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ASD-NT INTIMATE RELATIONSHIPS

Caregiver burden and relationship satisfaction in ASD-NT intimate relationships

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CAREGIVER BURDEN AND RELATIONSHIP SATISFACTION IN ASD-NT INTIMATE RELATIONSHIPS

Abstract

Autism Spectrum Disorder (ASD) is a pervasive developmental disorder featuring difficulties with socio-emotional reciprocity, communication, and repetitive patterns of behaviour, as well as narrowed interests that hinder daily functioning (APA, 2013). However, the symptoms of ASD vary among individuals. Therefore, some people are unable to live independent lives (Hofvander et al., 2009), while others are able to live independently and develop intimate relationships with others. These couplings, referred to as ASD-Neurotypical (NT) relationships, were the focus of this study. Adopting a mixed methods approach, quantitative and qualitative data regarding relationship satisfaction, positive communication patterns, and social support was collected across both groups (i.e., ASD, $N = 12$, and NT, $N = 60$). Caregiver burden was assessed among NT partners. The findings suggest that relationship satisfaction and perceptions of positive communications are lower among NT partners than those with ASD. Further, caregiver burden was comparatively high and negatively related to relationship satisfaction. Finally, a moderating pattern related to social support was suggested by the quantitative data and supported by the qualitative findings. A framework informed by the a priori research questions was imposed on the qualitative data. The themes identified are as follows; caregiving, receiving care, social support and communication, as well as disconnection, grief and sorrow.

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Declaration

I declare that this submission is my own work and that to the best of my knowledge and belief it contains no material previously published or written by another person, nor material which has been accepted for the award of another degree or diploma at a university or institution of higher learning.

The data that forms the basis of this submission was obtained from research project utilizing a self-selected sample. The project was conducted with the approval of the Macquarie University Ethics Committee (Human Research). The protocol number is 5201500073.

A handwritten signature in blue ink, reading 'N. Millar-Powell', with a stylized flourish at the end.

Naomi Millar-Powell

October 8th, 2015

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ASD-NT INTIMATE RELATIONSHIPS

Dedication

For mum and dad. I miss you both every day.

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CAREGIVER BURDEN AND RELATIONSHIP SATISFACTION IN ASD-NT INTIMATE RELATIONSHIPS

Autism Spectrum Disorder is a pervasive developmental disorder featuring difficulties with socio-emotional reciprocity, communication, and repetitive patterns of behaviour, as well as narrowed interests that hinder daily functioning (APA, 2013). The symptoms of ASD vary among individuals according to the severity of autism, the age of the person, and their intellectual ability. This variation in symptom expression leads to differences in functioning. Therefore, while some people are unable to live independent lives (Hofvander et al., 2009), others, who are higher functioning, are able to live and operate independently within society. Recent accounts suggest that higher functioning individuals often develop intimate relationships with others, who may or may not have ASD [individuals without ASD are referred to as neurotypical (NT) within the literature] (Howlin, 2004; Lau & Peterson, 2011; Renty & Roeyers, 2006). The features of ASD suggest that ASD-NT couplings may face unique challenges developing and maintaining mutually satisfying intimate relationships. Until recently diagnostic manuals recognised distinct forms of autism. However, a revision of the diagnostic criteria has resulted in pervasive developmental disorders, such as Asperger syndrome, being subsumed into a single entity; Autism Spectrum Disorders (ASD). For the purposes of this discussion the author will refer to ASD in accordance with the abovementioned changes to the Diagnostic and Statistical Manual of Mental Disorders (APA, 2013).

Theories associated with ASD

Relevant to the study of ASD is theory of mind (ToM); namely the capacity to ascribe mental states (e.g., emotions, beliefs, and intentions) to ones' self and others (Baron-Cohen, Leslie, & Frith, 1985). Deficits in this ability to *mind-read* others is a core, but variable, feature of ASD. This heterogeneity in ToM abilities among individuals with ASD is reflected in variations in research findings. For example, Baron-Cohen and colleagues (1985) report that

young children with ASD and intellectual delay tend to fail false belief tasks (understanding that different people have different thoughts about the same situation). However, other research findings suggest that as verbal ability develops to the level of a typically developing 12 year old, children with ASD also do well on these tasks (Fisher, Happe, & Dunn, 2005). Similarly, Scheeren, Rosnay, Koot, and Begeer (2013) report that higher functioning individuals with ASD performed as well as their typically developing peers on tasks that required second order reasoning (consideration of a person's thoughts and feelings about another individuals mental state). The researchers argue this performance on second order belief tasks is due to developed reasoning skills and verbal ability. However, they also acknowledge that people with higher functioning ASD may still display ToM deficits in complex social contexts (Scheeren et al., 2013). Therefore, individuals with ASD may find it difficult to understand emotions (their own and others), engage in and interpret meaning in social communication, as well as explain and predict the behaviour of others.

The theory of executive dysfunction suggests that ASD symptoms are a function of deficits in executive function, or the cognitive processes involved in goal-directed behaviour (Howlin, 2004). These processes include planning, organisation, working memory, and cognitive flexibility in problem solving. Empirical support for the theory of executive dysfunction is variable, with results revealing both intact (Happé, Booth, Charlton, & Hughes, 2006) and impaired planning abilities among adults with ASD (Ozonoff, Pennington, & Rogers, 1991). Further, a subsequent study by Sachse et al. (2013) failed to detect deficits in inhibition, planning, or cognitive flexibility, however difficulties with spatial memory were noted. Taken together, findings suggest that, tasks requiring executive function may prove difficult for some individuals with ASD (e. g., managing finances, organizing family events, and compromising).

The theory of weak central coherence posits that people with ASD have an information processing style that features superior memory and attention for detail. However, this enhanced memory and focus is at the cost of global processing (Frith & Happe, 1994; Happe, 2010). Murray, Lesser, and Lawson (2005) suggest this detailed, yet fragmented view, is an outcome of atypical attention allocation or *monotropism*. This narrow attentional focus may be advantageous in certain contexts (e.g., professions that require detailed analysis such as accounting or engineering). However, situations that call for a broad cognitive perspective (e.g., reciprocal conversation or managing a project) may prove difficult, as the person with ASD is focused on small, irrelevant details at the cost of the global context. Empirical support for the theory of weak central coherence varies between studies, with findings identifying superior performance on pure pitch tone tasks (i.e., discriminating between similar tones) among individuals with ASD compared to typically developing peers (Bonnell et al., 2010). However, research by White and Saldana (2011) found no difference in performance scores (accuracy and reaction time) on an embedded figures test between individuals with ASD and controls. This divergence in findings may represent uneven patterns of performance across perceptual modalities (e.g., auditory and visual) among individuals with ASD. Alternatively, these contrasting results may be an artefact of sample characteristics. For example, Bonnell et al. (2010) examined auditory discrimination among adolescents and adults, while White and Saldana (2011) investigated visuospatial abilities among children (aged 6-16 years). Nevertheless, some individuals with ASD may show great aptitude for tasks requiring superior attention to detail (e.g., technical writing), however, they may struggle with tasks requiring global processing (e.g., interacting with others in a social context).

Overall, these theories reviewed account for a wide range of symptoms associated with ASD. Further, the variation of findings in the body of research suggest that there is significant heterogeneity among this population. While acknowledging that the abovementioned theories cannot explain all of the symptoms associated with ASD, they do provide a framework for understanding some of the socio-communicative features of ASD that may impact intimate relationships. Such features will be discussed as follows; difficulties with detecting and interpreting non-verbal communication, poor reciprocal responsiveness, formal language difficulties, and inflexible behaviours, interests, and cognition.

Features of ASD and Intimate Relationships

Research suggests that relationship-centric behaviours influence relationship satisfaction. These behaviours include mutual disclosure of intimate thoughts and feelings (Dindia & Timmerman, 2003), and reciprocal responsiveness based on an understanding of a partner's needs (Reis, 2007). These relationship-centric behaviours create feelings of intimacy and trust, thereby increasing relationship satisfaction (Reis & Shaver, 1988). Consequently, if relationship-centric behaviours are crucial for relationship satisfaction, it stands to reason that ASD symptoms may inhibit such behaviours. In essence, ASD symptomology may disrupt intimate partner behaviour, which may ultimately reduce relationship satisfaction. Therefore, some ASD-NT couplings may experience difficulty maintaining relationship satisfaction in their intimate relationship.

Communication deficits. Recognizing and understanding emotions in others may be impaired in some individuals with ASD (Hobson, 2002). Distress or frustration in a partner may not be detected due to limitations in ToM and difficulties identifying and interpreting non-verbal cues (e.g., facial expression, gesturing, and variations in vocal prosody; Howlin, 2004). Extreme

displays of emotion (e.g., anger) may be perceived, but because subtle non-verbal cues are missed, the individual with ASD may be bewildered by these *outbursts*. Further, the partner with ASD may respond to these intense displays in ways that do not meet the needs of a partner (e.g., leaving them alone to “get over it”; Attwood, 2015, p. 320). Therefore, the inability to detect and interpret non-verbal communication may limit important relationship-centric behaviours (e.g., sensitive responding) between ASD-NT partners and in turn, reduce feelings of intimacy and relationship satisfaction.

Relational reciprocity. Reciprocal responsiveness in social communication may be challenging for some people with ASD. Despite an earnest desire to communicate with a partner, reciprocal conversations or engaging in small talk may not seem logical or necessary to the partner with ASD (Attwood, 2015). Similarly, self-disclosure may be limited due to difficulty identifying and verbalizing their own emotional state (Ryan & Räisänen, 2008). They may prefer instead to exchange facts or discuss a topic of particular interest to them (e.g., computer science, the joy of train travel, or television programs) (Howlin, 2004). Such deficits in social communication may be compounded by an inability to detect non-verbal cues indicating that they are monopolizing the conversation or that a conversation partner is bored (MacDonald et al., 1989). Thus; reciprocal sharing of thoughts and feelings, as well as self-disclosure may be restricted in ASD-NT couplings, thereby undermining perceptions of relational connectedness, intimacy, and trust between the partners.

Disparate expression and comprehension abilities. Deficits with formal language may underlie some socio-communicative limitations evident in ASD. Individuals with high functioning ASD may have advanced levels of expressive speech, however, their comprehension of speech within a social context may be poor (Howlin, 2004). This pattern of advanced

expressive vocabulary and impaired comprehension may mean that the person with ASD has difficulty deciphering requests or instructions. Further, this discrepancy is compounded by a proclivity toward literal interpretation of speech. For example, when asked ‘Would you like to mow the lawns?’ or ‘Would you like to have some lunch?’ their response may be ‘No thank you’ to both requests. In this instance the intention of the former request is misinterpreted: ‘would you like’ has been interpreted as a literal inquiry of their preference, rather than a direct request (Happe, 1995). These deficits in speech and comprehension may lead to miscommunication and frustration between ASD-NT couplings, ultimately undermining relationship satisfaction.

Inflexible features. Inflexible interests, behaviour, and beliefs are a core feature of ASD. Special interests may develop around particular subjects such as mastering musical techniques or collecting sporting memorabilia (Szatmari et al., 2006). These special interests provide a great deal of pleasure for the person with ASD and they may spend many hours pursuing their interest, often at the exclusion of their partner. Similarly, inflexible behaviours, such as adhering to rigid routines or completing tasks in a prescribed manner may be a feature of ASD (APA, 2013; Attwood, 2015). Therefore, the NT partner may feel that their lives are dominated by their partner’s rigid insistence on routine, leaving little room for spontaneity. While these characteristic behaviours may provide comfort for the partner with ASD, the relational needs of the NT partner may be neglected. Accordingly, the NT partner may experience feelings of isolation and loneliness (Attwood, 2015). Further, some people with ASD find it difficult to be flexible in their thinking, especially in terms of changing their opinions or making compromises (Myhill & Jekel, 2008). This cognitive rigidity may cause significant problems resolving disagreements between the couple, leading to unresolved anger and resentment for both parties.

Executive function deficits. Another feature of ASD that may impact intimate relationships is impairments in executive function. The NT partner may have expectations about shared household tasks (e.g., paying bills, child rearing, and domestic chores) however, deficits in planning and organizational abilities may mean that the partner with ASD requires significant support to complete these activities (e.g., lists, step-by-step instructions, and prompting) (Wilson, Beamish, Hay, and Attwood, 2014). Therefore, NT partners may feel that their partner is totally dependent on them. This dependence may create a feeling of caregiver burden, whereby the NT person feels trapped by their partner's symptoms, which may be further compounded by a lack of awareness of the strain the NT person is experiencing by the partner with ASD (Myhill & Jekel, 2008).

