relative) least importance to relationship satisfaction, which included following religious and cultural traditions, accessing individual, couple or family therapy, and acknowledging how difficult it would be to raise a child with ASD alone (1, 10, 22, 45).

7.5 Discussion

This study identified two key viewpoints highlighting what is most important to maintaining relationship satisfaction from the perspective of couples raising a child with ASD who report being satisfied in their relationship with their partner. Both viewpoints highlighted the importance of love and friendship to the relationship; however, the viewpoints differed with regard to how this was achieved. Specifically, viewpoint one encapsulated the belief that maintaining a stable environment through open and honest communication was most important to relationship satisfaction, and this was labelled '*Building trust*'. Conversely, viewpoint two, labelled '*Building partnerships*', supported the notion that working as a team and sharing the parenting responsibilities was most important to maintaining relationship satisfaction.

Caregivers who shared the viewpoint *Building trust* prioritised communication processes and these have long been touted as vital to maintaining relationships and are commonly a key component of relationship interventions (45). Communication may be especially important when raising a child with ASD, due to the need to share information about complex caregiving needs (2, 12). Yet, the extraordinary stress often placed on caregivers can trigger negative interactions and undermine communication (46). In fact, a population-based study found that couple communication declined by 40% under stressful conditions (47). Furthermore, some parents of children with ASD manifest psychological conditions and/or present characteristics of ASD, thus experiencing social and communication challenges of their own (48, 49). Couples can be supported in improving communication processes that can bring clarity to challenges and enable informed decision making and collaborative problems solving (2, 12, 25). Being open, honest and freely able to share feelings can bring couples closer and create an atmosphere of trust, empathy and tolerance of differences (25). This can strengthen the parenting system and improve family stability and functioning. Caregivers prioritised effective resolution of conflict as an important component of communication. This has been supported by extant research that shows that conflict management not only promotes positive couple interactions and satisfaction in the relationship, but also minimises challenging behaviours in children (50-52). This is important as challenging behaviours in children may be a major stressor that impacts on relationship satisfaction in couples raising a child with ASD (8, 18, 53, 54).

Those who shared the viewpoint *Building partnerships* highlighted the importance of prioritising the relationship and developing a sense of teamwork in raising their child with ASD. Often, families reorganise themselves around the child with ASD which, as a consequence, may lead to neglect of other areas of family life (55). Furthermore, the demands of caregiving can be emotionally and physically exhausting, leaving caregivers with little time and energy for their relationship (56, 57). However, couples can maintain relationship satisfaction by consciously making an effort to nurture their relationship, as one caregiver explains: “As much as the therapy and the specialists and the medical appointments are important, your relationship is also important. If you want to stay married, you need to work on it” (12). Couples achieve this in different ways; some formalise couple time with date nights, while others will ensure they get time together in the evenings when the children are in bed, even if it is just watching television together (12). Regardless, caregivers agreed on the need for time as a couple without the children.

The findings of the present study suggest that working as a team to share the responsibilities of parenting a child with ASD can lead to a closer relationship. In support of this claim, a study using a 7-day diary found that parents who were more satisfied with the time their partner spent in child care reported a higher level of relationship satisfaction (58). Yet, caregiving demands can result in role specialisation, whereby the mother reduces or quits paid work to assume the role of primary caregiver, while the father engages in paid employment, often increasing hours to accommodate for decreased income (58). To facilitate relationship satisfaction, clinicians can work with couples to identify ways to strengthen the parenting partnership such that a sense of teamwork is generated. One way to do this is by developing dyadic coping, which is a focus of relationship education programmes such as the Couples Coping Enhancement Training that has shown to have positive outcomes in the general population (59-61).

Families, and indeed, the ASD population itself, are highly heterogenous. Each family must find its own pathway through challenges, fitting their situation, personal strengths and resources (25). Professionals need to customise their support and offer flexibility of interventions. However, the present study highlights two very important viewpoints of couples who reported relationship satisfaction and offers insight into areas to strengthen when supporting families. Professionals can encourage open and honest communication by modelling this behaviour in interactions with families and can encourage teamwork by inviting both parents to meetings and therapy sessions. Services can support families by offering flexible hours, home visits and child minding services. Relationship education can be incorporated into other parent education forums, to raise awareness of the importance of relationship satisfaction, communication and developing strategies to cope together as a couple raising a child with ASD to prevent distress. Families who are struggling could be referred to specialist services, such as family and couple therapists and relationship programmes. Many relationship education programmes already focus on communication, recognising it to be among the most important predictors for relationship success (45); however, recent studies have shown that a focus on dyadic coping (such as teamwork) are vital in helping reduce stress that can impede communication (61). This research supports the inclusion of both these factors, which has been empirically supported by evaluations of Couples Coping Enhancement Training (59-61). Future research endeavours could focus on adapting such programmes for use with couples raising a child with ASD to reduce relationship distress and promote satisfaction in the couple relationship, thereby providing a potential source of family resilience.

7.5.1 Limitations

Some of the feedback from participants captured the limitations of this study. Firstly, some participants reported that the Q-sort took too long to complete and that it was too difficult differentiating between statements that they considered to be equally important, particularly if they had ‘perfectionistic’ tendencies or held ambiguous opinions. While the average completion time was 21 minutes, the range was great with some individuals taking up to an hour to complete. Secondly, while attempts were made to make the Q-statements as broadly representative of the concourse as possible, participants highlighted some factors they felt were important to relationship satisfaction that were missing. These included faithfulness, appropriate funding, acceptance that the child’s ASD is not anyone’s fault, and having a close family; these factors should be considered in future research. Also, it must be reiterated that the viewpoints discussed are merely the factors *most* important to relationship satisfaction by the majority of caregivers in this study; all of the statements are important to some degree and generalisations must be made with caution as every family has different needs at different stages of its lifespan. Another possible limitation was the decision to present a two-factor solution rather than a three-factor one. Apart from the scree plot supporting a two-factor solution, the three-factor correlation scores indicated a closer relationship between factors one and three (0.63) than between factors two and three (0.40), suggesting that factor three was merely subordinate to factor one. The factor array analyses in conjunction with the concourse further confirmed this decision.

7.6 References

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Chapter 8 Discussion and conclusion

8.1 Overview of the research and summary of findings

ASD is a lifelong condition that can place cumulative and chronic strain on caregivers and the couple relationship, however, many couples maintain relationship satisfaction and this may serve as a protective factor for families. For example, relationship satisfaction can influence family stress and wellbeing (1, 2); child development and behaviours (3); and ultimately outcomes of ASD intervention (4, 5). For this reason, there is a need to better understand how relationship satisfaction is maintained so that meaningful support can be provided to couples raising a child with ASD. To date, however, research has predominantly focused on deficits and negative outcomes, overlooking the positive adaptation achieved by many couples (e.g. 6, 7-10). Thus, this thesis aimed to explore the nature of relationship satisfaction in couples raising a child/children with ASD and how it is maintained. Couples who have maintained relationship satisfaction are an important source of first-hand experience from whom researchers can learn to inform family-centred practice. The first step to achieving this aim involved a systematic review of the literature followed by two studies in which existing population-based data were analysed. Together these confirmed the research need, highlighted gaps and informed the following three phases of investigation.

8.1.1 Setting the scene

The first chapter of this thesis introduced the research and its study significance. The second chapter comprised a systematic review of the literature conducted with two aims: 1) To compare relationship satisfaction in couples with and without a child with ASD; and 2) To determine factors associated with relationship satisfaction in couples with a child with ASD. A meta-analysis revealed that, on average, couples raising a child with ASD experienced lower levels of relationship satisfaction than their counterparts whose children did not have ASD. A narrative synthesis revealed diversity in the way that couples adjust, with some studies reporting resilience in couples who maintained a strong, fulfilling relationship. It was unclear why some couples adjusted positively and others did not, but a number of factors were implicated. Risk factors included challenging child behaviours, parental stress and poor parent psychological wellbeing. Protective factors included positive cognitive appraisal and social support. However, it was noted in the review that complex dynamic relationships appeared to exist between these factors and relationship satisfaction. A theoretical model was adapted to encapsulate this revelation and provide a foundation for future research.

Chapter 3 and 4 each comprised of a manuscript summarising the results of a secondary analysis of cross-sectional data from a previous Western Australian population-based study. The rationale for these analyses was to contextualise the systematic review findings by utilising data from a local population of families and to determine the need and direction of future research. The purpose of Chapter 3 was to explore the co-parenting experience and its associated factors. The dependent variable was derived from a question in the survey that asked how raising a child with ASD impacted on the co-parent relationship. Data from 496 families were used in logistic regression analysis and findings revealed that 29% of caregivers indicated that their child's ASD diagnosis had a very negative effect on their co-parent relationship, which was associated with three factors: 1) Family stress; 2) A negative parent relationship with their children without ASD; and 3) Long distances travelled to the nearest medical facility. Given the positive association between co-parenting and relationship satisfaction (11, 12), this was taken as strong evidence for the need to explore relationship satisfaction in WA families due to the impact of raising a child with ASD. Findings also confirmed the importance of studying the effects of raising a child with ASD on different levels of the family system, especially relationships between family members and the family as a whole.

The findings from Chapters 2 and 3 highlighted family stress as a key risk factor for relationship satisfaction, thus, Chapter 4 was designed to explore stress in 543 families and the factors associated with severe stress levels. Findings showed that 44% of families reported severe or very severe family stress, 54% reported mild to moderate stress and a minority (2%) reported no stress associated with having a child with ASD in the family. Severe (and very severe) family stress was associated with four factors: 1) Reduced ability to socialise; 2) Not having accessed individual therapy; 3) Negative co-parenting relationship; and 4) High out of pocket expenses due to the costs associated with raising a child with ASD. The child and sociodemographic factors studied were not found to significantly impact on family stress, suggesting that ecological factors, such as family relationships, play a more important role in the experience of stress in families of a child with ASD. Taken together, Chapter 3 and 4 demonstrated a close relationship between co-parenting, relationship satisfaction and stress related to raising a child with ASD. Moreover, the findings showed that a child with ASD can impact on the family through various levels of the family system, confirming the importance of a family-systems approach to stress, coping and relationship satisfaction.

8.1.2 The gap

The background research revealed a number of areas of deficiency. Most notably, existing research was overwhelmingly focused on negative outcomes. The review and analyses of local population data strongly demonstrated the diversity of family responses to raising a child with ASD and many report positive outcomes. These families are valuable sources of first-hand experience to learn from in pursuit of achieving better outcomes in couples and families with a child with ASD. Also, apparent from the background research was the lack of dyadic data and the consideration of each parent’s likely bidirectional influence on each other. Most studies focussed on parent’s individual stress and coping, disregarding the increasing evidence from the general population that dyadic coping may be one of the strongest predictors of relationship satisfaction (13). There is ample evidence of the importance of social support to families raising a child with ASD, but few studies distinguish between the sources of such support (14). Those that do have confirmed that partner support is considered by many caregivers to be the most valuable (15, 16). Yet, the exact nature of partner support requires further investigation. The one relevant publication studying couples raising a child with ASD found a positive association between *supportive* dyadic coping and relationship satisfaction (17), however, partner support is only one dimension of the complex construct that is dyadic coping (18).

Furthermore, many studies explored relationship satisfaction and dissatisfaction as a continuum, assuming they are opposites of a single dimension. Yet, there is increasing evidence to suggest that, although closely related, the two dimensions are independent and should, therefore, be studied as categorical variables (19). Moreover, the prevailing research was limited by the statistical analyses used; most predominantly they used measures of central tendency restricting their ability to capture individual differences. Qualitative designs can supplement quantitative designs to provide a more comprehensive understanding of the nature of relationship satisfaction and capture common essences, as well as unique differences. Thus, the impetus for a three-phased research project was borne to bridge the identified gaps.

8.1.3 Bridging the gap

Chapter 5 comprised a cross-sectional survey of a convenience sample of 127 caregivers from 83 WA families. The survey collected data on relationship satisfaction, parenting stress, dyadic coping and sociodemographic variables. The findings revealed that a majority of participants (66%) reported relationship satisfaction with no significant difference between males and female caregivers. These participants were more likely to report low stress, decreased use of negative dyadic coping, and increased use of positive dyadic coping than those who reported relationship dissatisfaction. Positive dyadic coping was much more strongly associated with relationship satisfaction than negative dyadic coping, supporting a strengths-based approach to intervention whereby the greatest focus should be on strengthening positive couple behaviours, rather than merely eliminating the negative. Such an approach offers hope and lends itself to empower parents for change (20). The findings from this study were more positive than results from the co-parenting study of Chapter 3. There was a positive association between co-parenting and relationship satisfaction, although it is relevant to note that inclusion for participation in this study was restricted to cohabiting couples, whereas the co-parenting sample included separated parents, which likely introduced a sampling bias.

8.1.4 Unchartered territory

Using an explanatory sequential design, Chapter 6 extended on the findings from Chapter 5 by applying phenomenology to explore, in depth, the lived experience of relationship satisfaction in a purposive sample. The sample was screened using the relationship satisfaction questionnaire, as described in Chapter 5. Couples who scored above the cut-off for relationship satisfaction were invited to a face-to-face interview with the researcher. Data from 11 couple interviews were used in thematic analysis to explore how each couple maintained satisfaction in their relationship. The overall essence that emerged from the data was captured in the quote “We are in this together” and encapsulated three main themes. These themes described the way couples coped together to raise their child with ASD and were central to their relationship satisfaction experiences. The first theme *shared beliefs* constituted the three sub-themes of acceptance, focusing on the positives and existential meaning. The second theme “teamwork” described the way couples worked in partnership to nurture the family, themselves and their relationship. The final theme “shared experiences” captured the importance of effective communication, humour and emotional support to relationship satisfaction. These findings extend beyond the results of the previous chapter by describing the dyadic coping behaviours and strategies used by couples that enhance their relationship satisfaction.

Consistent with exploratory sequential designs, Chapter 7 extended upon Chapter 6 by applying Q-methodology to identify characteristics of individuals that shared common views. The study involved a statement sorting activity, in which 43 participants were required to place a total of 54 statements on a grid in order of their relative importance to maintaining satisfaction in their relationship with their partner. These statements were predominantly derived from the concourse of interview data obtained in Chapter 6. Varimax factor analysis generated a two factor (i.e., a two key viewpoints) solution; one highlighting the importance of building trust through effective communication, while the other prioritised the importance of building a strong partnership by working as a team to share the responsibilities associated with raising a child with ASD. Findings confirmed the importance of strengthening dyadic coping strategies, including communication, which should be embedded within family centred interventions.

8.2 Synthesis of findings

The first key finding of this thesis was the diversity of adaptive responses in families. The background research indicated that couples with a child with ASD were at greater risk of relationship dissatisfaction than couples with a child without ASD. Despite this risk, the majority of couples raising a child with ASD maintained a satisfying relationship with their partner. Strengthening the couple relationship may help to mitigate the challenges associated with raising a child with ASD and facilitate positive family adaptation. For families who are struggling, this finding adds balance to the negative picture too often portrayed in the literature and media, and offers hope and possibility for a better future and will guide the application of family focussed ASD interventions.

The second key finding was that couples who maintained relationship satisfaction were far more likely to engage in positive dyadic coping strategies and to report less parenting stress than couples who were dissatisfied in their relationship with their partner. This finding supports dyadic stress and coping theory (21). With the aim of strengthening the theoretical foundations for future research and intervention, dyadic coping has been added as a mediator to the model presented in the systematic review of Chapter 2. These dyadic coping strategies and their significance to relationship satisfaction were explored further through qualitative analysis that have been detailed in the model description and are explained in greater detail in the next section.

8.2.1 Model of relationship satisfaction in the context of a child with ASD

A Model of Relationship Satisfaction in the Context of a Child with ASD was adapted from the Model of Marital Quality and Psychosocial Wellbeing in the Context of Child Disability (22) and evolved over the development of the thesis. The original model can be seen in Figure 8-1. This was first adapted in Chapter 2 based on the findings of the systematic review, and is presented in Figure 8-2. The model was further refined based on the synthesised outcomes of the research constituting this thesis, as can be seen in Figure 8-3. In each model, the arrows show associations rather than causal relationships. Double arrows indicate bidirectional relationships. Grey boxes reflect factors that may influence (and be influenced by) relationship satisfaction. White boxes denote factors that may play a mediating role in relationship satisfaction. Factors in the model are interrelated and embedded in broader family and societal contexts, captured by the oval shapes. Pathways (associations) are numbered and correspond to the numbers in superscript in the text below:

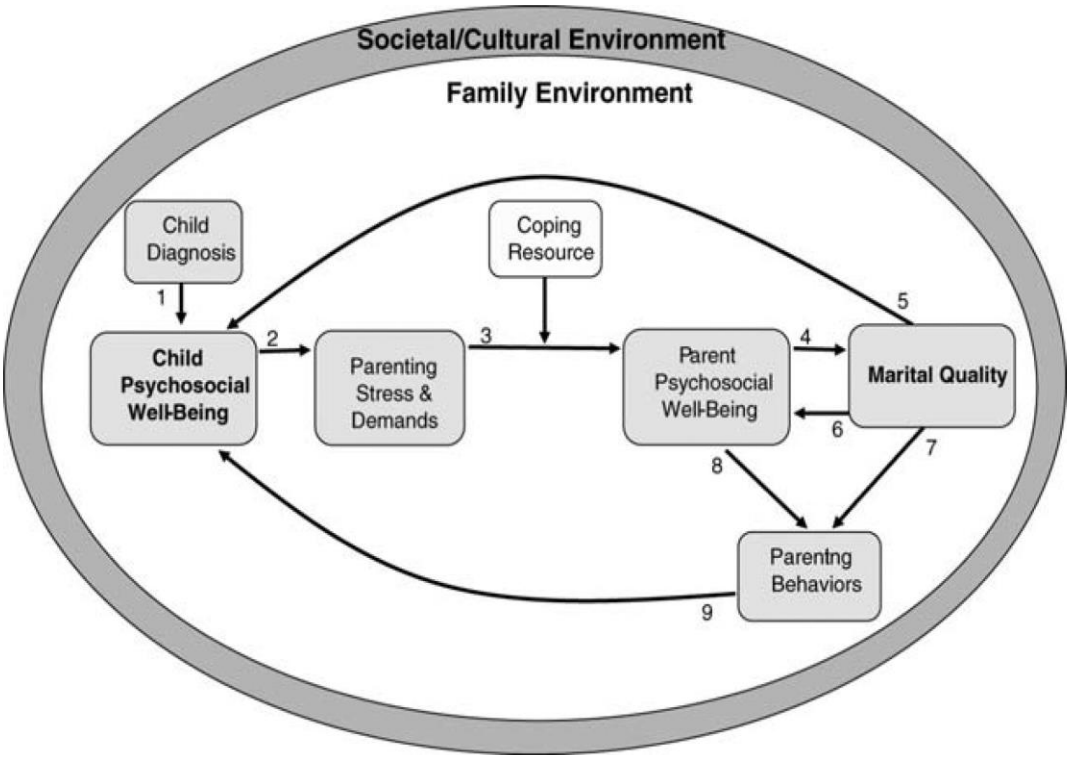

Figure 8-1. Model of Marital Quality and Psychosocial Wellbeing in the Context of Child Disability (22).

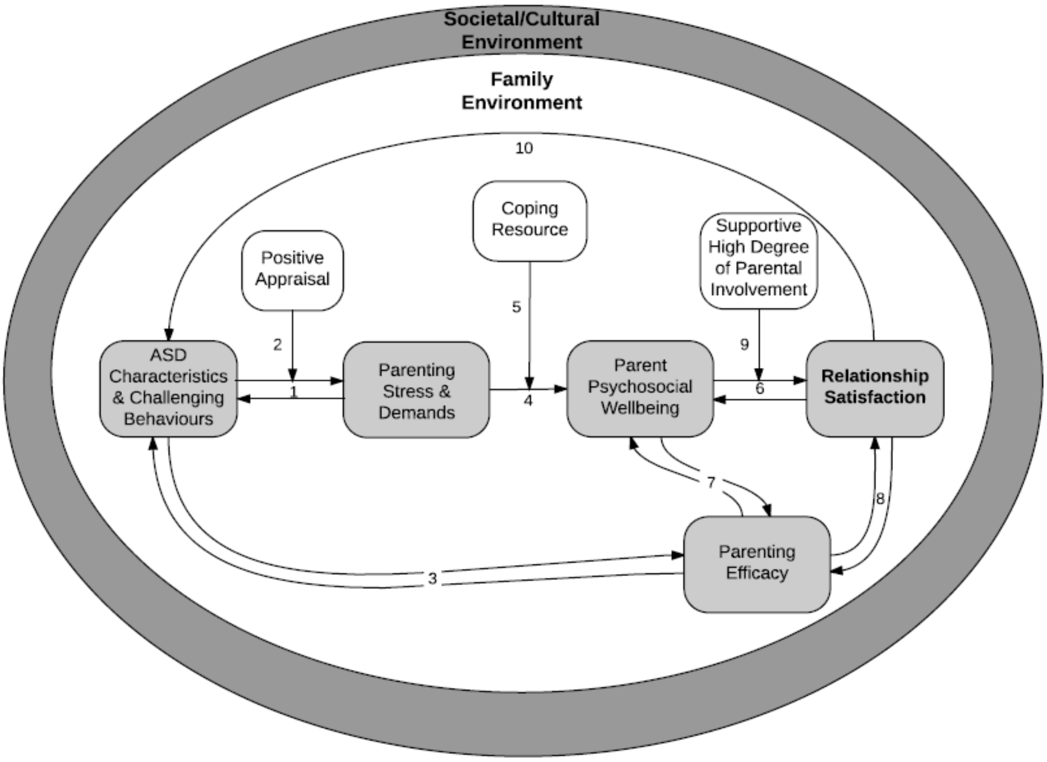

Figure 8-2. Model of Relationship Satisfaction in the Context of a Child with ASD.