In sum, the symptoms associated with ASD may prevent or disrupt relationship-centric behaviours that are important for relationship satisfaction. In essence, impairments in communication, social reciprocity, and formal language deficits, as well as inflexible behaviours and interests may undermine relationship-centric behaviours that are important for the development and maintenance of intimacy, connectedness and trust in intimate relationships. In addition, the isolation and loneliness experienced by the NT partner and anger and resentment felt by both partners may also contribute to reduced relationship satisfaction in ASD-NT intimate relationships.

ASD-NT Intimate Relationship Research

Findings from the small body of peer-reviewed literature examining ASD-NT intimate relationships have revealed inconsistent findings. For example, Pollman, Finkenauer, and Begeers (2010) report that relationship satisfaction was lower among men with high Autism Quotient scores (AQ; Baron-Cohen, Wheelwright, Skinner, & Martin, 2001) compared to

respondents with low AQ scores. Further, relationship-centric behaviours (disclosure and responsiveness) and feelings (trust and intimacy) acted as mediators in the association between autistic traits and relationship satisfaction. The researchers suggest that autistic traits inhibit relationship-centric behaviours, which in turn reduce perceptions of intimacy and trust, leading to relationship dissatisfaction. However, a subsequent study by Lau and Peterson (2011) found that relationship satisfaction was relatively high among individuals with ASD. The divergence in findings between these studies may be explained by differences in participant characteristics. That is, the participants in Pollman and colleagues study (2010) were male, while the majority of participants in Lau and Peterson's (2011) research were female. This gender-based variation in relationship satisfaction may be an outcome of partner choice among females with ASD. That is, females may make partner choices based on similarity, as opposed to males with ASD who seek partners with compensatory characteristics (Attwood, 2015). Further, recent research suggests that ASD symptom expression may differ by gender. For example, Hiller, Young, and Weber (2014) identified superior socio-emotional abilities among females with ASD, compared to their male counterparts (e.g., behaviour adaptation based on the social context, reciprocity in conversation, and verbal/non-verbal language integration). These clinical and empirical observations suggest that females with ASD either choose partners that have similar socio-emotional needs, or alternatively, they are able to perform relationship-specific behaviours (e.g., responsiveness and disclosure) that contribute to relationship satisfaction.

Research examining the experience of the NT partner provides insight into the effects of ASD on relationship adaptation and satisfaction. Renty and Roeyers (2007) found that relationship adaptation in NT respondents was inversely related to their partner's symptom severity. However, a subsequent study found that female partners of men with high AQ scores

did not report lower relationship satisfaction than the partners of men with low AQ scores (Baron-Cohen et al., 2001; Pollman, Finkenauer, & Begeers, 2010). Conversely, Lau and Peterson (2011) claim that relationship satisfaction was lower among NT partners in their study, compared to those of a control group engaged in NT-NT intimate relationships. However, it should be noted that the authors did not provide the relationship satisfaction scores by diagnostic grouping, but by attachment style (e.g., avoidant and secure) making an interpretation of relationship satisfaction amongst ASD-NT couples harder to interpret. However, the use of clinical samples by Renty and Roeyers (2007) and Lau and Peterson (2011) suggest that a consistent theme of reduced relationship satisfaction may be emerging among NT partners. However, more research is needed to clarify these findings.

Renty and Roeyers (2007) examined the role of social support as a possible mediator in the association between ASD symptom expression and relationship adaptation in ASD-NT intimate relationships. Social support was found to act as a mediator in the relationship between the stressor of ASD symptom expression and relationship adaptation for both partners. Approach-coping (e.g., confrontive coping, seeking social support, planful problem solving, and positive reappraisal) was examined as a possible predictor of relationship adaptation in ASD-NT intimate relationships (Renty & Roeyers, 2007). Approach-coping was not related to relationship adaptation for the partner with ASD. This finding is understandable given the nature of socio-communicative difficulties associated with ASD (e.g., language and problem solving deficits, a preference for lone pursuits, and cognitive rigidity). Similarly, approach-coping was not associated with relationship adaptation for the NT partner. Interestingly, the male partner self-reported lower levels of autism-specific behaviours, compared to those identified by their NT spouse. The differences in reported ASD traits may explain the unexpected result regarding

approach-coping for the NT partner. That is, limited self-awareness and ToM abilities in the partner with ASD may inhibit the use of approach-coping strategies by the NT partner.

Recent research on ASD-NT intimate relationships has revealed a unique interaction pattern among these couplings. Wilson, Beamish, Hay, and Attwood (2014) explored prompt dependency as a unique feature of ASD-NT intimate relationships. Prompting is understood to be the stimuli used to produce behaviour (e.g., direct instructions, demonstrations, and non-verbal gestures) that may not spontaneously occur (MacDuff, Krantz, & McClannhan, 2001). Prompting strategies are typically employed with children who have ASD to aid learning (Cooper, Heron, & Heward, 2007). As children meet the required targets the use of prompting strategies should be gradually reduced (Cooper et al., 2007). However, research suggests that children with ASD may become reliant on prompts, rather than the accompanying cues meant to facilitate the target behaviours (MacDuff et al., 2001). Adopting a qualitative design, Wilson et al. (2014) investigated the occurrence of prompt dependency in adults with ASD. Further, they explored the effects of prompt dependency on communication and reciprocal interactions in ASD-NT intimate relationships. The results of their thematic analysis suggest that adults with ASD do display prompt dependence behaviour. Furthermore, prompting was used by the NT partner to facilitate intimacy and connectedness in ASD-NT intimate relationships. Interestingly, NT partners described their role in the relationship as a '*carer or mother*' (Wilson et al., 2014, p. 8). This shift toward the role of caregiver by the NT partner may contribute to reduced relationship satisfaction in ASD-NT intimate relationships.

The small body of available peer-reviewed literature has provided an important foundation for research into ASD-NT intimate relationships but more research is sorely needed, especially to help clarify inconsistencies that have been noted in the broader literature. In

addition, studies examining the experience of the NT partner were found by Bostock-Ling, Cumming and Bundy (2012) to lack consistency, be at risk of bias, and have limited generalizability (NHMRC, 2008) further indicating the need for additional research in this area. Overall, it is clear that further research is necessary to address these gaps in knowledge.

In contrast to the paucity of empirical research in this area, a large amount of non-scholarly publications are available on this topic. These resources include face-to-face and online support groups expressing the views and concerns of this population, as well as recommendations regarding intervention methods. Support groups for individuals engaged in ASD-NT intimate relationships are established in several states in Australia (e.g., QAPS in Queensland and ASPIA in NSW), suggesting that there is a significant proportion of the Australian population experiencing relationship difficulties due to the presence of ASD. Further, clinical and anecdotal accounts report that intimate partnerships with people who have ASD can be very challenging, with negative mental health outcomes for both partners (e.g., anxiety and depression). However, treatment for this population is typically informed by clinical experience and non-evidence based literature (Bostock-Ling, Cumming, & Bundy, 2012). This practice is clearly not in line with the expectation that treatment is informed and supported by research, especially given the current prevalence rates of ASD in Australia (1:61.5; Buckley, 2013). Thus, research that clarifies issues around relationship satisfaction in ASD-NT intimate relationships is clearly needed to inform clinical practice.

Research Rationale

In sum, the limited scope of the existing literature on ASD-NT intimate relationships and the current approach to treatment for this population suggest that more research is needed. In addition, the current prevalence rates of ASD (1:61.5; Buckley, 201) suggest that a significant

proportion of the Australian population is either directly or indirectly affected by this condition.

However, the prevalence rates are based on data derived from children and adults who require government financial assistance, which may not be representative of people with ASD who are engaged in intimate relationships (Buckley, 2013). Therefore, based on an assumption of prevalence underestimation, it would seem that conducting research into ASD-NT intimate relationships will provide broad benefits to the Australian community, and beyond. Such research needs to address key factors such as caregiver burden, relationship satisfaction, social support, and patterns of communication.

Caregiver Burden

NT partners appear to have lower relationship satisfaction than partners with ASD and symptom severity has been identified as a predictor of this phenomenon (Renty & Roeyers, 2007). However, the findings from Wilson et al.'s (2014) study suggest that it is not symptom severity *per se*, but caregiver burden associated with symptom expression and co-morbid behaviours that may contribute to relationship dissatisfaction among NT partners. To date, caregiver burden has not been examined as a possible predictor of relationship satisfaction among NT partners. However, caregiver burden has been investigated among parents caring for adolescents and young adults with ASD. This literature may provide some insight into the effects of caregiver burden on relationship satisfaction among NT partners, especially as NT partners identify themselves as caregivers (Wilson et al., 2014). Further, the symptoms associated with ASD in childhood do persist into adulthood; therefore, NT partners may experience similar strains as parent caregivers (Howlin, Goode, Hutton, & Rutter, 2004). A review of the parental caregiving literature will follow a brief overview of stressors that may be associated with caregiving in ASD-NT intimate relationships.

Caregiving Stressors

Intimate relationships often involve reciprocal affective caring and behavioural caregiving. However particular circumstances may mean that caregiving becomes a unidirectional process, whereby the burden of caring is placed solely on one individual within the relationship (Pearlin, Mullan, Semple, & Skaff, 1990). The stress process model developed by Pearlin et al. (1990) proposes that both primary and secondary stressors may be present in the caregiving context. *Primary stressors* in caregiving may arise due to the nature of care required, which is dictated by the needs of the person receiving care (e.g., instructions, prompting, and assistance with managing anxiety). Other factors such as resistance toward caregiving from the partner with ASD may also increase the caregiver burden of the NT partner. Inflexible and entrenched behaviours and beliefs from the partner with ASD may also be a source of stress for the NT partner (APA, 2013).

Primary stressors often lead to other difficulties or *secondary stressors* including role strains, which occur outside the caregiving context (Pearlin et al., 1990). For example, conflict between the caregiver and others due to differences in beliefs about the level of difficulty the person with ASD may be experiencing and the impact of ASD symptoms on the NT partner. Anecdotal accounts suggest that disbelief in others about the inherent difficulties in ASD-NT intimate relationships is a significant source of stress for NT partners (private communication, July, 2015). Further, these role strains, in conjunction with caregiving demands, may contribute to other secondary stressors such as intrapsychic strains that are embedded in the caregiving context (Pearlin et al., 1990). For example, caregivers may experience a sense of role captivity where they feel trapped by caregiving responsibilities and their partners ASD symptoms.

Therefore, primary and secondary stressors may contribute to the burden that NT partners may experience in ASD-NT intimate relationships.

There is significant variance in responses to stressors associated with the caregiving role (Pearlin et al., 1990). Social support has been offered as one factor contributing to this variation. For example, research suggests that carers of individuals with traumatic brain injuries who have greater social support higher levels of relationship satisfaction (Hank, Rapport, & Vangel, 2007). In addition, the role of social support has been examined among carers of children with ASD (Weiss et al., 2013; Stuart & McGrew, 2009). Stuart and McGrew (2009) report that social support was strongly related to lower levels of caregiver burden and negatively related to relationship distress. Social support may therefore also play an important role for individuals engaged in ASD-NT intimate relationships.

Caregiver burden among the parents of children and young adults with ASD is reportedly high. Similarly, carers of children with ASD are at greater risk of experiencing psychological distress than parents of typically developing children (Bouma & Schweitzer, 1990). Within the body of literature, caregiver burden and distress are attributed to different factors. For example, one study found that caregiver burden among carers of adolescents with ASD is predicted by symptom severity. Further, both symptom severity and number of children in the family with ASD was predictive of pessimism and depression among mothers who were caregivers (Abbeduto et al., 2004). However, findings from Bromley, Hare, Davison, and Emerson's (2004) study suggest that distress or caregiver burden was associated with low levels of informal social support and challenging behaviours in the child with ASD. The divergence in the factors identified as predictors of caregiver burden in these two studies may be an artefact of the measures employed. Both studies used maternal-report measures, however Abbeduto et al.