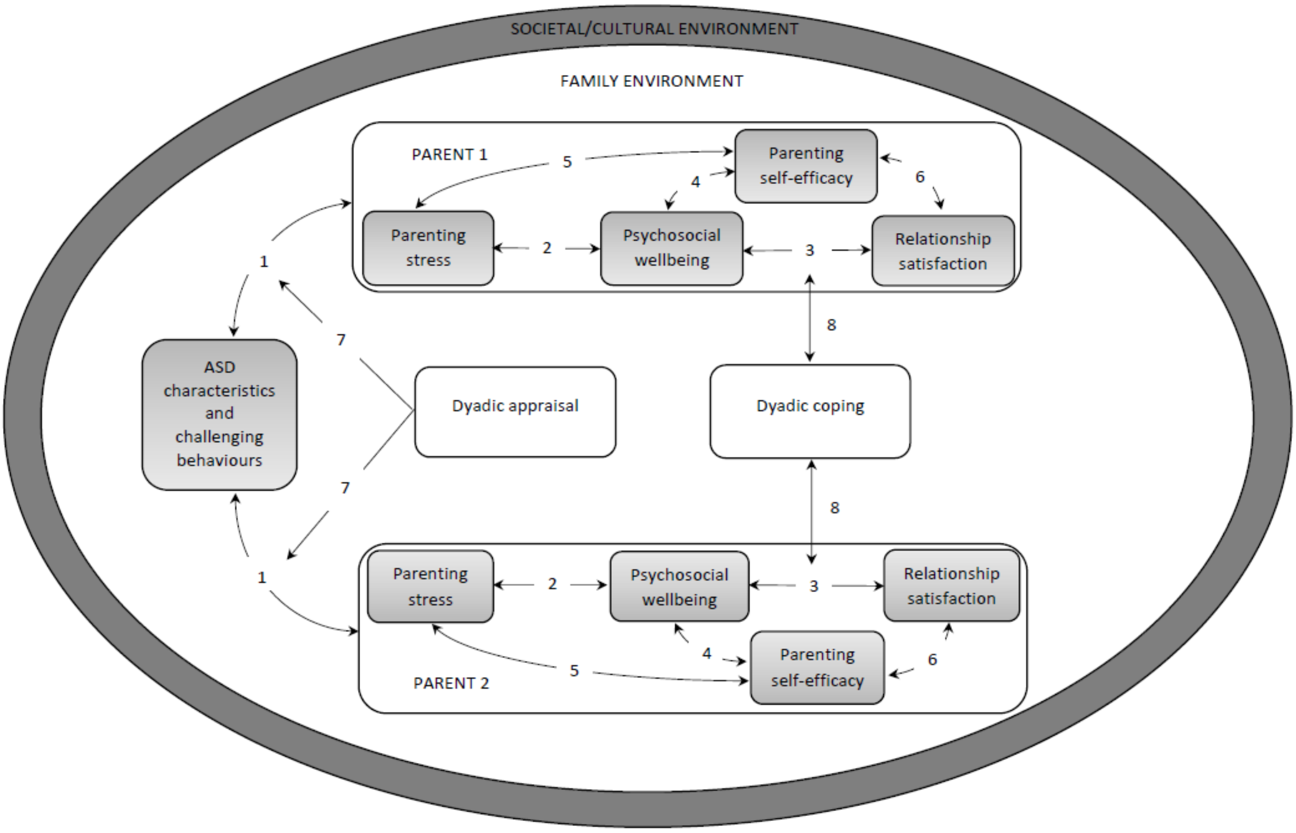

Figure 8-3. The final Model of Relationship Satisfaction in the Context of a Child with ASD based on the synthesis of thesis findings.

8.2.1.1 Parents and the child with ASD: Mutual influences

ASD is associated with a number of characteristics that impact on the child's psychosocial wellbeing and, reciprocally, the parents' stress, psychosocial wellbeing, parenting self-efficacy and ultimately relationship satisfaction creating complex, dynamic family processes (17, 23-27)[1]. For example, a longitudinal study found that relationship satisfaction in couples co-varied with fluctuations in challenging behaviours in the child with ASD over the course of seven years (24). Another study found a positive association between marital quality and two key social outcomes in their child with ASD in middle childhood: the number of playmates and participation in group play (23). Stress is exceptionally high in couples raising a child with ASD (6), attributed mostly to parental demands (9, 28). Arguably, the challenging behaviours that commonly co-occur in children with ASD are one of the primary sources of parenting stress (29-31). Bidirectionally, parenting stress can escalate challenging behaviours (32). It can have a bidirectional impact on parental psychosocial wellbeing (9, 28, 33, 34)[2]. There is evidence that parents of children with ASD are more likely to meet the diagnostic criteria for depression and anxiety than those parenting a child without ASD (9). Importantly, however, parenting stress may not be entirely responsible for this phenomenon; genetic factors may predispose parents to mental health conditions (35-37). Furthermore, there is strong evidence of cross-partner effects whereby the psychological wellbeing of one parent can affect the other (17, 38, 39). Stress management and psychological wellbeing can be enhanced by adequate social support (8, 26, 27, 40-42), however, many parents report decreased ability to socialise and diminished social networks (34, 43-45). Therefore, their partners become a vital source of support (15, 16, 46).

The psychological and social wellbeing of caregivers has been associated with relationship satisfaction and the association is bidirectional (25, 33, 47)[3]. Psychosocial wellbeing can affect partner interactions; for example, studies from the general population have shown that people with depression are less likely to smile, make eye contact or otherwise engage in positive couple interactions, diminishing satisfaction with the relationship (48, 49). The findings from Chapter 6 of this thesis give support to this part of the model; couples who reported satisfaction in their relationship attributed it, in part, to nurturing their physical, psychological and social health. Satisfied couples actively supported each other in this endeavour, which not only promoted wellbeing, but also helped develop a fondness for each other, thereby creating a positive feedback loop. Stress and wellbeing may also impact on the opportunity for couples to spend quality time together (50). The satisfied couples in this research minimised this impact through active efforts to spend quality time together, be it through pre-planned date nights or simply sharing a drink on the porch after the children went to bed. This maximised their opportunities for creating shared experiences, engaging in mutual emotional self-disclosure and fostering intimacy; all important aspects of relationship satisfaction (51).

Parenting stress and psychological wellbeing both reciprocally affect parenting self-efficacy (17, 43, 52-55)[4, 5]. Often, parents of children with ASD have difficulty interpreting and responding to their child’s cues and their intended interactions do not lead to the expected outcome (56). Thus, parents can feel disempowered and doubt their ability to manage their child’s behaviours leading to frustration, anger, loneliness, anxiety and/or depression (57-59). However, improving self-efficacy through caregiver workshops has been shown to reduce challenging behaviours in children, demonstrating a promising area of intervention (60).

Parenting self-efficacy and relationship satisfaction have been found to be associated in cross-sectional studies, however, a causal direction is not clear (33, 61)[6]. A longitudinal study suggests that marital satisfaction does not predict parenting self-efficacy across time in couples raising a child with ASD (33); however, studies from the general population suggest that parenting self-efficacy can moderate parenting stress on relationship satisfaction, at least in fathers (62). Furthermore, both fathering self-efficacy and relationship satisfaction can predict father involvement in child care (63) which, hypothetically, might have crossover benefits to marital satisfaction for mothers. This line of reasoning warrants further exploration.

8.2.1.2 The mediation of dyadic processes

The initial model presented in the systematic review of Chapter 2 has been expanded to recognise the interdependence of partners and include coping processes intrinsic to the couple relationship as these were key findings presented in

Chapters 5 to 7. Positive cognitive appraisal has been recognised in the extant literature as an important mediator that buffers the potential negative impact of raising a child with ASD on parental wellbeing, resourcefulness and relationship satisfaction (17, 64, 65)[7]. A stress event in itself may be a poor predictor of parental outcomes, more important are the perceptions of the event and coping resources available to the couple (18). There is mounting evidence that parents who perceive the challenges associated with raising a child with ASD as manageable and meaningful and who held optimism, were less likely to feel stressed and more likely to experience relationship satisfaction (14, 17, 61, 66-70). Findings from the interviews in Chapter 6 of this thesis strongly suggested that satisfied couples shared beliefs that guided how they appraised their child with ASD and challenges that arose. Couples reported the importance of both partners accepting their situation and reframing challenges positively to maintain satisfaction in their relationship. Similarly, another study revealed that one parent's ability to make sense of their situation and their ability to find benefits in having a child with ASD influences their partner's appraisals (71). Surprisingly, even though dyadic appraisal is a sound theoretically concept, it has received scant attention in the research pertaining to families with a child with ASD. Family systems theorists have long touted that dynamic transactions occur within families and it is recognised that each partner's stress appraisals must be considered in synchrony with the other's (51). Dyadic appraisal is a complex process; put simply, it involves each partner initially making an individual evaluation, then considering it in context of their partner's appraisal before making an attempt to integrate the two views (18). This can be covert (by comparing the assumed view of the partner) or overt (through open discussion). If agreement is found by both partners then a common, or *dyadic*, appraisal results. If an agreement is not met, there is the potential for the resulting discord to create an additional source of stress contributing to marital dissatisfaction (18, 51). Dyadic appraisal is, thus, an important prerequisite to coordinated coping efforts.

When stress has the potential to affect both partners in a couple, a dyadic coping process is initiated (18). This might involve the act of one partner providing support to the other or a collaborative effort to deal with a common stressor; the aim being to maintain equilibrium in the individual and couple subsystems and their relationships with broader social systems (18, 51). However, dyadic coping is only one way that stressors are managed; individual coping strategies remain important when stressors primarily concern one partner. Only when the enacted coping strategies have shown to be unsuccessful and spill over into the relationship is dyadic coping activated (18, 51). There is evidence that dyadic coping is a stronger predictor of relationship satisfaction than individual coping and it can mediate individual coping efforts (13).

Although utilised as a tool for stress management, dyadic coping also has the benefit of enhancing relationship quality[8]. Dyadic coping achieves this by fostering commitment, mutual trust and a sense of togetherness and the belief that the relationship is a reliable supportive resource in times of need; thus, the more constructively couples manage stress, the more likely their chance of relationship satisfaction (51). There is robust empirical evidence to support the role of dyadic coping in maintaining relationship satisfaction in the general population (72), as well as caregivers of children with ASD (17, 73). This has been further supported by the findings reported in Chapter 5.

For dyadic coping to be enacted, both partners need to be motivated, which is influenced by intrinsic factors, such as marital satisfaction (hence the bidirectional relationship), or extrinsic factors, such as the presence of children (18). The findings from the interviews in Chapter 6 supported this, revealing that couples were motivated to work together as a team in the shared belief that it was in the best interest of their child with ASD. Effective dyadic coping requires the co-occurrence of two factors: competence in individual coping skills, such as individual appraisal and coping and competence in dyadic coping skills (such as communication, coordination and organisation; 18). As expected, these skills were voiced as important to relationship satisfaction by the interviewed couples. Couples delivered a strong sense of being *in it together*. That is, they felt unified with their partner in the common goal of raising their family. This involved sharing beliefs that shaped their appraisal of stressful encounters, working together as a team to look after each other and the family, and open and honest communication and emotional sharing.

8.2.1.3 Broader family and socio/cultural influences

Although discussed separately, all factors in the model are interrelated and embedded in broader family and societal contexts. For example, there is the need to consider additional life stressors unrelated to parenting, such as work and financial stress that can spill over into the relationship to compound parenting stress experiences (74, 75). Societal attitudes are a particular source of external stress, with parents with a child with ASD reporting that they experience stigma and blame for their child’s behaviours (7, 76). Availability of resources and access to services also influence outcomes for the child with ASD, their parents and the couple relationship (52, 77). The impact of these influences will be discussed further in the section on recommendations for clinical practice.

8.3 Recommendations for future research

To gain a more comprehensive and holistic picture of the experiences of families raising a child with ASD, strong theoretical underpinnings are required to structure future research. This will provide guidance for the appropriate use of study designs and methodologies, so that study findings can be appropriately synthesised and compared (78). The culmination of research findings from this thesis has led to the advancement of a theoretical model. Future research is required to test the model to provide empirical support for family-centred clinical interventions (78).

Parts of the model need further examination; most notably, dyadic appraisal and dyadic coping. Very little is understood about how partners influence each other’s appraisal of stressful events; similarly, there is a lack of comprehension of how they cope together in response to various types of stressors. This research shows the importance of dyadic coping in maintaining relationship satisfaction; however, research from the general population also shows that dyadic coping can have an impact on other areas of functioning, such as child behaviours (79, 80). This is a salient finding, given that challenging behaviours are highly prevalent in children with ASD and have been cited as a key source of parenting stress (32, 81, 82). Thus, research to support the development and evaluation of programmes to enhance dyadic coping can lead to interventions for families raising a child with ASD that not only improve relationship satisfaction, but also child outcomes.

Importantly, the model should be tested in different sub-populations and family structures as their experiences and support needs may differ considerably. Special consideration should be given to at-risk families, such as those from low socioeconomic backgrounds or living in regional and remote communities (83), and in families whereby one or both parents have a mental illness or ASD. Furthermore, given the proposed high rate of divorce (84), exploring co-parenting in separated families is another relevant avenue for research.

The model could also be expanded to consider other family members. For example, the couple relationship can influence the relationship between a child with ASD and their siblings (85), and this could incorporated into the model. The findings from Chapter 3 also highlighted an association between the co-parenting alliance and the relationship of parents with their children without ASD. Issues may arise, such as siblings' need to vie for attention, adopt a caregiver's role, hide their own concerns for fear of further burdening the parents, or reduced participation in extra-curricular activities; while parents may feel guilt around perceived neglect, embarrassment or hurt to their children without ASD (44, 86-88). Further investigation of these relationships was outside of the scope of this thesis but requires further research. Furthermore, researchers need to be cautious of exclusively capturing the mother's perspectives and assuming they are representative of other family members (78). It has been demonstrated that mothers view the relationship between their child with ASD and siblings differently from the siblings themselves (85).

The model presented supports multiple method approaches to research. Sophisticated modelling techniques can be applied to explore the inter-relatedness of variables at different levels of the family system, and account for the interdependency of couple data. Using multiple waves of data collection across time would also be valuable, due to the changing nature of both ASD and relationship satisfaction over time and the co-varying response of relevant variables. Utilisation of measures other than self-report, such as coded observations of dyadic coping behaviours and interactions, can provide additional data on relationship properties that are not limited to the subject's own awareness and insight into their relationship quality (19). Qualitative designs can add depth of understanding to the meanings underlying family transactions and take into account the vast heterogeneity of families raising a child with ASD.

Further, it is important that both positive and negative couple experiences are researched if a holistic, strengths-based approach to intervention is to be achieved.

To date, the research literature has overwhelmingly emphasised negative outcomes. Yet, as this thesis reveals, many couples demonstrated positive couple adaptation. These couples, paradoxically, reported on both relationship strains and rewarding experiences, and by dealing with adversity together, their relationship was strengthened. It is therefore important to regard positive and negative aspects of relationship quality separately as variables that co-exist, rather than polar ends of a single continuum (19). Greater emphasis on the inherent capacity of families to utilise their own resources is critical (89).

8.4 Recommendations for clinical practice

8.4.1 Service delivery

Family-centred approaches are touted as best practice (78, 90-92). However, it could be argued that an intervention focused on the needs of a child with ASD alone is incomplete without taking into account the needs of the entire family - especially the couple relationship, which is regarded as the nucleus around which the family functions (93). This thesis demonstrated that working with families with a child with ASD requires a multifaceted approach that gives consideration to the various layers of the family system; family members, the relationships between them, as well as the relationships between the family and broader sociocultural contexts. The complexity and lifelong course of ASD calls for an understanding of couples to ensure caregivers receive the support necessary to nurture their child and achieve the best family outcomes possible (91). Such family-centred approaches can reduce family stress, improve wellbeing, and ultimately enable parents to make better decisions regarding their child’s care (91, 94).

The importance of early intervention to strengthen couple relationships and reduce distress cannot be overstated, as the diagnostic period can be especially challenging for couples raising a child with ASD (52, 95). Interventions should not be restricted to families in distress; instead, a strengths-based approach targeting key aspects related to building resilience should be employed. Such an approach would promote positive family adjustment, empower families, reduce family vulnerabilities and increase family resourcefulness to effectively manage future challenges (20).

Involving both parents in assessment, goal setting and intervention is critical to gain a rich understanding of the family's unique experiences, belief systems and create an environment that encourages couples to communicate, share responsibilities and work together as a team. To achieve this, flexibility in models of service delivery is essential. For example, providing meeting times outside standard working hours, providing child-minding services or offering home visits so that both parents can actively participate.

8.4.2 The therapeutic relationship

Family-centred practice is not just about *what* is done but *how* it is done (96). Clinicians who work from a strengths-based approach will encourage couples to refocus on their strengths and capabilities as they navigate the, all too common, deficit-focused medical model of service delivery (86). A therapeutic relationship grounded in family-centred principles invites relational authenticity and collaboration (97). This can encourage parents to communicate and work together more effectively to raise their child with ASD, which were found to be important components of relationship satisfaction in Chapters 5, 6 and 7. Clinicians can achieve this by providing both parents with honest and easy to understand information, opportunities to address questions they may have, and the use of positivity to temper the processing of testing information (97). Positivity and acceptance were other attributes recognised as important in facilitating relationship satisfaction by the couples interviewed in Chapter 6. Therapists can encourage couples to examine their belief systems; develop an understanding and acceptance of their situation and child with ASD; affirm strengths and envisage a better future (86). Caregivers have previously identified the desire for professionals to provide a sense of optimism (83), and this thesis endorses this notion. Moreover, there is emerging evidence for the effectiveness of positive thinking training in caregivers of children with ASD (98).

8.4.3 Raising awareness of the importance of relationship satisfaction

The findings illuminated in this thesis play a vital role in the dissemination of much needed information about the importance of relationship satisfaction in couples raising a child with ASD and ways to strengthen it. Healthcare providers should be trained to evaluate the couple relationship, provide relevant education and make appropriate referrals. Such training should begin during undergraduate years and be reinforced as ongoing professional development. It is vital that this information is filtered down to couples to highlight the value of relationship satisfaction and its importance to positive family adaptation when dealing with challenges associated with raising a child with ASD. A sense of hope should be fostered and couples should be empowered to prioritise their relationship alongside other therapy goals and identify ways to fortify their relationship, by examining their belief systems and strengthening dyadic coping behaviours. By doing this, couples can provide a solid foundation for child-centred interventions that typically involve high levels of parental involvement, the effectiveness of which may be influenced by their dyadic coping abilities (4, 5, 99). If parents are not provided with the necessary supports and resources, they are unlikely to have the time and resources to carry out their parenting responsibilities and interact with their children in ways that enhance development (96).

To support couples raising a child with ASD, agencies and health professionals can offer information in different mediums, such as information sessions, face-to-face communications, pamphlets, newsletters and websites with links to relationship research and relevant services. This will enable caregivers to access information at their own pace using their preferred method of learning (97). Furthermore, existing parent training programmes could be modified to incorporate components of relationship education.

8.4.4 Couple relationship training

Couple relationship training can help promote healthy relationships and prevent future distress. Furthermore, when parenting programmes involve both parents and are supplemented with components that address dyadic coping, they have greater positive effects on the entire family by reducing parenting stress, improving parental involvement (particularly in fathers) and ultimately optimising child adjustment and behaviour (100, 101).

The Couples Coping Enhancement Training (21, 102) may be particularly beneficial for couples with a child with ASD, as it goes beyond teaching constructive communication and enhances dyadic coping in the context of both daily hassles and significant life stressors, although it is yet to be evaluated in this context. The training programme can be delivered traditionally by an educator in small groups or can be undertaken using self-directed learning materials so that couples can complete the program privately, in their own time. Both modes of delivery have repeatedly shown positive outcomes in the general population, such as improved relationship satisfaction and psychological health (102-109), as well as improved parenting and child behaviours (100, 110). For example, one study showed that the Couples Coping Enhancement Training resulted in enhanced couple relationship satisfaction, reduced dysfunctional parenting and reduced behavioural challenges in children when compared to the Triple P parenting programme and control groups and results were stable for one year (110). It is recommended that such a program be adapted for delivery to couples raising a child with ASD, with the view of it being offered by ASD services using a family-centred approach. At the very least, ASD services should provide information regarding where to access evidence-based relationship programmes and provide referrals as necessary.

8.4.5 Advocacy

Health professionals working with families with a child with ASD also have an advocacy role to fulfil. Advocacy is required to promote policy change at all levels to ensure authentic family-centred practice. It is paramount that ASD services and their staff receive adequate training and resources to support couples in maintaining a healthy relationship. To achieve this, education of the importance of the couple relationship is required to ensure funding is allocated to assist with the costs of relationship education and training; couple counselling; and also respite, so that couples can attend appointments together as well as spending quality time as a couple. Families are often stretched financially due to the costs of therapy and reduced employment resulting from the child’s caregiving needs (34, 111) and may not recognise the relationship as a priority investment given their child’s needs. Thus, health professionals need to advocate on their behalf.

8.5 Strengths and limitations of the research conducted in this thesis

The application of a strengths-based framework was a forte of the thesis. Couples who reported maintaining relationship satisfaction were identified, acknowledged as a valuable asset, and their experiences were used to guide health professionals with how to best support families in meaningful ways. The findings reinforced the appropriateness of such an approach, revealing the importance of positivity and optimism and drawing on strengths within families.

This research was theoretically driven and bridged an identified gap in understanding how couples cope together to manage the challenges associated with raising a child with ASD and maintain relationship satisfaction. The inclusion of fathers was a strength of the research, as many studies capture only the mother's perspective as representative of the family. Furthermore, the research looked beyond the parents as individuals and investigated relationship characteristics between partners and the influence they have on each other, guided by a systemic-transactional conceptualisation of stress and coping (18). The interdependence between partners was taken into account through appropriate statistical procedures and explored explicitly in interviews with partners together. The theoretical model presented in the discussion section draws together the key findings and provides firm foundations for further research from a family systems perspective.

Another strength of this thesis was the application of different methods, which helped to accommodate for some of the limitations of any single method (112). It allowed for a comprehensive understanding of relationship satisfaction and improved validity through the triangulation of different sources to compare, confirm and expand upon findings (113). The cross-sectional survey of Chapter 5 had the advantage of standardised measures and statistical analyses while the qualitative component facilitated a rich appreciation of unique and varied experiences. The use of both explanatory and exploratory sequential designs (between Chapters 5-6, and 6-7 respectively) facilitated congruence between the phases of research such that one informed the next.

There were a number of limitations to the thesis that require discussion; limitations specific to each study have been delineated in the discussion sections of individual manuscripts. The first limitation was the static portrayal of relationship satisfaction in the cross-sectional survey of Chapter 5, as relationship satisfaction is considered a continually evolving construct best captured through multiple waves of data collection (114, 115). Furthermore, the study design did not allow for causation to be determined, nor did analyses capture the complex inter-relationships between variables. The model proposes that dynamic associations exist, but this requires further testing for confirmation.