(2004) employed the Autism Behavioural Checklist (ABC; Krug, Arick, & Almond, 1980) which is designed to assess ASD-specific behaviours (e.g., aggression and destructive behaviours, sensory issues, socio-communicative deficits, and somatoform displays) and Bromley (2004) measured challenging behaviours with the Developmental Behaviour Checklist (DBC; Einfeld & Tonge, 1995). The DBC is a broad measure of emotional and behavioural disturbance for children with intellectual and developmental delays assessing the following domains; self-absorption, autistic relating, disruptive and asocial behaviour, as well as emotional disturbance and anxiety. The domains captured in the DBC are actually key features associated with ASD. Therefore, although Bromley (2004) identified *challenging behaviours* as a key predictor of caregiver burden, it appears that the DBC actually captures *ASD symptom severity*. Therefore, both studies seem to identify symptom severity as a key predictor of maternal well-being associated with caregiver burden.

A subsequent study by Cadman et al. (2012) examined the levels of and factors associated with caregiver burden among carers of adolescents and young adults with ASD. The results support previous findings of high caregiver burden among this population. In fact, the burden experienced by parents was comparable to those providing care for people with acquired brain injuries. Cadman and colleagues (2012) attribute caregiver burden to the presence of co-morbid psychiatric symptoms, as measured by the Strengths and Difficulties Questionnaire (SDQ), rather than ASD symptom severity. In addition, the carers perception of the caregiving needs of the person with ASD (e.g., social, physical, practical, and mental health needs) was a significant predictor of caregiver burden (co-morbid psychopathology and needs accounted for 34% of the variance in caregiver burden). Interestingly, there was no relationship between caregiver burden and the perception of needs of the person with ASD. This finding is in line with

the low levels of autistic behaviours reported by participants with ASD in Renty and Roeyers (2007) study. It may well be that this lack of awareness of the need for care, in combination with the demands of *actual needs* contribute to caregiver burden among those caring for individuals with ASD

The Present Study

The abovementioned studies provide empirical support for the presence of caregiver burden among carers of children, adolescents, and young adults with ASD. Although caregiver burden has not been investigated among the population engaged in ASD-NT intimate relationships, it is reasonable to assume that NT partners may experience similar challenges that may erode relationship satisfaction. Therefore, the current study will add to the scant literature on ASD-NT intimate relationships by investigating caregiver burden among NT partners engaged in ASD-NT intimate relationships. Further, the effects of caregiver burden on relationship satisfaction will also be examined. In addition the role of social support, in the expected relationship between caregiver burden and relationship satisfaction will also be investigated. The study will examine these issues two ways- through an analysis of quantitative data from individuals in ASD-NT relationships, and then by qualitative analysis of interviews with a subset of this group. The following hypothesis will be tested;

H1. It is predicted that NT participants will report lower relationship satisfaction, than respondents with ASD.

H2. Positive patterns of communication are expected to be perceived less often by NT participants than partners with ASD.

H3. It is predicted that caregiver burden will be comparatively high among NT respondents.

H4. Caregiver burden is expected to be significantly, negatively related to relationship satisfaction.

H5. Social support is predicted to moderate the relationship between caregiver burden and relationship satisfaction.

Method

Research Strategy

This study adopted a mixed methods approach to explore the nature of ASD-NT intimate relationships. Cross-sectional quantitative data was collected via two versions of an online questionnaire. Further, a semi-structured interview was employed to collect qualitative data. The quantitative component examined research questions related to the basic interpersonal and intrapersonal patterns. The quantitative findings were then used, along with a priori research questions to guide a more qualitative analysis of these relationships.

Participants in the Cross-Sectional Study

The Macquarie University Ethics Review Committee granted approval for the current study (see Appendix A). The participants were recruited from community organisations and private psychology practices whose members/clients have ASD or are partnered with people who have ASD. Support organisations and psychologists with an interest in ASD-NT intimate relationships were contacted via email by the author and were invited to distribute an advertisement about the study among their members/clients (see Appendix B). The respondents were asked to provide consent by clicking on a tab in the online questionnaire that would allow them to progress through the survey (see Appendix C).

A total of 110 people attempted the online questionnaire, however, 38 respondents were prevented from completing the survey as they did not meet the requirements of the validation

screening. The inclusion criteria is noted as follows; The participants must be 18 years or over, have a diagnosis of ASD or be in an intimate relationship with someone who has had a diagnosis of ASD (for longer than one year), and reside with their partner. Thus, 72 responses were included in the analysis, of which 62 (86.1%) were female and 10 (13.8%) were male, with the ages ranging from 27 to 72 ($M = 47.26$, $SD = 11.47$). Sixteen point seven percent ($N = 12$) reported that they had ASD and 83.3% ($N = 60$) were partnered with someone who had ASD. Further descriptive statistics by diagnostic group are provided in the result section for both the quantitative and qualitative components of the study.

It is important to note that the population of interest ($N = 72$) in the cross-sectional study represented a very specific sub-group of the Australian population. Thus, recruiting a substantial sample proved difficult, especially among individuals with ASD. Further complicating recruitment was the fact that participants drawn from support groups and psychologists may have been experiencing significant distress (as evidenced by the fact that they sought support). This suggests that the sample method may have failed to recruit many individuals engaged in fulfilled and satisfying ASD-NT intimate relationships. For this reason the findings of the present study should be thought of as only indicative of a sub-population of people involved in ASD-NT intimate relationships.

Measures for Cross-Sectional Data Collection

Online questionnaires. All of the participants completed measures of relationship satisfaction, communication patterns, social support, and loneliness. Individuals who noted that their partner had ASD were directed to a second version of the survey that also assessed caregiving. The first page outlined the study, providing information about the researchers and their contact details. Confidentiality and ethics information were also noted (see Appendix C).

Demographic questions. The demographic section contained seven questions (see Appendix C). The participants reported if they or their partner had ASD by answering the following questions; “Are you currently in an intimate relationship with someone who has had a diagnosis of Asperger Syndrome?” and “Have you been diagnosed with Asperger Syndrome?” In addition, the participants were asked to provide information about the diagnosis (e.g., who made the diagnosis and when the diagnosis was made). Years of cohabiting were noted in response to the question “How many years have you been married/living in a de-facto relationship?” The respondents also provided their age and gender.

Relationship satisfaction. The ENRICH Marital Satisfaction Scale (EMS; Fowers & Olson, 1993) is a 15-item measure that includes the Satisfaction and Idealistic Distortions sub-scales from the ENRICH Marital Inventory (Fowers & Olson, 1987). The Marital Satisfaction sub-scale has 10 items assessing global marital satisfaction across 10 domains (e.g., communication, sexual relationship, and religious orientation) (e.g., “I am very happy with how we handle role responsibilities in our marriage”). Items are scored on a 5-point Likert-type scale ranging from 1(strongly disagree) to 5(strongly agree), with higher scores indicating greater relationship satisfaction. The Marital Satisfaction sub-scale has demonstrated good internal reliability ($\alpha = .81$) and test-retest reliability ($\alpha = .86$) over a 4 week period (Fowers & Olson, 1987). Previous research has supported the criterion and construct validity of the EMS (Fowers & Olson, 1993; Fowers & Olson, 1989). In the present study the EMS demonstrated acceptable reliability for the NT group ($\alpha = .79$) and the ASD diagnostic group ($\alpha = .86$).

The Idealistic Distortion sub-scale (IDS) is a 5 item check scale assessing the tendency to report unrealistically high marital satisfaction (e.g., “Our relationship is a perfect success”), the total score of which corrects the Marital Satisfaction sub-scale score (i.e., The Marital

Satisfaction and Idealistic Distortion sub-scales are individually summed. Based on the Marital Satisfaction and Idealistic Distortion sub-scale raw scores, the percentile scores (PCT) for each scale are drawn from a norm table. The percentile scores are then inserted into the following formula: $EMS\ score = PCT - [(.40 \times PCT) (ID \times .01)]$. When calculated, this formula yields an individual, corrected Enrich Marital Satisfaction score). The Idealistic Distortion sub-scale (IDS) has demonstrated excellent internal reliability ($\alpha = .92$) and test-retest reliability ($\alpha = .92$) over a 4 week period (Olson et al., 1987). Moderate reliability was evident in the IDS for the NT group ($\alpha = .69$) and the ASD diagnostic group ($\alpha = .82$).

Communication patterns. The Communication Patterns Questionnaire- Short Version (CPQ-SF; Christensen & Heavey, 1990) has 11 items drawn from the Communication Patterns Questionnaire (CPQ; Christensen & Sullaway, 1984). The CPQ-SF is scored on a 9 point scale ranging from 1 (very unlikely) to 9 (very likely) and it assesses communication patterns between couples in two contexts: when an issue or problem arises and during discussions of the issue or problem. Six items measure two complementary patterns of negative communication as follows; one partner criticizes their partner when discussing an issue and the other person defends themselves (male criticizes/female defends; female criticizes/male defends) and finally, one partner demands while the other withdraws during a discussion (male demands/female withdraws; female demands/male withdraws). The internal consistency of the criticize/defend sub-scale is reported as ($\alpha = .83$) and the demand/withdraw subscale has demonstrated moderate internal consistency ($\alpha = .71$; Futris, Campbell, & Neilsen, 2010). The remaining items assess symmetrical communication patterns (e.g., mutual compromise, expressing feelings, discussion, blaming, and avoidance). Of the 5 items assessing symmetrical communication, 3 measure

overall positive interactions. Futris et al., (2010) reported that the positive interaction subscale had barely adequate internal reliability ($\alpha = .61$).

In the present study the negative subscale of the CPQ-SF was not included in the analysis due to poor reliability among the NT group ($\alpha = .44$). However, the positive sub-scale demonstrated acceptable to very good internal reliability (NT group, $\alpha = .70$ and ASD diagnostic group, $\alpha = .90$), and was thus used in the analysis.

Caregiver burden. The Role Captivity (RC) measure (Pearlin, et al., 1990) is a 3 item scale that assesses the extent to which a person feels incumbent in the role of caregiver (e.g., “wish you were free to live your own life”) and assessing the extent to which partners feel trapped by their partners behaviours (e.g., “wish you could run away”). The items are scored on a 4-point frequency scale ranging from 1 (not at all) to 4 (very much), with higher scores suggesting feelings of being trapped in a caregiving role. The role captivity measure has demonstrated good internal reliability (Cronbach’s alpha between .82 and .89; Gaugler, Davey, Pearlin, & Zarit, 2000) among carers of relatives with Alzheimer's disease. In the present study the RC had good internal reliability ($\alpha = .86$).

Social support. The Expressive Support Scale (ESS; Pearlin, et al., 1990) is an 8-item scale that measures perceptions that others will be available for support, can be trusted and are encouraging (e.g., “you have a friend who you feel you can trust”). The items are scored on a 4-point agreement scale ranging from 1 (strongly disagree) to 4 (strongly agree), with higher scores indicating a greater perception that others are supportive. The ESS has good internal consistency ($\alpha = .87$; Pearlin, et al., 1990). In the present study the ESS had excellent internal reliability for both the NT group ($\alpha = .90$) and the ASD diagnostic group ($\alpha = .94$).

Procedure

The participants completed the online questionnaire in their own homes on their own computers. The opening page of the questionnaire was an informed consent information letter outlining the purpose of the research, information about confidentiality, and the prize draw, as well as contact information for the researchers and ethics information. Respondents who agreed to participate noted their informed consent by clicking on an arrow to begin the survey (participants were able to download a copy of the consent information for their records). Several screening questions based on the inclusion and exclusion criteria were completed first by the participants (e.g., “what is your age?”, “have you/your partner been diagnosed with ASD?”, and “do you live in the same house as your partner?”). The inclusion criteria for participants were as follows; the respondent was in an intimate relationship (for at least 1 year) with someone who has had an ASD diagnosis, or have had an ASD diagnosis themselves. Further, the respondent must have had an adequate level of English to complete the questionnaire, be at least eighteen years of age, and cohabit with their partner.

At the conclusion of the questionnaire participants were invited to provide their contact details to enter a prize draw for a set of 5 movie tickets valued at \$100. In addition, respondents were able to download a participant resource pack (listing various phone counselling services, non-scholarly books on ASD-NT intimate relationships, and contact details of Australian psychologists offering services to this population; see Appendix D). Further, respondents were invited to leave their contact details to note their interest in participating in a telephone interview and to provide implied informed consent for the qualitative component of the study. Participants who nominated to be interviewed were then contacted to set a time and date to conduct the

interview. All of the individuals who indicated their willingness to participate in the interview were entered into the second prize draw for 1 of 2 \$100 Coles vouchers.