Additional limitations involved recruitment and sampling. Participants were recruited from a list of families who volunteered to be contacted regarding research. This potentially created a self-selection bias of participants who were interested in research and could spare the time to participate. Thus, families who were under great stress may have been under-represented leading to inflated levels of relationship satisfaction in the sample. However, this proved a practical advantage in screening for the interviews in which relationship satisfaction was a prerequisite for inclusion.

Parents of children with ASD were heterogeneously sampled due to recruitment difficulties, which resulted in small samples. Variables, such as child ASD severity, age/developmental stage of the child, length of the couple relationship, time since diagnosis, were not accounted for and may have confounded the results. The samples studied were also found to be relatively affluent, thus, research findings cannot be generalised to those from low socioeconomic backgrounds who may have very different experiences, especially given that economic resources have been identified as a factor that influences family adaptation in the face of adversity (116).

The sole use of self-report lends itself to social desirability bias and recall bias, in which couples may have portrayed their relationship in a more desirable, positive light than may have been observed using other more objective measurement tools, as posited by other researchers (19). Again, this might have inflated the number of couples reporting relationship satisfaction.

8.6 Summary and conclusions

A healthy, satisfying couple relationship may serve as a protective factor for families managing the pervasive and enduring challenges associated with raising a child with ASD (33, 117). The quality of the relationship influences parenting stress and personal wellbeing (1, 2, 118, 119). Furthermore, it can foster child development due to the couple's role in shaping healthy belief systems, social-emotional environments, parenting practices and parent-child relationships within a supportive family structure (100, 120-122). For couples raising a child with ASD, parental wellbeing and relationship satisfaction can play an integral role in the child's access to, and effectiveness of, interventions (4, 5, 99, 123). Strengthening the couple relationship can promote family resilience and provide the critical foundations for long-term therapeutic caregiving.

Despite the significance of the couple relationship to family outcomes, few studies have explored relationship satisfaction in couples raising a child with ASD, particularly from the perspective of couples who have adapted positively. These couples are believed to be a valuable source of first-hand information from which clinicians can learn, guiding them in meaningful family-centred interventions. Thus, the overall aim of this thesis was to explore relationship satisfaction in couples raising a child with ASD and identify factors that promoted it.

Findings from Chapter 5 highlighted the variability of relationship outcomes in couples raising a child with ASD and revealed that the majority of the couples sampled reported relationship satisfaction. In support of dyadic stress and coping theory (18), couples who reported relationship satisfaction also reported less parenting stress and greater use of positive dyadic coping strategies and less use of negative dyadic coping strategies than couples who were dissatisfied in their relationship with their partner. Phenomenological inquiry in Chapter 6 was used to further explore the role of dyadic coping in relationship satisfaction. Emerging from couple interviews was the essential theme of being *in it together*; that is, sharing belief systems; working as a team to raise the family and care for each other; and engaging in effective communication and emotional support. Using Q-methodology in Chapter 7, two viewpoints emerged; one highlighted the importance of building trust through effective communication while the other prioritised the importance of building a strong relationship through team work and sharing of responsibilities. These should be considered as important areas of meaningful intervention; however, not exclusively, as individual family experiences differ. The discussion chapter synthesises the findings in a theoretical model with an accompanying description to scaffold future research and clinical practice.

By using a strengths-based rather than problem-based perspective, the findings of this thesis have extended existing research literature to inform family-centred intervention, recognising that a healthy family, steered by a healthy couple relationship, optimises child function. The ASD diagnosis cannot be changed, but the family's adaptive processes are malleable (86). It is important to look for strengths within the family to help them manage the associated challenges; the couple relationship is one such resource that can promote family resilience and facilitate an environment for the child with ASD to flourish. Health professionals can work alongside families to raise awareness of the importance of prioritising the couple relationship and identifying ways in which they can more effectively work in partnership to raise child with ASD.

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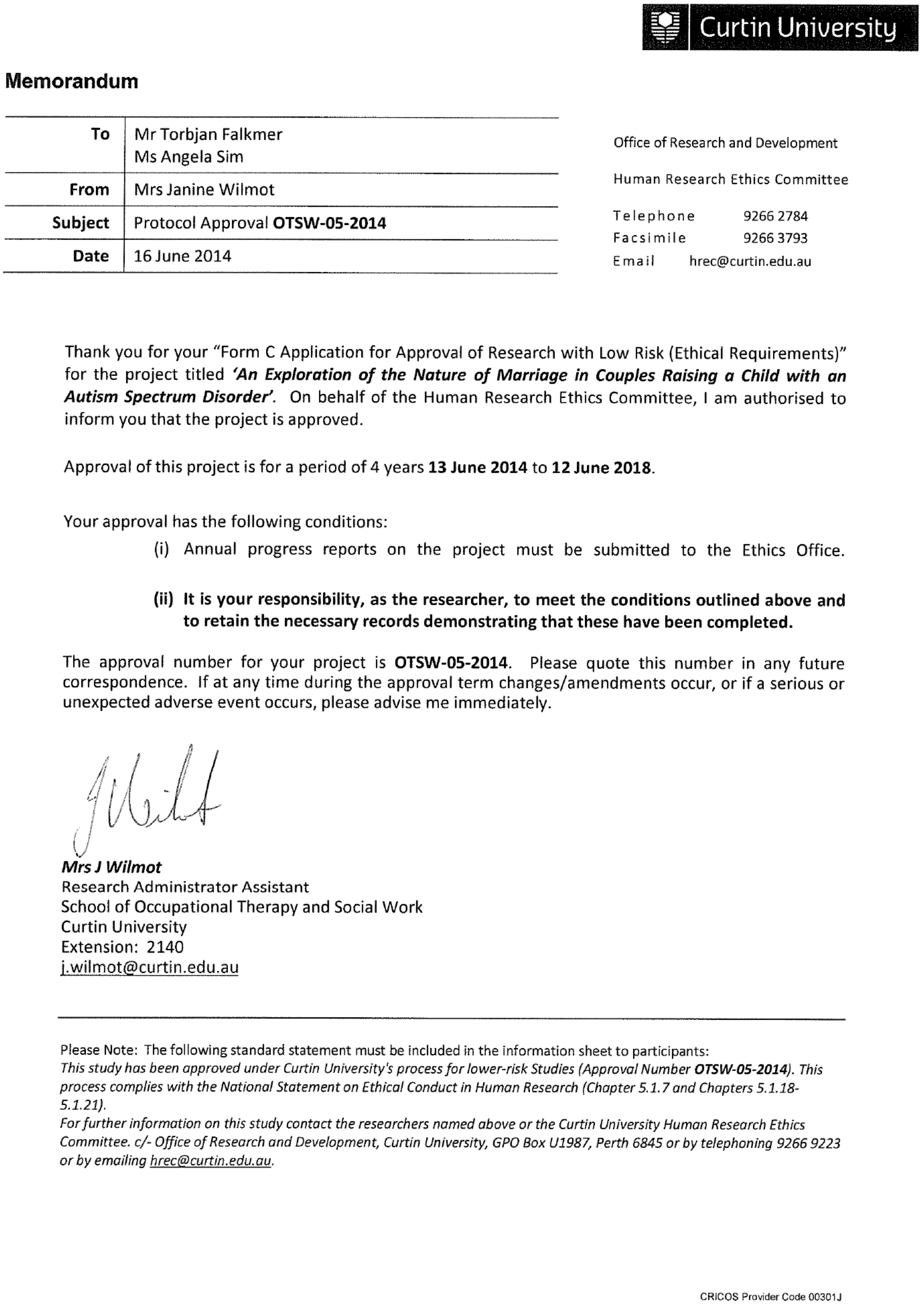
Every reasonable effort has been made to acknowledge the owners of the copyright material used in this thesis. The original authors of the questionnaires and model used were contacted and written approval was obtained for their use in the PhD research. I would be pleased to hear from any copyright owner who has been omitted or incorrectly acknowledged.

Angela Sim

Date: 17 February 2018

Appendix A Human Research Ethics Committee approval



Curtin University

Memorandum

To	Mr Torbjan Falkmer Ms Angela Sim
From	Mrs Janine Wilmot
Subject	Protocol Approval **OTSW-05-2014**
Date	16 June 2014

Office of Research and Development
Human Research Ethics Committee

Telephone 9266 2784
Facsimile 9266 3793
Email hrec@curtin.edu.au

Thank you for your "Form C Application for Approval of Research with Low Risk (Ethical Requirements)" for the project titled ***'An Exploration of the Nature of Marriage in Couples Raising a Child with an Autism Spectrum Disorder'***. On behalf of the Human Research Ethics Committee, I am authorised to inform you that the project is approved.

Approval of this project is for a period of 4 years **13 June 2014** to **12 June 2018**.

Your approval has the following conditions:

(i) Annual progress reports on the project must be submitted to the Ethics Office.

(ii) It is your responsibility, as the researcher, to meet the conditions outlined above and to retain the necessary records demonstrating that these have been completed.

The approval number for your project is **OTSW-05-2014**. Please quote this number in any future correspondence. If at any time during the approval term changes/amendments occur, or if a serious or unexpected adverse event occurs, please advise me immediately.

Mrs J Wilmot
Research Administrator Assistant
School of Occupational Therapy and Social Work
Curtin University
Extension: 2140
j.wilmot@curtin.edu.au

Please Note: The following standard statement must be included in the information sheet to participants:
*This study has been approved under Curtin University's process for lower-risk Studies (Approval Number **OTSW-05-2014**). This process complies with the National Statement on Ethical Conduct in Human Research (Chapter 5.1.7 and Chapters 5.1.18-5.1.21).*
For further information on this study contact the researchers named above or the Curtin University Human Research Ethics Committee. c/- Office of Research and Development, Curtin University, GPO Box U1987, Perth 6845 or by telephoning 9266 9223 or by emailing hrec@curtin.edu.au.

Appendix B Participant information and consent

B.1 Chapter 5 survey

Maintaining Relationship Satisfaction While Raising a Child with Autism Spectrum Disorder

Being a parent can be rewarding, but it can also be challenging. Being a parent of a child with special needs can have additional challenges that affect the entire family, including the parent relationship. We are interested in discovering what it takes to achieve and maintain satisfaction in relationships in couples raising a child with autism spectrum disorder (ASD).

For this study we are seeking couples who are living together, either in a marital or de-facto relationship, and caring for a child or children with ASD aged between 3 and 18 years. Couples do not need to be the biological parents of the child; however, they must be the primary caregivers and reside in the same house.

Your participation in this research involves completing and returning four brief questionnaires which will take approximately 20-30 minutes to complete. The first questionnaire asks for information about you and your family; the second contains questions about the degree of happiness in your relationship with your partner; the third asks you to rate the level of stress experienced in your parenting role; and the final questionnaire identifies the coping strategies you use when dealing with stress related to your relationship with your partner. Provided are two sets of questionnaires, one set for you and one for your partner. We ask that you complete these questionnaires independently and return each one in a separate prepaid envelope. Once the questionnaires are sealed in their envelopes, you are free to discuss your experience with your partner, should you wish to.

All information collected in this study will be recorded without names or any other identifying information. Questionnaires will only be identified by a code number. Only approved researchers will have access to the completed questionnaires, and your individual results will not be reported unless required by law. Group data will be published as scientific papers or conference presentations.

IF YOU AGREE TO COMPLETE AND RETURN THESE QUESTIONNAIRES YOU WILL BE CONSENTING TO YOUR PARTICIPATION IN THE RESEARCH, and may be contacted again to participate in future stages of this project. However, your participation in this study is entirely voluntary, and you will be free to withdraw from the research at any time, without providing a reason and without repercussion. In this case, any results or records of your participation will be destroyed, unless you agree otherwise.

Please do not hesitate to contact the researchers, Angela Sim or Professor Torbjorn Falkmer if you have any questions regarding the research project.

Angela Sim
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Torbjörn Falkmer
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Email: T.Falkmer@curtin.edu.au
Phone: 9266 9051

This research has been reviewed and given approval by the Curtin University Human Research Ethics Committee (approval number OTSW-05-2014). Should you wish to make a complaint on ethical grounds, please contact the Human Ethics Committee (Secretary), phone: 9266 2784, email: hrec@curtin.edu.au, mail: C/- Office of Research and Development, Curtin University of Technology, GPO Box U1987, Perth WA 6845

B.2 Chapter 6 interviews

Maintaining Relationship Satisfaction While Raising a Child with Autism Spectrum Disorder

Thank you for taking part in the initial phase of this research project by completing the survey on parenting stress, couple coping and relationship satisfaction. Your contribution is highly valued.

The second phase of our research involves carrying out interviews to explore the experiences of couples while raising a child with ASD. If you agree to participate in this phase, you and your partner will be invited to partake in an interview together with the principal researcher, Angela Sim. This will take approximately 1 hour and can be conducted at a place of your choice. You will be given the opportunity to tell your story about the experiences you have had while raising your child with ASD, how you and your partner have adapted and how you keep your relationship strong and fulfilling. The sessions will be audio-taped to facilitate accuracy with transcription and will be treated as strictly confidential. To compensate you for your time and effort, a $50 Coles Myer gift card is being offered. This will be given at the time of the interview or mailed in the case of a Skype interview.

There is no obligation to accept this invitation; your participation in this study is entirely voluntary. If you do agree, you will be free to withdraw from the research at any time without providing a reason. In this case, any results or records of your participation will be destroyed, unless you agree otherwise.

All information collected from the interviews will be recorded without names or any other identifying information. All data, including the audio-recording, will be kept in locked storage and only approved researchers will have access to it. Only group data will only be published as scientific papers or conference presentations (no individual results will be reported).

Please do not hesitate to contact the researchers, Angela Sim or Professor Torbjorn Falkmer if you have any questions regarding the research project.

Angela Sim
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This research has been reviewed and given approval by the Curtin University Human Research Ethics Committee (approval number OTSW-05-2014). Should you wish to make a complaint on ethical grounds, please contact the Human Ethics Committee (Secretary), phone: 9266 2784, email: hrec@curtin.edu.au, mail: C/- Office of Research and Development, Curtin University of Technology, GPO Box U1987, Perth WA 6845

B.3 Chapter 7 Q-sort

Maintaining Relationship Satisfaction While Raising a Child with Autism Spectrum Disorder

Thank you for your participation in the earlier phases of this project. Your time and continued commitment to this research endeavour is invaluable.

The final phase of this project is designed to determine the factors that are most important to maintaining relationship satisfaction in couples raising a child with autism. Participation involves completing a Q-sort activity and brief questionnaire. For the Q-sort, participants will be asked to place statements on a grid according to how important they are to maintaining relationship satisfaction. The grid is scaled from least important (on the left) to most important (on the right). Completed grids will be compared for similarities and differences to help us better understand parent viewpoints. The questionnaire gathers background information about you, your child and your relationship. The research findings will help guide the development and provision of services that are meaningful for families raising a child with autism.

There are three options for participating:

1/ **Online** – For people who have access to a PC (the program is not compatible with Macintosh software).

2/ **On paper** – The researcher will post the activity and questionnaire with an addressed, reply paid envelope.

3/ **With the researcher** – If preferred, the researcher can meet with you to complete the Q-sort. This can be arranged at a time and place most convenient for you.

To compensate you for your time and effort, a $70 Coles Myer gift card is being offered. This will be posted to you upon receipt of the completed Q-sort.

All information collected from the Q-sort and questionnaire will be recorded without identifying information. Raw data will be kept in locked storage and only approved researchers will have access to it. Only group data will be published as scientific papers or conference presentations, no individual results will be reported. Participation in this study is entirely voluntary and you will be free to withdraw from the research at any time without providing a reason. In this case, any results or records of your participation will be destroyed, unless you agree otherwise.

Thank you for your continued interest in autism research. Please do not hesitate to contact the researchers, Angela Sim or Professor Torbjörn Falkmer if you have any questions.

Angela Sim
PhD Candidate
School of Occupational Therapy and Social Work
Email:angela.chamberlain@postgrad.curtin.edu.au
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Torbjörn Falkmer
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This research has been reviewed and given approval by the Curtin University Human Research Ethics Committee (approval number OTSW-05-2014). Should you wish to make a complaint on ethical grounds, please contact the Human Ethics Committee (Secretary), phone: 9266 2784, email: hrec@curtin.edu.au, mail: C/- Office of Research and Development, Curtin University of Technology, GPO Box U1987, Perth WA 6845

B.4 Example consent form

Maintaining Relationship Satisfaction While Raising a Child with Autism Spectrum Disorder

I …………………………………...have read the information provided concerning this study, and any questions I have asked have been answered to my satisfaction.

☐ I agree to participate in this activity, realising that I may withdraw at any time without reason and without prejudice.

☐ I have been advised as to what data are being collected, what the purpose is, and what will be done with the data upon completion of the research.

☐ I understand that all information provided will be treated as strictly confidential, and will not be released by the investigator unless required by law.

☐ I agree that research data gathered for the study may be published provided that neither my name, nor other identifying information, is used.

Signed: ………………………………………………….

Date: ……………………………………..

Appendix C Chapter 5 survey

Relationship Satisfaction Survey

Q1 Please enter your unique identifier code (this is a 4-digit code found in your information letter or email. E.g. 602B): ______________________________

Information About You and Your Child

Below are some questions about you and your family. Please answer all of the questions by marking the box next to your answer. If you are unsure of an answer, please mark the button next to the response that best describes your circumstances. If you are raising multiple children with ASD, please select just ONE child and refer to them consistently when answering the questions. You are not required to complete a survey for each child.

Q2 Please indicate your marital status:

☐ Married and living with your partner
☐ Unmarried and living with your partner
☐ Married but not living together
☐ Single parent

Q3 Are you living with, and caring for a child with an autism spectrum disorder (ASD)?

☐ Yes
☐ No

Q4 What is your gender?

☐ Male
☐ Female
☐ Other

Q5 What is the gender of your child diagnosed with ASD?

☐ Male
☐ Female
☐ Other

Q6 What is your diagnosed child’s current age (in years and months; e.g. 2 years 4 months)? ____

Q7 What is your relationship to the child diagnosed with an ASD?

☐ Biological Mother
☐ Biological Father
☐ Grandmother
☐ Grandfather
☐ Foster Mother
☐ Foster Father
☐ Step Mother
☐ Step Father
☐ Other

Q8 How many children are you and your partner the primary carers for?

☐ 1
☐ 2
☐ 3
☐ 4
☐ More than 4

Q9 How many children that you and your partner care for have a diagnosis of ASD?

☐ 1
☐ 2
☐ 3
☐ 4
☐ More than 4

Q10 What is your child's official ASD diagnosis?

☐ Autistic Disorder (Autism)
☐ High-functioning Autism
☐ Asperger's Syndrome
☐ Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS)
☐ Rett's Syndrome
☐ Childhood Disintegrative Disorder
☐ Other ____________________

Q11 Does your child with ASD also have a diagnosis of cognitive impairment/intellectual disability or similar?

☐ No
☐ Yes (please specify) ____________________

Q12 Does your child with ASD have any other diagnosed psychological/mental health conditions?

☐ No
☐ Yes (please specify) ____________________

Q13 Does your child with ASD have any other physical or medical conditions or diagnoses?

☐ No
☐ Yes (please specify) ____________________

Q14 How close are you to your MEDICAL facility (G.P., paediatrician etc).

☐ Less than 2 kilometres
☐ 2-5 kilometres
☐ 6-10 kilometres
☐ 11-20 kilometres
☐ 21-30 kilometres
☐ Greater than 30 kilometres

Q15 How often have you utilised respite care for your child with ASD?

☐ Never
☐ Occasionally
☐ Weekly
☐ Fortnightly
☐ Monthly

Q16 What services do you currently access, or have you accessed in the past, for yourself? Please tick ALL that apply.

☐ Group counselling/support group
☐ Family therapy/counselling or couples therapy/counselling
☐ Individual therapy/counselling
☐ Respite care for your children
☐ Parent training classes
☐ Other

Q17 How would you rate your family's overall strain/stress due to your child's ASD diagnosis?

☐ No stress
☐ Mild stress
☐ Moderate stress
☐ Severe stress
☐ Very severe stress
☐ Worst possible stress

Q18 How has your child's diagnosis of ASD affected YOUR relationship with your OTHER children?

☐ A great positive impact on your relationship
☐ A slight positive impact on your relationship
☐ No impact on your relationship
☐ A slight negative impact on your relationship
☐ A great negative impact on your relationship
☐ Not applicable/only have one child

Q19 How has your child's diagnosis affected YOUR relationship with your partner/co-parent?

☐ A great positive impact on your relationship
☐ A slight positive impact on your relationship
☐ No impact on your relationship
☐ A slight negative impact on your relationship
☐ A great negative impact on your relationship

Q20 How much of an impact has having a child with an ASD had on your ability to get out and socialise?

☐ No impact
☐ Mild impact
☐ Moderate impact
☐ Severe impact
☐ Very severe impact
☐ Worst possible impact

Q22 How would you rate YOUR level of social support?

☐ Lots of social support
☐ Some social support
☐ A little social support
☐ No social support

Q23 What is your current postcode? __________________

Information About Your Relationship with Your Partner

COUPLES SATISFACTION INDEX

1. Please indicate the degree of happiness, all things considered, of your relationship.

Extremely Unhappy	Fairly Unhappy	A little Unhappy	Happy	Very Happy	Extremely Happy	Perfect
0	1	2	3	4	5	6

Most people have disagreements in their relationships. Please indicate below the approximate extent of agreement or disagreement between you and your partner for each item on the following list.