Semi-structured interviews

Participants

Twenty one of the 72 questionnaire respondents agreed, and participated in, the recorded interviews. Twenty eight point five percent ($N = 6$) had a diagnosis of ASD and 71.4 % ($N = 15$) were partnered with someone who had been diagnosed with ASD. Of the respondents who had ASD, one was female and five were male. All of the participants in the NT group were female.

Interview focus areas. A semi-structured interview was employed as an adjunct to the quantitative data collection as a means of collecting descriptive in-depth information from participants. The overarching research questions informing the interview process are noted as follows;

1. Is caregiving and care receiving a feature of ASD-NT intimate relationships?
2. Does caregiving contribute to caregiver burden? What factors evident in ASD-NT intimate relationships exacerbate caregiver burden?
3. What factors might be protective of relationship satisfaction among individuals engaged in care taking or care receiving roles?

The questions posed during the interview were focused on physical and psychological health (e.g., “do you have any chronic health conditions?”), the process of and responses to the ASD diagnosis (e.g., “what emotions/thoughts did you experience after the diagnosis?”), and positive, as well as negative aspects of having ASD/being partnered with someone who has ASD (e.g., “can you bring to mind any of the positive aspects of having ASD/being partnered with someone who has ASD?”). Further, relational coping strategies (e.g., “do you have any strategies

for dealing with relational needs?") and special interests (e.g., "how does your partner feel about your special interest?") were also discussed (see Appendix E for a full list of questions).

All of the interviews were conducted via telephone and were recorded (with the participants consent) by a Zoom bi-directional recorder. Prior to commencing the interviews, the participants were reminded that the interview was recorded and that they could end the interview at any time without consequence. Similarly, they were reminded that they could decline to answer any questions that they were uncomfortable answering. The interviews ranged in length from 30 minutes to 1.5 hours, which were then transcribed by an independent transcription service. Throughout the interviews, reflective statement summaries were used to determine the accuracy of the interviewer's interpretation of the participant's responses (Cho & Trent, 2006).

Qualitative Data Analysis

The thematic content analysis adhered to the procedure recommended by Braun and Clarke (2006) as follows; 1. Iterative review of the data 2. Developing working codes related to the overarching research questions. 3. Generating themes from the working codes 4. Cross checking theme content with working codes 5. Defining resultant themes.

Results

Overview

The statistical analysis for the current study was completed using version 22.0 of the SPSS software package. For all significance tests, the type 1 error rate was set at .05. The distributions of the independent and dependent variables were inspected. With the exception of the scale for relationship satisfaction among NT respondents, each of the scales administered in the current study met the assumptions of normality, skewness, and kurtosis. In the relationship

satisfaction scale the distribution showed positive skew and kurtosis for the NT group. Therefore a non-parametric test (Mann-Whitney test) was employed to test hypothesis 1.

Descriptive Statistics

The descriptive statistics of the participants are noted in table 1. In sum, the majority of NT respondents were female, aged under 69 years, who had been in an ASD-NT intimate relationship from 1 to 46 years. Three quarters of the ASD diagnostic group were males aged under 72, and the remainder of the ASD diagnostic group were females aged under 36. Individuals in the ASD diagnostic group had been in an ASD-NT intimate relationship from 8 to 46 years.

Table 1

Descriptive statistics, Means (Standard Deviation or %) and Minimum and Maximum

Characteristics of NT group, N = 60			
Variables	Means (S.D/%)	Minimum	Maximum
Age	49.28 (10.78)	29	69
Gender			
Female	59 (98.33%)	---	---
Male	1 (2.8%)		
Length of Relationship	19.68 (12.12)	1	46
Years since Diagnosis	4.58 (5.73)	<1	33
Characteristics of ASD diagnostic group, N = 12			
Variables	Means (S.D/%)	Minimum	Maximum
Age	46.72 (12.64)	27	72
Gender			
Female	3 (25%)	---	---
Male	9 (75%)		
Length of Relationship	22.82 (11.03)	6	46
Years since Diagnosis	6.45 (5.64)	1	15

Note. Standard deviations or percentages appear in parenthesis beside the mean scores.

Table 2*N's, Cronbach alphas, means, standard deviation for NT group*

Variable	N	Cronbach α	Mean	S.D.
Caregiver burden	58	.865	9.06	2.59
Relationship satisfaction	59	.791	10.18	8.43
Social support	60	.909	23.61	5.21
Positive communication patterns	59	.708	11.32	5.77

Table 3*N's, Cronbach alphas, means, standard deviation for ASD group*

Variable	N	Cronbach α	Mean	S.D.
Relationship satisfaction	7	.863	19.5	5.21
Social support	12	.940	24.83	5.82
Positive communication patterns	12	.909	19.50	5.82

Hypothesis 1: Relationship Satisfaction levels among ASD and NT groups

It was predicted that NT participants would report lower relationship satisfaction, than those with ASD. As expected, on average, relationship satisfaction levels were lower among the NT population ($Mdn = 5.00$), compared to the ASD diagnostic population ($Mdn = 28.88$), $U = 620.00$, $z = 4.30$, $p < .0005$, $r = .52$.

Hypothesis 2: Perceptions of Positive Communication among ASD and NT groups

It was predicted that positive patterns of communication would be perceived less often by NT participants than respondents with ASD. As expected, on average, NT participants perceived interactions in their relationship to be less positive ($M = 11.32$, $S.D = 5.46$) than respondents with ASD ($M = 19.50$, $S.D = 5.21$), $t(63)$, -4.72 , $p = < .0005$, 95% CI $[-11.64, -4.71]$, $r = .51$.

Hypothesis 3. Caregiver Burden among NT respondents

Hypothesis 3 predicted that caregiver burden would be high among NT respondents. The mean care giver burden score for the NT population was 9.06 ($S.D = 2.59$). Norms of caregiver burden among normal populations were not available. Therefore, the mean score for caregiver burden among NT participants was compared to previous research examining this phenomenon among 3 populations of carers (i.e., caring for people with dementia, elderly, and frail elderly people). Carers of people with Alzheimer's reported a caregiver burden mean score of 6.20 ($S.D = 2.3$) (Morano & Sanders, 2006). Similarly, carers of elderly and frail elderly people reported caregiver burden mean scores of 6.40 and 5.72, respectively (Lyons, Zarit, & Townsend, 2000; Noonan & Tennstedt, 1997). The mean score of 9.06 (in a 12 point caregiver burden scale) among NT partners, suggests that this population is experiencing high levels of caregiver burden, compared to other groups of caregivers.

An independent samples T-test was computed to compare the aggregated mean of the abovementioned studies ($M = 6.10$) and the mean for the current study ($M = 9.06$), which was significant ($t(2) = 7.31, p = .01, d = 1.03$). Overall, the data suggest that caregiver burden among NT partners was comparatively very high.

Hypothesis 4: Relationship between Caregiver Burden and Relationship Satisfaction

Hypotheses 4 predicted that caregiver burden would be significantly, negatively related to relationship satisfaction. As expected, caregiver burden was strongly and significantly negatively related to relationship satisfaction, $r(56) = -.66, p < .0005$. This finding suggests that greater caregiver burden is associated with lower relationship satisfaction.

Bivariate relationships

Prior to testing hypothesis 5 relating to the negative relationships between caregiver burden and relationship satisfaction, a bivariate correlation analysis was carried out to examine the relationship between the variables of interest (see table 4). As previously noted, caregiver burden was strongly negatively related to relationship satisfaction. Similarly, caregiver burden was moderately negatively associated with social support and positive patterns of communication. Relationship satisfaction was moderately positively related to communication patterns and social support. The relationship between social support and positive patterns of communication was positive and approaching moderate strength, but did not reach significance.

Table 4*Correlation matrix for NT group*

Variable	N	1	2	3
Caregiver burden	58	1		
Relationship satisfaction	59	-.66**	1	
Social support	60	-.32*	.26*	1
Positive communication patterns	59	-.48**	.36**	.25

** $p < 0.01$ level (2-tailed). * $p < 0.05$ level (2-tailed).

Hypothesis 5: Moderating Influence of Social Support

Hypothesis 5 predicted that social support would moderate the relationship between caregiver burden and relationship satisfaction so that there would be a stronger relationship between caregiver burden for those with more social support. In particular, it was thought that at lower levels of caregiver burden, relationship satisfaction would be greater for those with more social support. To test these predictors the social support data was separated into quartiles, with the bottom and top quartiles (i.e., the groups highest and lowest in social support) being compared in an ANOVA where relationship satisfaction was the dependent variable, caregiver

burden a predictor variable and levels of social support a between subjects factor. There was a significant main effect for caregiver burden such that greater burden predicted lower relationship satisfaction ($F(1, 25) = 10.72, p = .003$). There was no significant main effect for social support group ($F(1, 25) = 1.91, p = .179$), and no significant interaction ($F(1, 25) = 1.29, p = .226$). However it should be noted that the observed power was very low (.195) and the effect size for both analyses was moderate for the social support main effect $\eta^2 = .07$ and very close to moderate for the interaction $\eta^2 = .05$), suggesting that the low statistical power may have resulted in a type 2 error (i.e., a failure to find a true effect). Although it should be interpreted with caution, the interaction graph reveals a pattern in the expected direction (see Figure 1). When examining this interaction, it should be noted that the overall mean satisfaction for the two groups was noticeably different ($M = 6.49, SD = 2.79$ for the low support group and $M = 12.60, SD = 10.22$ for the high support group) and this difference is particularly noticeable at low levels of caregiver burden. However, there is a clear downward trajectory, whereby the greater the caregiver burden the lower the relationship satisfaction. Because the high support group had considerably higher levels of relationship satisfaction at low levels of burden, the decline in relationship satisfaction as burden increased was far more marked, reaching the same low level as the low support group at the extreme end of the 12 point caregiver burden scale (i.e., at a score of 12). Overall, caregiver burden seemed to have more impact on reducing relationship satisfaction for those who were more socially isolated, but such conclusions are tentative given the lack of significance of the interaction.

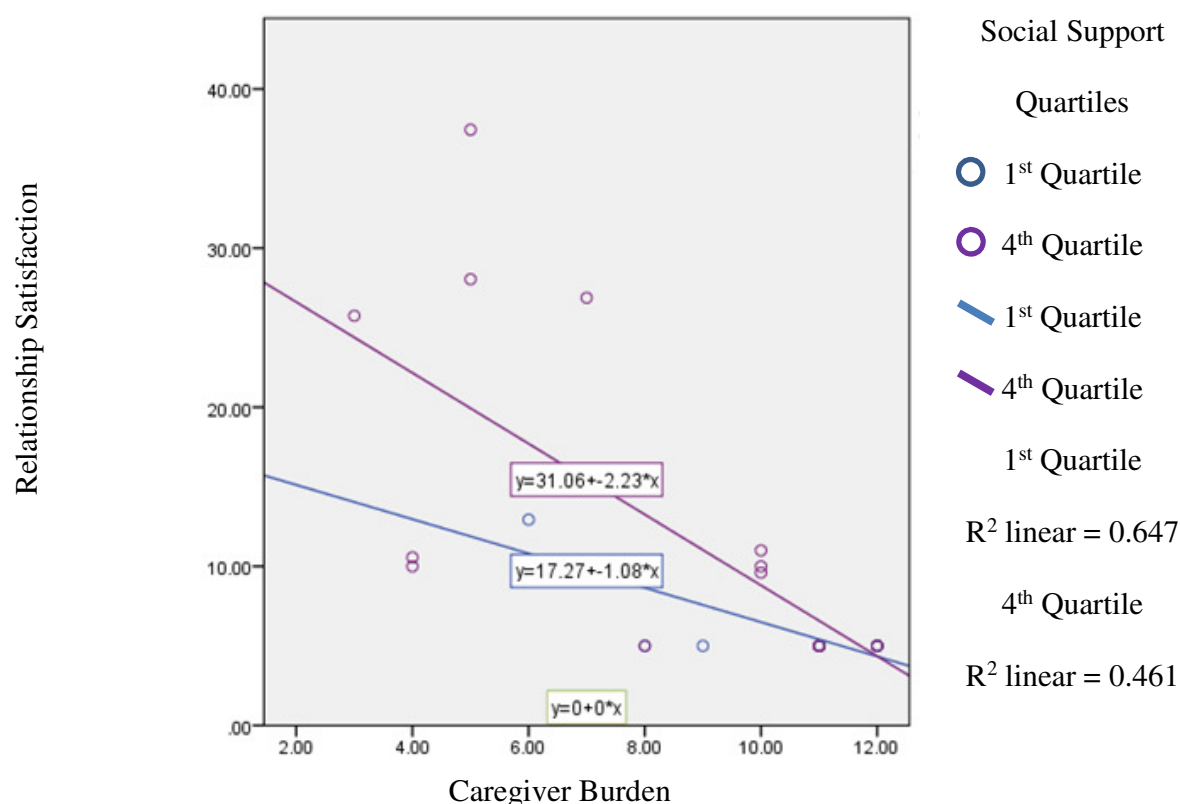


Figure 1: Interaction graph for social support

Summary of Quantitative Findings

In sum, the results suggest that relationship satisfaction was low among the NT group, compared to the ASD diagnostic group. In addition, caregiver burden was found to be comparatively high among the NT group and further, this burden was strongly negatively associated with relationship satisfaction. Finally, although no statistically significant moderating effect was found for social support, the direction of results are indicative that individuals with greater levels of social support may experience a steeper decline in relationship satisfaction as caregiver burden increases. Analysis of the qualitative data will be conducted in order to further examine this potential moderating role of social support.