	Always Agree	Almost Always Agree	Occasionally Disagree	Frequently Disagree	Almost Always Disagree	Always Disagree
2. Amount of time spent together.	5	4	3	2	1	0
3. Making major decisions.	5	4	3	2	1	0
4. Demonstrations of affection.	5	4	3	2	1	0

	All the Time	Most of the Time	More Often Than Not	Occasionally	Rarely	Never
5. In general, how often do you think that things between you and your partner are going well?	5	4	3	2	1	0
6. How often do you wish you hadn't gotten into this relationship?	0	1	3	4	5	6

	Not at all True	A Little True	Somewhat True	Mostly True	Almost Completely True	Completely True
7. I still feel a strong connection with my partner.	0	1	2	3	4	5
8. If I had to live my life over, I would marry (or live with/date) the same person.	0	1	2	3	4	5
9. Our relationship is strong.	0	1	2	3	4	5
10. I sometimes wonder if there is someone else out there for me.	5	4	3	2	1	0
11. My relationship with my partner makes me happy.	0	1	2	3	4	5
12. I have a warm and comfortable relationship with my partner.	0	1	2	3	4	5
13. I can't imagine ending my relationship with my partner	0	1	2	3	4	5
14. I feel that I can confide in my partner about virtually anything.	0	1	2	3	4	5

15. I have had second thoughts about this relationship recently.	5	4	3	2	1	0
16. For me, my partner is the perfect romantic partner.	0	1	2	3	4	5
17. I really feel like part of a team with my partner.	0	1	2	3	4	5
18. I cannot imagine another person making me as happy as my partner does.	0	1	2	3	4	5

	Not at All	A Little	Somewhat	Mostly	Almost Completely	Completely
19. How rewarding is your relationship with your partner?	0	1	2	3	4	5
20. How well does your partner meet your needs?	0	1	2	3	4	5
21. To what extent has your relationship met your original expectations?	0	1	2	3	4	5
22. In general, how satisfied are you with your relationship?	0	1	2	3	4	5

	Worse than all others (Extremely Bad)					Better than all others (Extremely Good)
23. How good is your relationship compared to most?	0	1	2	3	4	5

	Never	Less than once a month	Once or twice a month	Once or twice a week	Once a day	More often
24. Do you enjoy your partner's company	0	1	2	3	4	5
25. How often do you and your partner have fun together?	0	1	2	3	4	5

For each of the following items, select the answer that best describes *how you feel about your relationship*. Base your responses on your first impressions and immediate feelings about the item.

INTERESTING	5	4	3	2	1	0	BORING
BAD	0	1	2	3	4	5	GOOD
FULL	5	4	3	2	1	0	EMPTY
LONELY	0	1	2	3	4	5	FRIENDLY
STURDY	5	4	3	2	1	0	FRAGILE
DISCOURAGING	0	1	2	3	4	5	HOPEFUL
ENJOYABLE	5	4	3	2	1	0	MISERABLE

Reference: Funk JL, Rogge RD. Testing the ruler with item response theory: Increasing precision of measurement for relationship satisfaction with Couples Satisfaction Index. Journal of Family Psychology. 2007;21(4):572-83.

Information About Your Stress as a Parent

PARENTAL STRESS SCALE (PSS)

The following statements describe feelings and perceptions about the experience of being a parent. Think of each of the items in terms of how your relationship with your child or children typically is. Please indicate the degree to which you agree or disagree with the following items by placing a tick ☑ or cross ☒ in the appropriate box.

	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
1. I am happy in my role as a parent.	☐	☐	☐	☐	☐
2. There is little or nothing that I wouldn't do for my child(ren) if it was necessary.	☐	☐	☐	☐	☐
3. Caring for my child(ren) sometimes takes more time and energy than I have to give.	☐	☐	☐	☐	☐
4. I sometimes worry whether I am doing enough for my children.	☐	☐	☐	☐	☐
5. I feel close to my child(ren).	☐	☐	☐	☐	☐
6. I enjoy spending time with my child(ren).	☐	☐	☐	☐	☐
7. My child(ren) are an important source of affection for me.	☐	☐	☐	☐	☐
8. Having child(ren) gives me a more certain and optimistic view for the future.	☐	☐	☐	☐	☐
9. The major source of stress in my life is my children.	☐	☐	☐	☐	☐
10. Having child(ren) leaves little time and flexibility in my life.	☐	☐	☐	☐	☐
11. Having child(ren) has been a financial burden.	☐	☐	☐	☐	☐
12. It is difficult to balance different responsibilities because of my child(ren).	☐	☐	☐	☐	☐
13. The behaviour of my child(ren) is often embarrassing or stressful to me.	☐	☐	☐	☐	☐
14. If I had to do it over again, I might decide not to have child(ren).	☐	☐	☐	☐	☐
15. I feel overwhelmed by the responsibility of being a parent.	☐	☐	☐	☐	☐
16. Having child(ren) has meant too few choices and too little control over my life.	☐	☐	☐	☐	☐
17. I am satisfied as a parent.	☐	☐	☐	☐	☐
18. I find my child(ren) enjoyable.	☐	☐	☐	☐	☐

Reference: Berry JO, Jones WH. The parental stress scale: Initial psychometric evidence. Journal of Social and Personal Relationships. 1995;12:463-72.

Information About Your Coping Strategies as a Couple

DYADIC COPING INVENTORY (DCI)

This scale is designed to measure how you and your partner cope with stress. Please indicate the first response that you feel is appropriate. Please be as honest as possible. Please respond to any item by marking the appropriate case, which is fitting to your personal situation. There are no false answers.

This section is about how you communicate your stress to your partner.

	Very rarely	Rarely	Some-times	Often	Very often
1. I let my partner know that I appreciate his/her practical support, advice or help.	☐	☐	☐	☐	☐
2. I ask my partner to do things for me when I have too much to do.	☐	☐	☐	☐	☐
3. I show my partner through my behaviour when I am not doing well or when I have a problem.	☐	☐	☐	☐	☐
4. I tell my partner openly how I feel and that I would appreciate his/her support.	☐	☐	☐	☐	☐

This section is about what your partner does when you are feeling stressed.

	Very rarely	Rarely	Some-times	Often	Very often
5. My partner shows empathy and understanding to me.	☐	☐	☐	☐	☐
6. My partner expresses that he/she is on my side.	☐	☐	☐	☐	☐
7. My partner blames me for not coping well enough with stress.	☐	☐	☐	☐	☐
8. My partner helps me to see stressful situations in a different light.	☐	☐	☐	☐	☐
9. My partner listens to me and gives me the opportunity to communicate what really bothers me.	☐	☐	☐	☐	☐
10. My partner does not take my stress seriously.	☐	☐	☐	☐	☐
11. My partner provides support but does so willingly and unmotivated.	☐	☐	☐	☐	☐
12. My partner takes on things that I normally do in order to help me out.	☐	☐	☐	☐	☐
13. My partner helps me analyse the situation so that I can better face the problem.	☐	☐	☐	☐	☐
14. When I am too busy, my partner helps me out.	☐	☐	☐	☐	☐
15. When I am stressed, my partner tends to withdraw.	☐	☐	☐	☐	☐

This section is about how your partner communicates when he/she is feeling stressed.

	Very rarely	Rarely	Some-times	Often	Very often
16. My partner lets me know that he/she appreciates my practical support, advice or help.	☐	☐	☐	☐	☐
17. My partner asks me to do things for him/her when he/she has too much to do.	☐	☐	☐	☐	☐
18. My partner shows me through his/her behaviour that he/she is not doing well or when he/she has problems.	☐	☐	☐	☐	☐
19. My partner tells me openly how he/she feels and that he/she would appreciate my support.	☐	☐	☐	☐	☐

This section is about what you do when your partner makes known his/her stress.

	Very rarely	Rarely	Some-times	Often	Very often
20. I show empathy and understanding to my partner.	☐	☐	☐	☐	☐
21. I express to my partner that I am on his/her side.	☐	☐	☐	☐	☐
22. I blame my partner for not coping well enough with stress.	☐	☐	☐	☐	☐
23. I tell my partner that his/her stress is not that bad and help him/her to see the situation in a different light.	☐	☐	☐	☐	☐
24. I listen to my partner and give him/her space and time to communicate what really bothers him/her.	☐	☐	☐	☐	☐
25. I do not take my partner's stress seriously.	☐	☐	☐	☐	☐
26. When my partner is stressed I tend to withdraw.	☐	☐	☐	☐	☐
27. I provide support, but do so unwillingly and unmotivated because I think that he/she should cope with his/her problems on his/her own.	☐	☐	☐	☐	☐
28. I take on things that my partner would normally do in order to help him/her out.	☐	☐	☐	☐	☐
29. I try to analyse the situation together with my partner in an objective manner and help him/her to understand and change the problem..	☐	☐	☐	☐	☐
30. When my partner feels he/she has too much to do, I help him/her out.	☐	☐	☐	☐	☐

This section is about what you and your partner do when you are both feeling stressed.

	Very rarely	Rarely	Some-times	Often	Very often
31. We try to cope with the problem together and search for ascertained solutions.	☐	☐	☐	☐	☐
32. We engage in serious discussion about the problem and think through what has to be done.	☐	☐	☐	☐	☐
33. We help one another to put the problem in perspective and see it in a new light.	☐	☐	☐	☐	☐
34. We help each other relax with such things like massage, taking a bath together, or listening to music together.	☐	☐	☐	☐	☐
35. We are affectionate to each other, make love and try that way to cope with stress.	☐	☐	☐	☐	☐

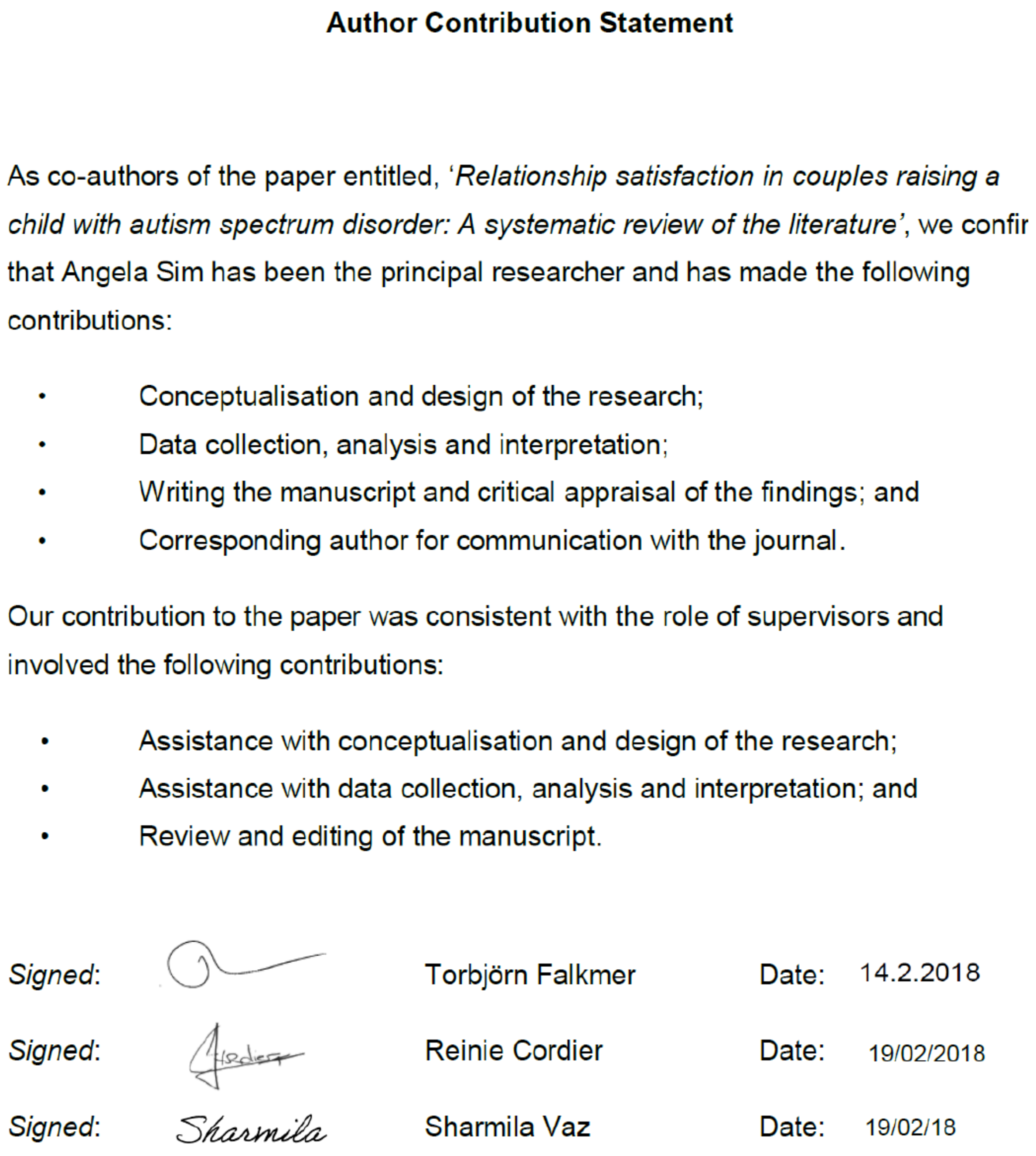
This section is about how you evaluate your coping as a couple.