Thematic Analysis

The qualitative data were analysed in accordance with the recommendations for thematic analysis of qualitative data of Braun and Clarke (2006). Working codes were developed, which with iterative revision, formed condensed themes. The data were then analysed by a second researcher to ensure the reliability of the themes identified by the author. Additional themes to those noted by the author were identified by the second researcher. However, due to the deductive framework imposed on the data only the themes relevant to the current study will be discussed herein. The overarching research questions informing the interview process are as follows;

1. Is caregiving and receiving care a feature of ASD-NT intimate relationships?
2. Are there factors evident in ASD-NT intimate relationships that contribute to caregiver burden?
3. For ASD-NT intimate relationships are there buffering mechanisms that reduce the impact of caregiver burden?

Themes were found in the data across interpersonal and intrapersonal domains for both groups. The results are grouped by domain (i.e., *interpersonal* and *intrapersonal*) and considered by themes capturing the experience of both groups (i.e., NT and ASD diagnostic group; with the exception of the themes of *Emotional distance* where only a NT perspective is reported). Each theme is described and illustrative examples are provided. To ensure the respondents' privacy, participants are identified by a pseudonym chosen by the researcher.

Caregiving

All of the NT respondents reported that they identified as either a caregiver, parent or manager of their partner with ASD, as opposed to an intimate partner.

“I think anyone who’s a partner of an Asperger person is actually a carer ...you don’t want to be a carer, you want to be a partner.” (Rachel)

The caregiving theme related directly to the partner with ASD, the wider social issues related to ASD symptoms and domestic concerns. For example, caregiving involved the management of the care recipient’s socially inappropriate behaviour (e.g., inappropriate jokes, abruptness, and monopolizing conversations) and the constant need to prompt them to perform everyday tasks (e.g., feeding pets, tidy personal belongings, and gardening).

“He does joke a lot and quite a lot of the jokes are inappropriate for certain settings, so we have under the table kick the foot, or something like that. If I can’t reach him then I growl, I make growling noises.” (Courtney)

Direct instruction was also noted as part of the NT partner’s caregiving responsibilities. Several NT respondents reported that they provided *social scaffolding* (verbal briefs about social rules) prior to or after social occasions, to reduce the possibility of their partner behaving inappropriately, as well as attempting to manage their partners social anxiety.

“He won’t understand that somebody was trying to get away and I’ll come and save them, and get his attention, and then I’ll explain on the way home that the person was uncomfortable and this is why.” (Crystal)

Managing family life was noted as a significant responsibility of many NT partners. These tasks involved the day to day running of the household (e.g., cleaning, cooking, care of

pets, and pool maintenance, etc.), decision making, and financial management, as well as caring for children. The following statement from *Peta* demonstrates the weight of responsibility many of the NT partners carry:

“I seemed to also end up with the responsibility for the house, the renovation, the maintenance, all the kids, everything they did, deciding which schools they'd go to, managing all the finances, managing our healthcare and our all our insurance, and buying the car, and our holidays.” (Peta)

Receiving Care

Most of the respondents in the ASD diagnostic group (90%) were aware that they were a recipient of care from their partner.

“I consider myself, because of my autism, on what you would call high maintenance in a relationship.” (Thomas)

Responses to receiving this higher level of care among the ASD diagnostic group ranged from resistance to gratitude. One participant noted that although they appreciated the outcome of care, at times, he resented his partner's style of caregiving, identifying it as ‘micromanagement’ (*Cory*).

“Well, you know I can appreciate the results of it. Sometimes I get a bit cross with it...I think that she tries to manage too many little details of something and that's when I get a bit cross.” (Cory)

Conversely, many of the participants in the ASD group expressed gratitude for the care they received from their NT partner, especially regarding problem solving and managing ASD symptoms (e.g., communication difficulties and navigating social interactions). The following statements reflect perceptions of receiving care among the ASD diagnostic group:

“I am blessed by having the most understanding, and the best partner ever. And this is not just my opinion.....it comes across quite clear that she especially, I especially, I really like that she's such an understanding partner.” (Thomas)

“Elizabeth has helped me to do a lot of social things that I would never have been able to do on my own, like figuring out how to deal with situations and how to deal with difficult people, especially at work, and how to negotiate even basic things like getting a refund. Without Elizabeth I wouldn't have been able to do a lot of things.” (Sloan)

In sum, it appears that caregiving and the receiving of care are features of ASD-NT intimate relationships. Caregiving in the context of these unique relationships involves not only the care of the partner with ASD, but also a wide range of tasks involved in family life. However, it appears that responses to receiving this level of care vary among individuals in the ASD diagnostic group.

The Personal Cost of Caregiving

The personal cost of caregiving emerged as an important subtheme of caregiver burden among NT partners. Caregiving appears to have an impact on the physical and emotional health of the individual, as well as eroding feelings of respect toward their partner. Respondents reported feeling exhausted, overwhelmed, and trapped by their caregiving responsibilities:

“I didn't realise to what extend I was shouldering the burden for all of that, until I got sick and had a very cold hard look at why I got sick.”(Bethany)

“I'm exhausted living with someone with Asperger's because you're in denial that you're exhausted. Yes, yes. You get exhausted in every way - physically, emotionally...” (Bree)

“I can ask him to do anything and he will do it. But the problem is I get overwhelmed with thinking for him and thinking for me.” (Brenda)

“I'm trying to keep it happening for everybody else at my own expense. What I would like to do is just leave and live somewhere else because I feel that I'm just in crisis management all the time.”(Bethany)

Several NT participants reported that caregiving responsibilities had eroded the sense of respect they had for their partner. For example, *Brenda* felt that she often treated her partner like a “child.” *Crystal* reported feeling that directing and prompting her partner was “emasculating” for him. Similarly, respondents were aware of the negative impression their behaviour as a caregiver created among their family and wider social context.

“So I'd have to...treat him as a child and explain things to him.” (Brenda)

“I feel like it's emasculating him to have to tell him to do it all the time...” (Crystal)

“...the kids saw me as the dominating, controlling, manipulating wife and mother because they saw me telling him what to do or what not to do.” (Rachel)

Although most NT participants consistently reported a high personal cost of giving care to their partner with ASD, this was not always the case. For example, one participant identified a positive outcome of caregiving - the gradual improvement in her partner's executive function due to adopting strategies she had suggested:

“....he has trouble organising himself but when he puts things on his phone and then... looking at his phone all the time, then he was able to do that, so I do believe with repetition and consistency, learning can come.” (Brenda)

In terms of awareness of this personal cost by partners with ASD, some showed awareness of the effects that caregiving had on their NT partner.

“Yes, so that's right, she does remind me. Not always positively, but of course it will be irritating to her too, to have to do that at times.” (Cory)

A deeper appreciation of the cost of caregiving prompted one respondent to adopt strategies to enable the NT partner to enjoy some respite. Further, they also reported feeling sad about the impact that their care needs had on their partner:

“I need a lot of attention, a lot of care, and a lot of understanding. And at times that gets too much for my partner to handle. As in, sometimes I’ve just got to leave her alone, or I have to get out of the house, or very occasionally she has to go away on a little holiday for a couple of days, or go visit someone, just because I’m overwhelming her. I don’t make any judgement of it. I know she’s going to come home again...I do feel, not exactly guilty, but I realize even unconsciously I’m the cause of it, so I feel sad about that” (Thomas)

In sum, caregiving in the context of ASD-NT intimate relationships appears to have more negative than positive effects for individuals engaged in these unique relationships, especially for the NT partner, but this is not always the case. Most noticeably, the psychological and physical health of NT partners suffered. However, attitudinal, behavioural and affective, responses to giving- and receiving- care varied between individuals and diagnostic groups.

Social Support

Social support was identified as an important theme among NT participants. For some, accessing social support outside of the intimate relationship was considered crucial for maintaining psychological health and coping with caregiving demands:

“I think me going out and about and refreshing myself, and having new experiences helps me to feel more satisfied. Yeah it definitely feels healthy to be doing that.” (Bethany)

Contextual support (i.e., support within the ASD-NT community) from others engaged in ASD-NT relationships appears to afford a sense of validation regarding the difficulties associated with these unique relationships. Further, identifying as ‘neurotypical’ (Courtney) seems to create

a feeling of comradery, whereby the individual perceives that a greater level of *expressive* support (i.e., having access to an accepting confidant) is available.

“Sometimes it is so frustrating, and you just think, oh man, I’m in this alone. But when you can have coffee with a girlfriend whose husband is very similar, and you say the same things at the same time, you laugh. That sort of just makes you feel so much better, that someone actually does understand, and there aren’t too many people that do understand how hard it can be.”

“I visit friends and have coffee quite often. That’s a big one, and I encourage all neurotypical wives to do that, come and join us for coffee.” (Courtney)

However, for some participants there was a perception that although support was somewhat helpful, it did not ameliorate core relational deficits (e.g., loneliness attributed to a lack of connection) and perceived burden within their intimate partnership.

“I’m still building up friendships, so I haven’t got the deep friendships that I’m needing I guess. But they get me out of the house and the exercise is really good for me, I’m feeling really stressed, so to a point it deals with that but it doesn’t go to my deepest need of being able to manifest a person and be accepted by that-- that lack of connection I guess...if all of a sudden I have nothing to do and no one to talk to then I get really lonely.” (Brenda)

“I don’t join in that conversation, and I’m happy to get them to talk, because it takes my mind away, because I’ve got no story that anybody really wants to hear. Nobody wants to hear me whinging about hubby, people don’t believe that someone could be like that.” (Joanne)

In sum, the effects of social support vary among individuals in this population. For some, support contributed to maintaining psychological health, validated their caregiving experience, and afforded a sense of comradery and belonging. For others though, social support fell short of

meeting core needs that would ordinarily be assuaged within an intimate relationship. In addition, the qualitative findings suggest that NT partners with high levels of social support had greater relationship satisfaction if burden was low, but lower relationship satisfaction if burden was high.

Communication

A significant proportion of NT partners (76%) reported experiencing communication difficulties in their intimate relationship.

“There's a lot of miscommunication. I'm not understanding what he's saying and he doesn't understand me, so that causes a lot of conflicts.” (Brenda)

Communication difficulties, which were attributed to underlying ASD symptoms, lead to problems interpreting verbal and non-verbal language, avoiding emotional conversations, and understanding abstract concepts. Four of the NT participants reported that their partner often misinterpreted their intentions in spoken communications. For example, understanding idioms [e.g., “a stitch in time saves nine” (Faith)] or failing to detect the different underlying intentions behind such statements as “...I'm going off to Sydney for the day, do you want to come?” and “Do you want to turn off the light?” (Faith). Another aspect of miscommunication reported by NT participants was the tendency of their partners to interpret speech literally:

"Can I tell you something funny?" And I told him the whole story.....he said, "Stop, stop, stop...The problem was that I had said, "Can I tell you something funny?" And he started waiting for the punchline, to laugh, and when no punchline to laugh came along, he got confused, and that's when he put his hand up and said, "Stop, stop." (Bethany)

Deficits in detecting non-verbal communication were also identified as an obstacle to effective social communication. Several of the NT participants discussed their partner's habit of

monopolizing conversations, unaware of the feelings of the listener (e.g., boredom), while discussing their 'pet subject' (Courtney). This inability to interpret non-verbal language also impacted interactions between the couple, as reported by *Bethany*:

"He would come home from work every day ... and talk at me, and I started to time him.....and he got up to 25 minutes one day without stopping...This used to go on and on and on."

Many of the NT participants felt that their partner avoided discussing subjects they were uncomfortable with or did not understand. For example, emotions or abstract concepts:

"He does not respond to any sort of emotion from me at all - so I can't be sad, I can't be angry, I can't be despondent. I can't present anything that he doesn't like or understand, because that means that he withdraws...disengaging from a conversation or a situation that he finds overwhelming." (Kim)

"...intangible concepts about behaviour and hopes and dreams, were just impossible to have a dialogue about. Then, even when I tried to explain those concepts, that made it worse, because he was so bamboozled by what I was saying. It was just words." (Bethany)

Some of the participants in the ASD diagnostic group were aware of the difficulties they had with communication and the impact these issues had on intimate relationships, and in particular, that these difficulties were related to verbal communication:

"...she'll say something but mean something else, or I would interpret it slightly different. Sort of like an open-ended question which may have a couple of different interpretations, which I'd interpret the wrong way". (David)

"I always want to discuss everything in terms of me. Even though I'll ask her what sort of day she's had, I'll always switch it then to what sort of day I've had." (Thomas)

One of the participants in the ASD group expressed concern about the relational effects of the difficulty they had expressing emotions with their partner:

“I think the problem that I've certainly experienced anyway, is that of expressing that feeling. The feeling can be there, but unless it's communicated, it just goes nowhere and in the end, of course, it breaks up relationships-- or the lack of expression of those sort of feelings damages relationships.” (Cory)

Overall, it appears that communication difficulties are common to many ASD-NT intimate relationships. NT respondents reported that their partner had problems with interpreting verbal or emotive communication and there was some recognition of this by the ASD partners. In addition, NT participants reported that non-verbal communication and understanding abstract concepts was problematic for their partner with ASD.

Adaptive Strategies for Better Communication

Several adaptive communication strategies such as *context* (e.g., removing potential sensory distractors) and *framing* (e.g., employing stories or visual aids), *reminders* (e.g., cognitive reminders to act on intentions) and *questioning* (e.g., inquiring directly about the partner's needs) were employed by both groups to address communication difficulties involving verbal and non-verbal communication, as well as expressing emotion:

“The other thing that I've done in the past is to talk to him in bed at night, with the lights out. There's no eye contact required, so you're removing that visual-- that additional sensory import, if you like, which would allow him to process.” (Kim)

“I have to put it across to him so he could understand it.... I will use analogies or give him pictures and explain it.” (Brenda)

“I'm very aware of doing that just at the moment. My wife went off to a forum yesterday, and I made a comment about, "It's good to have intelligent and commonsensical people going to these things” (Cory)

“Well...sometimes I ask when I'm sensing that, through the way she's acting, that she's not as happy as she should be. I ask her would she like a hug.” (Thomas)

Although adopting these strategies facilitated clearer communication, some NT partners felt that the use of such methods altered their communication style (e.g., becoming more “brutal”: Mandy) and ultimately the nature of their intimate relationship.

“I'm a very different person to the person I thought I would be, even to the person I wanted to be. I've found I've had to be a lot more direct.” (Crystal)

“I need to do it in a way that makes sense to him, so I have to kind of remove my own personality from the exchanges, and that has altered my-- I feel that that's fundamentally altering our relationship.” (Kim)

In addition, respondents with poorer communication strategies reported lower relationship satisfaction, and greater frustration, as their caregiving responsibilities and burden increased.

“That would have to be the most frustrating thing is the communication....It still comes to the point where I just don't rely on him for anything which is not the relationship I wanted to have with my husband because there's no respect there.” (Crystal)

In sum, participants in both groups reported employing various strategies to improve communication. However, some respondents reported that these accommodative behaviours were incongruent with how they viewed themselves, as well as altering the nature of their

intimate relationship. Similarly, those with poorer communication had less relationship satisfaction as caregiver burden increased.

Disconnection

Courtney stated during an interview “*We live alone together*”, this sentiment captures the theme of emotional distance and lack of support expressed by most of the NT participants. The feelings of relational disconnection was attributed to an absence of verbal and physical affection, the inability of their partner to provide support, and to meet their emotional needs:

“Intimacy is one of the things...because their kind of intimacy ...is very different from ours, and we don't feel loved... We don't feel cherished.” (Courtney)

“I really don't have much help from him, especially emotionally...My emotional cup is empty.” (Maureen)

“I finally realised that emotional needs in the marriage were never going to be met...I hoped that even if Mark acknowledged it, he might be able to step up and meet my emotional needs in some way, but the truth of the matter is, I don't think he's capable of that.”(Kim)

Most of the NT participants reported feelings of either anger, loneliness, frustration, or isolation in response to this emotional distance in their relationship.

“Oh, deep loneliness. Absolutely deep, crushing loneliness. I still feel that today though in a sense.” (Brenda)

However, most of the respondents had made a conscious decision to seek emotional companionship outside of their intimate relationship through family, friends, and others who are partnered with someone who has ASD.

“I do feel lonely and I guess that's why I think a laugh and a coffee with the girls during the week, when Mitchell's at work and what have you.” (Maureen)

Further, two of the NT partners reported choosing to focus on being positive, rather than the loneliness they were experiencing.

“I don't go down that road. There's plenty of people who are lonelier than I am. It's about gratitude for me...” (Joanne)

“...he was actually a gift to me because he has allowed me, through his non-involvement in a lot of my life, to actually go and explore who I am... I've always felt that I've been gifted with him...” (Rachel)

In sum, most of the NT participants reported some level of emotional disconnection in their intimate relationship, and for some participants this sense of isolation was profound. This disengagement and inadequate support lead to a variety of behavioural and affective outcomes; seeking support outside of the relationship, feeling isolated, and conversely, framing the disconnection as an opportunity for personal growth.

Intrapersonal Themes

Grief and Sorrow

Themes of grief and sorrow emerged across both groups regarding various aspects of loss. For example, the loss of a hoped for relationship, the incontrovertible nature of ASD, and the impact of ASD symptoms on NT partners.

“A grief and a realisation of not only what you've lost-- well, it's not only what I've lost, it's what I never had. What I've been waiting for, what I've never had, and indeed what I will never have. I will never have that.” (Kim)

“What gives me the chronic sorrow, is the fact that autism spectrum disorder is so final. It is so incontrovertible. There is just no getting around it. There's nothing you can do to make it lessen its impact.” (Bethany)

“Knowing the potential of what we could have if we didn’t have the issues of communication and feeling sad at the damage it causeswhere sometimes I do go into a state where I say horrible things.” (Sloan)

Many of the NT respondents reported they had sought help regarding their intimate relationship. However, due to the lack of knowledge about ASD among helping professionals (e.g., Psychologists, psychiatrists, and counsellors), they were either blamed or ignored:

“...“Oh, it's all you. It's all your fault. He's lovely. He's a lovely man. Comes across nice.” And you do have to do a lot of that. I think I counted up once, I've probably been to seven, eight, nine different sorts of-- one psychiatrist, couple of psychologists, couple of counsellors...” (Rachel)

“...one counsellor ...she kept saying, “Yes, but what about you? I don't care about what he's doing.” She just kept fobbing off what he was doing because she couldn't understand it. She just kept telling me to go out and find friends. It was this brush off.” (Bree)

“...I've had a knife stuck in my chest and it's not even being seen. And people are trying to help him and I have a knife in my chest. I'm not saying don't help him. But I'm saying, “Heal me, too.” (Brenda)

Further, some of the NT participants expressed sorrow for the limitations their partner experienced because of their ASD.

“I just feel sad for him a lot of the time because he does miss out on a lot of things because of his reactions to things as well.” (Maureen)

“The only sorrow I feel is that he's not remunerated for the worth that he is, and that really hurts because I can't really help him in that department.” (Courtney)

Moving beyond grief also featured as an important subtheme. Some individuals reported that they had previously experienced grief, but now felt acceptance about their diagnosis.

Conversely, one participant explained that they were now indifferent to their partner stating:

“I grieved for a long time and now I don't care, because there is no relationship.”

(Joanne)

In sum, the grief and sadness reported by various participants was associated with various losses (e.g., failing to obtain an idealized relationship and fruitless attempts at help-seeking, among others). Outcomes of grief varied among respondents, with some expressing sadness, and others acceptance or indifference.

Conclusions

Overall, the qualitative analysis identified themes associated with both interpersonal and intrapersonal domains. In particular, guided by the a priori research questions, the themes identified suggest that caregiving and receiving care are quotidian features of ASD-NT intimate relationships. Furthermore, this pervasive caregiving role is associated with physical, psychological, and relational effects that appear to either moderate or contribute directly to perceptions of caregiver burden and relationship satisfaction among the NT population. In addition, the qualitative findings suggest that NT partners with high social support had greater relationship satisfaction if burden was low, but lower relationship satisfaction if burden was high.

Discussion

The purpose of the current study was to examine perspectives of relationship satisfaction and the factors that may contribute to, or erode, satisfaction in ASD-NT intimate relationships. As such, the study adopted a mixed method design to examine this phenomenon. In the

quantitative component, perceptions of relationship satisfaction, positive communication patterns, and social support were assessed across both diagnostic groups (i.e., ASD and NT). In addition, caregiver burden was investigated among the NT group, and social support and positive communication patterns were also examined as possible moderator variables. It was predicted that NT participants would report lower relationship satisfaction, than those with ASD. Perceptions of communication patterns were expected to differ between groups (i.e., ASD and NT), such that, positive communication patterns would be perceived less often by NT respondents, compared to the ASD group. Caregiver burden was predicted to be high among NT participants and to be negatively related to relationship satisfaction. Further, social support and perceptions of positive communication patterns were hypothesized to moderate the expected relationship between caregiver burden and relationship satisfaction. Finally, the qualitative element of the study was guided by a priori research questions to elicit in-depth insight into the findings of the quantitative component.

Hypothesis 1. Relationship Satisfaction Levels among ASD and NT groups

It was predicted that NT participants would report lower relationship satisfaction, than those with ASD. The findings strongly support this hypothesis, with NT partners experiencing significantly lower levels of relationship satisfaction than individuals with ASD. This finding is consistent with some previous research on ASD-NT intimate relationships (Lau & Peterson, 2011; Renty & Roeyers, 2007) but conflicts with the results of Pollman et al.'s (2010) study, where an opposing pattern is reported. That is, relationship satisfaction was high among NT respondents and low among partners with high ASD traits. However, Pollman et al. (2010) relied on non-clinical data, while the current study drew from a clinical population. Further, there were noticeable differences in the mean length of relationship between the two populations (Pollman

et al., 2010, $M = 4.62$, current study, $M = 21.25$). It may be that Pollman et al. (2010) failed to detect lower relationship satisfaction in NT respondents because of the diagnostic status of the partners with high ASD traits, as well as the relative length of relationships. In addition, Pollman et al.'s (2010) study measured relationship satisfaction only 10 months after the participants were married. Therefore, although the participants with high Autism Quotient scores (AQ; Baron-Cohen, Wheelwright, Skinner, & Martin, 2001)) were not exhibiting clinical levels of ASD symptoms, they may still have had difficulty adapting to changes associated with early marriage. This poor adaptability, often associated with ASD (Bauman, 1999) may have negatively impacted relationship satisfaction in individuals with high ASD traits. However, the level of expressed ASD traits may not be enough to reduce relationship satisfaction among NT partners. Thus, sample characteristics such as diagnostic status and relationship length may explain these disparate findings. Overall, it would seem that the results from the current study offer more robust findings than those of Pollman et al. (2010), especially given its concurrence with previous research also drawn from clinical samples (Lau & Peterson; Renty & Roeyers, 2007).

Themes identified in the qualitative analysis provide some insight into why relationship satisfaction was lower among NT partners compared to those with ASD in this sample. The NT population identify as caregivers with high levels of responsibility, not only in terms of caring for the partner with ASD, but also the majority of tasks involved in family life (e.g., caring for children, household tasks, and family finances). This caregiving responsibility likely comes at significant personal cost, both emotionally and physically to the NT partner. Further, the caregiving role potentially alters how NT partners view themselves and their relationship, which is compounded by grief related to the incongruence between the *hoped* for, and the *actual* intimate partnership.