	Very rarely	Rarely	Some-times	Often	Very often
36. I am satisfied with the support I receive from my partner and the way we deal with stress together.	☐	☐	☐	☐	☐
37. I am satisfied with the support I receive from my partner and I find as a couple, the way we deal with stress together is effective.	☐	☐	☐	☐	☐

Reference: Bodenmann G. Dyadic Coping Inventory: Test manual. Bern, Switzerland: Huber Testverlag; 2008

Appendix D Author contribution statements

D.1 Chapter 2



Author Contribution Statement

As co-authors of the paper entitled, '*Relationship satisfaction in couples raising a child with autism spectrum disorder: A systematic review of the literature*', we confir that Angela Sim has been the principal researcher and has made the following contributions:

- Conceptualisation and design of the research;
- Data collection, analysis and interpretation;
- Writing the manuscript and critical appraisal of the findings; and
- Corresponding author for communication with the journal.

Our contribution to the paper was consistent with the role of supervisors and involved the following contributions:

- Assistance with conceptualisation and design of the research;
- Assistance with data collection, analysis and interpretation; and
- Review and editing of the manuscript.

Signed: Torbjörn Falkmer Date: 14.2.2018

Signed: Reinie Cordier Date: 19/02/2018

Signed: Sharmila Sharmila Vaz Date: 19/02/18

D.2 Chapter 3

Author Contribution Statement

As co-authors of the paper entitled, '*Factors associated with negative co-parenting experiences in families of a child with autism spectrum disorder*', we confirm that Angela Sim has been the principal researcher and has made the following contributions:

- Conceptualisation and design of the research;
- Data analysis and interpretation; and
- Writing the manuscript and critical appraisal of the findings.

My contribution to the paper was consistent with the role of co-author and involved the following contributions:

- Review and editing of the manuscript.

Signed: Julie Netto Date: 16/2/18.

Our contribution to the paper was consistent with the role of supervisors and involved the following contributions:

- Assistance with conceptualisation and design of the research;
- Assistance with data analysis and interpretation; and
- Review and editing of the manuscript.

Signed: Torbjörn Falkmer Date: 14.2.2018

Signed: Reinie Cordier Date: 19/02/2018

Signed: Sharmila Sharmila Vaz Date: 19/02/18

D.3 Chapter 4

Author Contribution Statement

As co-authors of the paper entitled, '*Factors associated with stress in families of children with autism spectrum disorder*', we confirm that Angela Sim has been the principal researcher and has made the following contributions:

- Conceptualisation and design of the research;
- Data analysis and interpretation; and
- Writing the manuscript and critical appraisal of the findings.

Our contribution to the paper was consistent with co-author and involved the following contributions:

- Review and editing of the manuscript.

Signed: A. Joosten Annette Joosten Date: 19/02/2018

Signed: Dave Parsons Date: 19/02/2017

Signed: Cally Smith Date: 21.02.2018

Our contribution to the paper was consistent with the role of supervisors and involved the following contributions:

- Assistance with conceptualisation and design of the research;
- Assistance with data analysis and interpretation; and
- Review and editing of the manuscript.

Signed: Torbjörn Falkmer Date: 14.2.2018

Signed: Reinie Cordier Date: 19/02/2018

Signed: Sharmila Sharmila Vaz Date: 19/02/18

D.4 Chapter 5

Author Contribution Statement

As co-authors of the paper entitled, *'Relationship satisfaction and dyadic coping in couples with a child with autism spectrum disorder'*, we confirm that Angela Sim has been the principal researcher and has made the following contributions:

- Conceptualisation and design of the research;
- Data collection, analysis and interpretation;
- Writing the manuscript and critical appraisal of the findings; and
- Corresponding author for communication with the journal.

My contribution to the paper was consistent with the role of statistician and involved the following contributions:

- Assistance with data analysis and interpretation; and
- Review and editing of the manuscript.

Signed: Richard Parsons Date: 15/2/2018

Our contribution to the paper was consistent with the role of supervisors and involved the following contributions:

- Assistance with conceptualisation and design of the research;
- Assistance with data collection, analysis and interpretation; and
- Review and editing of the manuscript.

Signed: Torbjörn Falkmer Date: 14.02.2018

Signed: Reinie Cordier Date: 19/02/2018

Signed: Sharmila Sharmila Vaz Date: 19/02/18

D.5 Chapter 6

Author Contribution Statement

As co-authors of the paper entitled, *'"We are in this together": Experiences of relationship satisfaction in couples raising a child with autism spectrum disorder'*, we confirm that Angela Sim has been the principal researcher and has made the following contributions:

- Conceptualisation and design of the research;
- Data collection, analysis and interpretation;
- Writing the manuscript and critical appraisal of the findings; and
- Corresponding author for communication with the journal.

Our contribution to the paper was consistent with the role of supervisors and involved the following contributions:

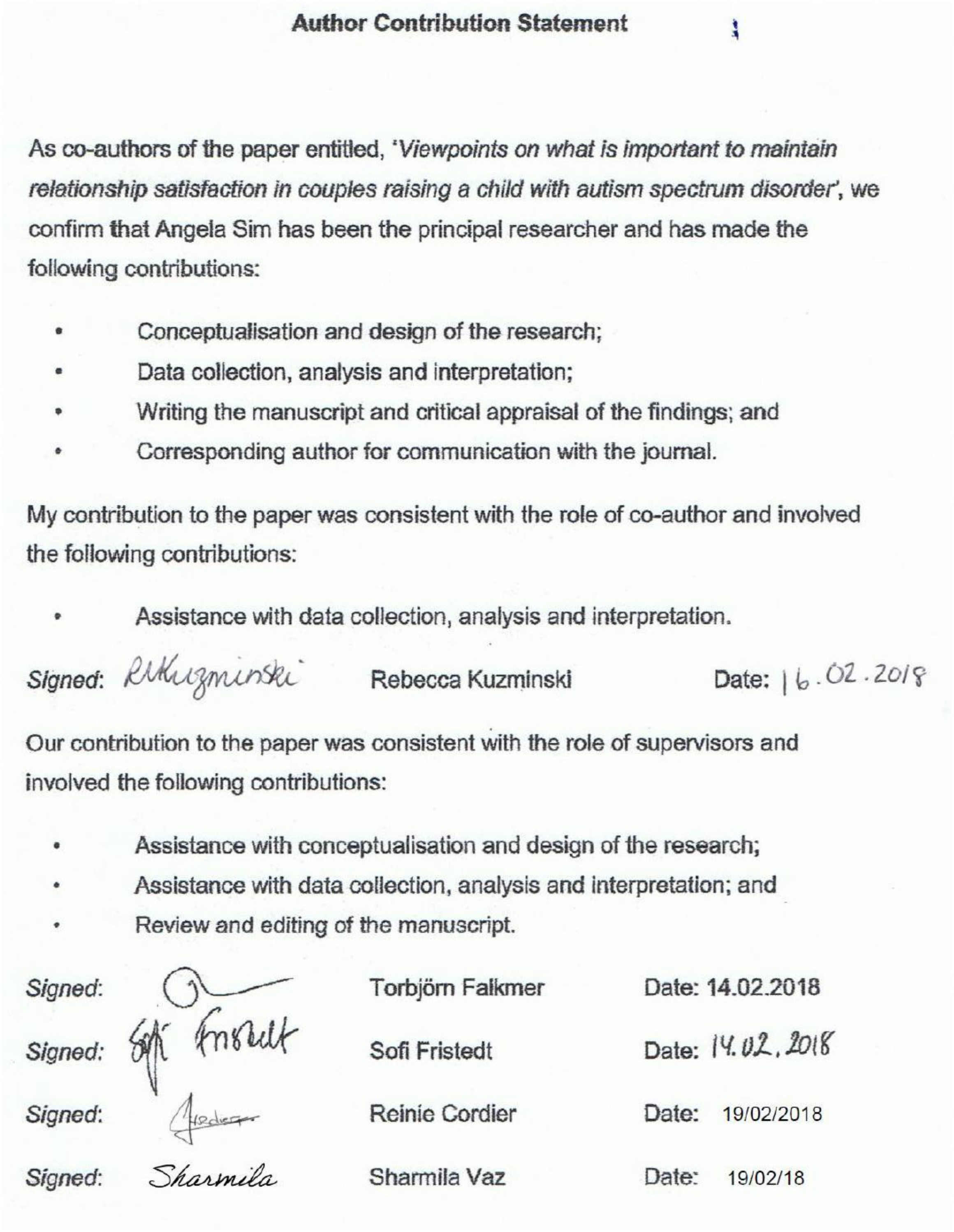
- Assistance with conceptualisation and design of the research;
- Assistance with data collection, analysis and interpretation; and
- Review and editing of the manuscript.

Signed: Torbjörn Falkmer Date: 14.2.2018

Signed: Reinie Cordier Date: 19/02/2018

Signed: Sharmila Sharmila Vaz Date: 19/02/18

D.6 Chapter 7



Author Contribution Statement

As co-authors of the paper entitled, '*Viewpoints on what is important to maintain relationship satisfaction in couples raising a child with autism spectrum disorder*', we confirm that Angela Sim has been the principal researcher and has made the following contributions:

- Conceptualisation and design of the research;
- Data collection, analysis and interpretation;
- Writing the manuscript and critical appraisal of the findings; and
- Corresponding author for communication with the journal.

My contribution to the paper was consistent with the role of co-author and involved the following contributions:

- Assistance with data collection, analysis and interpretation.

Signed: RKuzminski Rebecca Kuzminski Date: 16.02.2018

Our contribution to the paper was consistent with the role of supervisors and involved the following contributions:

- Assistance with conceptualisation and design of the research;
- Assistance with data collection, analysis and interpretation; and
- Review and editing of the manuscript.

Signed: Torbjörn Falkmer Date: 14.02.2018
Signed: Sofi Fristedt Sofi Fristedt Date: 14.02.2018
Signed: Reinie Cordier Date: 19/02/2018
Signed: Sharmila Sharmila Vaz Date: 19/02/18