In addition, relational disconnection may explain the findings regarding relationship satisfaction among the NT population. These feelings of disconnection reported by respondents were related to perceptions that the partner with ASD did not “*connect with*” (Bethany), or emotionally support the NT partner. Similarly, verbal and physical affection was noted as limited. These relational deficits appear to result in an accumulative affective deprivation, contributing to the observed levels of relationship satisfaction among the NT population.

Conversely, partners with ASD report comparatively high levels of relationship satisfaction, which may be attributed to receiving a high level of care. For example, receiving care increases perceived social competency, especially if the caregiver is considered to be a social guide for the individual with ASD. Similarly, the individual with ASD may be very aware of their shortcomings (e.g., difficulties with social interaction, and organisation), and the burden these limitations place on the NT partner. This awareness, combined with the perceived benefits of receiving care, may enhance feelings of gratitude toward the NT partner, and in turn increase relationship satisfaction.

Further, many individual’s with ASD have “*emotional cups*”, compared to the “*emotional buckets*” of NT partners (Attwood, 2015, p. 319), suggesting that the relational needs of the person with ASD are substantially less than those of the NT population. As one partner with ASD noted “*I need just enough, and no more*” (personal communication, August, 2015). As such, the effort required to meet the relational needs of partners with ASD is minimal compared to those of the NT population. In essence, individuals with ASD may be “*easily pleased*” (personal communication, August, 2015) and need ‘*just enough*’ verbal and affectional interactions fill their ‘*emotional cup*’, which would in turn, contribute to high relationship satisfaction among the ASD population (Attwood, 2015, p. 319). Therefore, although there may

be significant difficulties within the ASD-NT intimate relationship, the partner with ASD experiences satisfaction levels that are in line with their limited relational needs.

Overall, the evidence presented within the current study supports the notion that NT partners experience considerably lower levels of relationship satisfaction than individuals with ASD.

Hypothesis 2. Perceptions of Positive Communication among ASD and NT groups

It was predicted that positive patterns of communication would be perceived less often by NT participants than respondents with ASD. This hypothesis was supported, indicating that in general, NT participants perceived interactions in their relationship to be less positive than respondents with ASD. This finding accords with those of Wilson et al's (2014) qualitative analysis, whereby miscommunication, monopolizing, and avoidance strategies were identified by NT partners as key features of interactions with their partner with ASD. Further, consistent with previous research, those with ASD had some awareness of their difficulties with communication (Wilson et al., 2015).

This study extends the findings of previous research by revealing an appreciation among the ASD population of the potential effects of poor communication on relationships. In addition, this study identified adaptive strategies employed by both partners to improve communication. Examples of such strategies include avoiding potential sensory distractors (e.g., light, sound, and eye gaze) by discussing important issues in bed at night, using visual aids (e.g., pictures and text) to explain concepts, and cognitive strategies to ensure that verbal affection was expressed (e.g., planned self-reminders), as well as direct questioning regarding the NT partner's affectional needs (e.g., *"I ask her if she would like a hug."* Thomas).

Employing adaptive strategies improved interactions in ASD-NT relationships, however, the use of such methods altered the communication style of the NT partners. This modified style required NT partners to “*remove their own personality from the exchanges,*” becoming, as one participant noted, “*more brutal*”. In addition, adopting such strategies led some NT partners to view themselves as “*caregivers*” rather than intimate partners.

Indeed a theme of *disconnection* emerged as a likely underlying factor that could explain the quantitative findings regarding communication patterns. Disconnection was described in terms of a sense of isolation and loneliness that NT participants ascribed to the absence of verbal and physical affection, lack of practical support, and unmet emotional needs within the relationship. Given that ASD-NT intimate relationships feature communication difficulties and profound affectional deprivation, it is not surprising that NT participants report low positive interaction patterns within their intimate partnerships.

Hypothesis 3 and 4. Caregiver Burden among NT respondents

Caregiver burden was expected to be high among NT respondents, and was hypothesized to negatively relate to relationship satisfaction. This hypothesis was strongly supported, with caregiver burden among the NT population being comparatively high and strongly negatively related to relationship satisfaction. Drawing on the findings of other caregiver research based on the same measure of burden (The Role Captivity Measure; Pearlin et al., 1990). The level of caregiver burden among NT partners was found to be higher than those reported by carers of the elderly and dementia patients (Lyons, Zarit, & Townsend, 2000; Morano & Sanders, 2006; Noonan & Tennstedt, 1997). Overall, when compared with other carers, levels of caregiver burden among NT partners appears to be very high.

The results of the current study accord with previous research on burden among carers of children, adolescents, and young adults with ASD (Bouma & Schweitzer, 1999; Cadman et al., 2012) it is however, the first to examine caregiver burden in NT partners. Parent-child and intimate-partner relationships undoubtedly differ, primarily as one would expect to care for one's children but would be unlikely to enter an intimate relationship expecting to be a caregiver rather than equal partner. However, in this sample many NT partners found that they had taken on this role in their intimate relationship- indeed some reported feeling more like parents- and so similarities can be drawn between the burden experienced by parent *and* partner caregivers.

It can be speculated as to why caregiver burden was so high in comparison to the other caregiving populations. For example, 100% of the caregiver population in the current study were partnered with the care recipient, compared to only 17.6% in Noonan, & Tennstedt's study (1997). Levels of caregiver burden may vary according to the carer's relationship to the care recipient. That is, those who are partnered with the care recipient may experience greater levels of burden that are directly related to caregiving within an intimate relationship. Greif may also exacerbate the effect. Participants reported grief reactions to the incongruence between the partnership they had hoped for and the relationship, defined by ASD symptoms that they actually experienced. This grief and loss may add to caregiver burden. In addition, some of the NT partners expressed profound sorrow for the onerous struggle their partner faced daily and this may also have added an emotional burden.

Gender ratios may also contribute to the high levels of caregiver burden reported by NT partners. Previous research suggests that caregiver burden is higher among females than males (Barusch & Spaid, 1989). The comparative studies note an aggregate ratio of 23.7% male to 76.3% female, compared to 2% male and 98% female in the current study (Lyons, Zarit, &

Townsend, 2000; Morano & Sanders, 2006; Noonan, & Tennstedt, 1997). Therefore, gender bias may explain the high levels of burden reported among this population. However, Barusch and Spaid (1989) attribute increased burden among females to negative interactions with others regarding caregiving responsibilities (e.g., blame and criticism). This effect is also evident in the qualitative data in the current study. Many of the NT respondents reported having negative interactions with family and friends regarding the legitimacy of their caregiving role. Further, criticism and blame featured in interactions with professionals that they had sought help from (e.g., psychologists, psychiatrists, and counsellors). These negative reactions from social support networks appears to elicit negative affective responses (e.g., hopelessness, anger, and loneliness), thus contributing to the burden experienced by NT partners, and eroding relationship satisfaction.

Cohabiting with the care recipient may also affect levels of caregiver burden (Rodakowski, Skidmore, Rogers, & Schulz, 2013). All of the NT participants lived with their partner, compared to 58% of respondents in Morano and Sander's (2005) study and 53% in Noonan and Tennstedt's (1997) research. Therefore, cohabiting with the care recipient may introduce other variables that increase caregiver burden and decrease relationship satisfaction. For example, the physical and emotional cost of caregiving to the NT partner in addition to the scope of caregiving (e.g., social scaffolding, prompting, and managing family life) may all contribute to burden. Some respondents reported suffering from psychological (e.g., depression, anxiety, or stress) and/or physical ill-health (e.g., chronic fatigue, rheumatoid arthritis), as well as feeling exhausted and overwhelmed by the scale and relentlessness of their caregiving responsibilities.

In sum, the current study identified significant negative affective outcomes attributed to the role of caregiving, which may increase burden and reduce relationship satisfaction within ASD-NT intimate relationships for NT partners.

Hypothesis 5: Moderating effect of Social Support

Social support was expected to moderate the relationship between caregiver burden and relationship satisfaction among NT participants. This hypothesis had limited support with data showing the expected pattern but failing to reach significance, likely due to low power and participant numbers. Strong effect sizes suggest that such an effect was likely occurring but did not reach significance, thus suggesting a type 2 error (i.e., a failure to find a true effect) occurred. However, social support was confirmed as a key variable in the qualitative analysis. Overall, it seems that relationship satisfaction was higher at low levels of caregiver burden for partners with more social support. However, as burden increased, relationship satisfaction declined noticeably for this group. Relationship satisfaction was also generally lower for partners who felt more socially isolated. Therefore, it is reasonable to suggest that the relationship satisfaction of NT partners with greater social support may be less impacted by caregiver burden.

The proposed moderating role of social support in the current study aligns with previous research among carers of individuals with ASD. For example, carers of individuals with traumatic brain injuries with high levels of social support had greater relationship satisfaction and lower perceived caregiver burden (Hanks, Rapport, & Vangel, 2007). Similarly, Stuart and McGrew (2009), found that carers with greater levels of social support had higher levels of relationship adjustment and lower caregiver burden. Further, *contextual* support (i.e., support from the ASD community) was related to lower levels of caregiver burden, but not relationship adjustment. The quantitative component of current study did not assess contextual support,

however, the qualitative analysis identified social support as a moderating theme, with contextual support an important sub-theme of social support.

In general, the qualitative data suggests that social support may be influential in maintaining both psychological and physical health among NT partners. A sense of belonging and validation were reported as important outcomes of contextual support. This personal connection to others in similar caregiving relationships appeared to validate the legitimacy of the difficulties associated with ASD relationships, as well as providing an environment where partners could reflect, laugh, and in some cases grieve together. This collegian atmosphere seemed all the more important for participants who had experienced dismissive or damaging responses from helping professionals.

For some individuals social support did not ameliorate the difficulties associated with ASD-NT intimate relationships. In particular, the emotional pain associated with core relational deficits (e.g., connection and intimacy) and the extent of caregiving responsibility could not be ameliorated by social support.

In sum, the quantitative data (although non-significant) suggests that social support may moderate the relationship between caregiver burden and relationship satisfaction. Further, the qualitative analysis identified social support in general, and contextual support specifically, as important variables in the relationship between caregiver burden and relationships satisfaction. However, further quantitative research is needed to clarify the role of social support in ASD-NT intimate relationships.

Limitations

Several limitations of the current study must be noted. Firstly, as previously mentioned, low statistical power may have increased the likelihood of failing to find the true moderating

effects of social support (i.e., Type I error). In addition, the sample size was quite small ($N = 72$), (particularly in regards to individuals with ASD, $n = 12$) with a gender bias toward females in the NT group and male in the ASD diagnostic group. However, the level of distress associated with male ASD-female NT relationships may be due to gender influences on ASD symptom expression. This gender influence on symptom expression may have resulted in disparate relational effects than those that might be observed in female ASD-male NT or same sex ASD-NT intimate partnerships. This possible gender influence on ASD symptom expression and the associated effects of caregiver burden on relationship satisfaction warrants further attention in future research.

Alternatively, high caregiver burden among the NT population may be due to the gender bias in the current study. Research suggests that female carers report greater levels of distress than male caregivers (Hagedoor, Buunk, Kuijer, Wobbles, & Sanderman, 2000; Perz, Ussher, Butow, & Wain, 2011). This gender based variance in carer distress has been attributed to differences in perceptions of the caregiving role. Males adopt a competency based approach to caregiving, which may increase perceptions of self-mastery, while females may view caregiving as an expression of internalised ideals of the “caring self” (Ussher & Perz, 2010, p. 617). This idealised concept is informed by gendered norms regarding the role of women as self-sacrificing caregivers. However, these unrealistic standards can result in self-recrimination and perceptions of failure, which may lead to greater caregiver distress. Therefore, the gender bias in the current study may represent a significant confound as the results may be indicative of female NT partners only. In order to eliminate gender as a potential confound, future research should assess caregiver burden in Male NT partners of individuals with ASD.

The sample represented individuals engaged in ASD-NT intimate relationships rather than ASD-NT dyads. Therefore, the disparate levels of relationship satisfaction reported in the current study may not be representative of ASD-NT relationships, rather, the results may be indicative of poor relationship quality in general. Future research should address this limitation by assessing relationship satisfaction among ASD-NT dyads.

Sample selection is another possible limitation of this study. Participants were recruited via support networks for individuals with ASD and ASD-NT intimate relationship support groups. Therefore, the findings reported are representative of distressed individuals and may not reflect the experience of all ASD-NT intimate relationships. Further, the use of cross-sectional self-report measures may have introduced common method variance into the data. Therefore, the relationship between variables may be due to measurement error associated with the respondent's cognitive biases (e.g., consistency motif, social desirability, and mood state), rather than a true relationship between variables. Nevertheless, the results regarding NT caregiver burden accord with research involving three different caregiving populations, suggesting that this population is indeed experiencing high levels of distress. Further, the finding of reduced relationship satisfaction among NT partners aligns with previous studies on ASD-NT intimate relationships (Lau & Peterson, 2011; Renty & Roeyers, 2007), as does the likely moderating role of social support (Stuart & McGrew, 2009). These concurrent findings suggest that the results of this study are valid and should be interpreted as such.

Directions for future research and clinical implications

The quantitative and qualitative findings of the current study reveal interesting areas for further research. Firstly, alternative methods of recruitment may increase the willingness of individuals to participate in ASD-NT intimate relationship research. For example, direct

recruitment through family support networks for parents of children with ASD may result in greater ASD diagnostic group participation. In addition, further quantitative research is needed to confirm the validity of the qualitative findings. These findings include the role of caregiver and the personal psychological and physiological effects of caregiving in the context of ASD-NT intimate relationships. Further, the effects of communicative, relational, and affective deprivation, as well as grief on relationship satisfaction should be examined further to confirm the results of this study. Similarly, the potential moderating role of social support should be examined in a larger sample and in particular, the role of specific *contextual* social support warrants further attention.

Clinical implications

The current study has implications for clinical practice. The qualitative findings regarding the extent of caregiving responsibilities and expressive support, in addition to the inadequate responses of helping professionals, indicate that more awareness of ASD-NT intimate relationships is needed among psychologists, psychiatrists, and counsellors. In particular, any interventions would benefit from educating both partners, particularly in regards to disparate communication styles and coping strategies aimed at reducing caregiver burden (e.g., respite opportunities, cognitive reframing, and promoting contextual support). In addition, key issues should be explored, including issues around caregiver burden, grief and loss, emotional burnout/stress, depression and relationship satisfaction. Given the levels of distress evident in the sample reported here, and the apparent loss of hope by some NT partners, exploring for signs of clinical depression and suicide may be important when assessing NT partners seeking clinical help. Therapy should also consider possible protective factors including levels of social support. In light of the current findings, exploring protective factors would be particularly crucial for NT

partners experiencing high levels of caregiving burden. It is clear that satisfying NT-ASD partnerships are possible, and so taking a positive and strengths-based approach may be particularly valuable.

Conclusions

This study examined relationship satisfaction and communication patterns among ASD-NT intimate relationships. Levels of relationship satisfaction and perceptions of positive interactions were found to be lower among NT partners in comparison to those reported by individuals with ASD. The factors that appear to contribute to these findings include significant caregiver burden, the psychological and physical cost of caregiving to the NT partner, grief associated with a variety of losses (including a loss of hope), as well as the affective and relational deprivation evident in ASD-NT intimate relationships. These findings have important clinical implications regarding specifically tailored educational programs for helping professionals and both partners engaged in ASD-NT intimate relationships. In addition, these results highlight the need for greater support and respite interventions for NT partners to reduce caregiver burden and assist these unique couplings to develop and maintain mutually satisfying intimate relationships.

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Appendix A

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(Research)

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18 March 2015

Dr Wayne Warburton
Department of Psychology
Faculty of Human Sciences
Macquarie University
NSW 2109

Dear Dr Warburton

Reference No: 5201500073

Title: *Intimate relationships where one partner has an Autism Spectrum Disorder*

Thank you for submitting the above application for ethical and scientific review. Your application was considered by the Macquarie University Human Research Ethics Committee (HREC (Human Sciences & Humanities)) at its meeting on 27 February 2015.

I am pleased to advise that ethical and scientific approval has been granted for this project to be conducted at:

- Macquarie University

This research meets the requirements set out in the *National Statement on Ethical Conduct in Human Research* (2007 – Updated March 2014) (the *National Statement*).

This letter constitutes ethical and scientific approval only.

Standard Conditions of Approval:

1. Continuing compliance with the requirements of the *National Statement*, which is available at the following website:

<http://www.nhmrc.gov.au/book/national-statement-ethical-conduct-human-research>

2. This approval is valid for five (5) years, subject to the submission of annual reports. Please submit your reports on the anniversary of the approval for this protocol.

3. All adverse events, including events which might affect the continued ethical and scientific acceptability of the project, must be reported to the HREC within 72 hours.

4. Proposed changes to the protocol must be submitted to the Committee for approval before implementation.

It is the responsibility of the Chief investigator to retain a copy of all documentation related to this project and to forward a copy of this approval letter to all personnel listed on the project.

Should you have any queries regarding your project, please contact the Ethics Secretariat on 9850 4194 or by email ethics.secretariat@mq.edu.au

The HREC (Human Sciences and Humanities) Terms of Reference and Standard Operating Procedures are available from the Research Office website at:

http://www.research.mq.edu.au/for/researchers/how_to_obtain_ethics_approval/human_research_ethics

The HREC (Human Sciences and Humanities) wishes you every success in your research.

Yours sincerely



Dr Karolyn White

Director, Research Ethics & Integrity,
Chair, Human Research Ethics Committee (Human Sciences and Humanities)

This HREC is constituted and operates in accordance with the National Health and Medical Research Council's (NHMRC) *National Statement on Ethical Conduct in Human Research* (2007) and the *CPMP/ICH Note for Guidance on Good Clinical Practice*.

Details of this approval are as follows:

Approval Date: 27 February 2015

The following documentation has been reviewed and approved by the HREC (Human Sciences & Humanities):

Documents reviewed	Version no.	Date
Macquarie University Ethics Application Form	2.3	July 2013
MQ Online Questionnaire Participant Information and Consent Form (PICF) entitled <i>ASD-non ASD intimate relationships</i>	1	12/02/2015
MQ Participant Information and Consent Form-phone interview (PICF) entitled <i>ASD-non ASD intimate relationships</i>	1	12/02/2015
Online questionnaire: ASD participants and non-ASD participants		
Phone interview questions: partner with ASD		
Phone interview questions: non-ASD partners		
Participant resource pack	1	13/02/2015
Advertisement	1	13/02/2015
Take home flyer		
List of support groups and psychologists to be approached to support the project		
Letter to support groups	1	12/02/2015
Letter to psychologists	1	12/02/2015

Appendix B



A study about the nature of intimate relationships between people with Aspergers and their partners

The study will investigate these unique relationships within a framework of '*difference*' rather than '*disability*'. Our aim is to better understand personal experiences of the diagnostic process (self-diagnosed or by a health professional), the positive aspects and challenges of ASD, and what, if any, are the strategies that have been helpful in such relationships. Other areas that we are interested in include attitudes toward caregiving, coping, and social support, as well as anxiety.

If you agree to participate you will be asked to complete an anonymous online questionnaire, which will take approximately 30 minutes. You may then opt to take part in a 30-45 minute recorded phone interview.

As a token of our appreciation for your time you will have an opportunity to enter a prize draw to win a set of five movie tickets valued at approximately \$100 for the online questionnaire and one of two \$100 Coles vouchers for the phone interview. The study is being conducted by Naomi Millar-Powell (naomi.millar-powell@students.mq.edu.au; 0425 284 355) to meet the requirements of Masters of Research under the supervision of Dr Wayne Warburton (wayne.warburton@mq.edu.au; 02 9850 8643) of the Department of Human Sciences (Psychology), and Dr Julie Peterson (reception@otherhalf.com.au; 02 9880760) The ethical aspects of this study have been approved by the Macquarie University Human Research Ethics Committee. Access our study at https://mqedu.qualtrics.com/SE/?SID=SV_aaY4dWPvalk9jM1

Appendix C

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Qualtrics Survey Software

About you

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Dr Wayne Warburton
Senior Lecturer

Online participant Information and Consent Form

ASD-NT intimate relationships

You are invited to participate in an online anonymous survey. The purpose of the study is to investigate the nature of intimate relationships between couples where one of the partners has an Autism Spectrum Disorder (Aspergers) and the other partner does not. We are interested in your attitudes toward caregiving, coping, social support, and anxiety.

The study is being conducted by Naomi Millar-Powell (naomi.millar-powell@students.mq.edu.au; 0425 284 355) to meet the requirements of Masters of Research under the supervision of Dr Wayne Warburton (wayne.warburton@mq.edu.au; 02 9850 8643) of the Department of Human Sciences (Psychology), and Dr Julie Peterson (reception@otherhalf.com.au; 02 9880760) an associate supervisor and clinical psychologist. If you decide to participate you will be asked to answer some questions about caregiving, coping, social support, and anxiety. At the end of the survey you will be invited to participate in a telephone interview about living with ASD. The interview is

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entirely optional and you should only submit your name and contact details if you wish to participate.

Any information or personal details gathered in the course of the study are confidential, except as required by law. No individual will be identified in any publication of the results as all of the participant's responses are de-identified. Only Dr Warburtonon, Dr Peterson, and Mrs Millar-Powell will have access to the data. A summary of the results of the data will be made available to you on the website where you accessed this study or on the notice board in the psychologist's office where you read the advertisement. Alternatively, you may contact Naomi Millar-Powell on the phone number or email address listed above and request a copy to be posted to your home.

As a token of our appreciation of your time you will have an opportunity to enter a prize draw to win a set of five movie tickets valued at approximately \$100, which will be drawn at the end of the study.

Participants are unlikely to find the questions distressing; however, should you become upset whilst completing the study you should let the researcher know immediately. If you become upset after leaving the study, you can contact Dr Warburton (a registered psychologist) during working hours, as well as the Macquarie University Campus Wellbeing counselling service (9850 7497), the Salvation Army Care Line (1300 36 36 22), or Lifeline (13 11 14).

Participation in this study is entirely voluntary: you are not obliged to participate and if you decide to participate, you are free to withdraw at any time without having to give a reason and without consequence. Should you have any questions regarding the study please feel free to contact Naomi Millar-Powell on 0425 284 355. Please find a downloadable copy of this information and consent form for your records below.

The ethical aspects of this study have been approved by the Macquarie University Human Research Ethics Committee. If you have any complaints or reservations about any ethical aspect of your participation in this research, you may contact the Committee through the Director, Research Ethics (telephone (02) 9850 7854; email ethics@mq.edu.au). Any complaint you make will be treated in confidence and investigated, and you will be informed of the outcome.

I have read and understand the information above and any questions I have asked have been answered to my satisfaction. I agree to participate in this research, knowing that I can withdraw from further participation in the research at any time without consequence. I have been given a copy of this form to keep.

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By clicking on the red arrow at the bottom of the page you are agreeing to the statement above and will provide your consent. If you chose not to complete the survey simply log off the webpage.

Do you consent to participate in this study?

[Online consent form](#)

Are you currently in an intimate relationship with someone who has had a diagnosis (either by self, partner or health professional) of Asperger Syndrome

Yes

No

Have you been diagnosed (either by self, partner or health professional) with Asperger Syndrome?

Yes

No

Are you over 18?

Yes

No

Are you able to complete a survey in English without difficulty?

Yes

No

Have you been in your current relationship for less than one year?

Yes

No

How many years have you been married/living in a defacto relationship?

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What is your gender?

Male

Female

What is your year of birth?

Are you living in the same house as your spouse/partner?

Yes

No

The diagnosis of Asperger Syndrome was made by:

A health professional (e.g., family Doctor or Psychologist?)

Self-diagnosed

Partner

When was the diagnosis made (year)?

Fear of Negative Evaluation Scale

Read each of the following statements carefully and indicate how characteristic it is of you:

	1 = Not at all characteristic of me	2 = Slightly characteristic of me	3 = Moderately characteristic of me	4 = Very characteristic of me	5 = Extremely characteristic of me
1. I worry about what other people will think of me even when I know it doesn't make any difference.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. I am unconcerned even if I know people are forming an unfavorable impression of my partner	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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3. I am frequently afraid of other people noticing my partners social shortcomings.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. I rarely worry about what kind of impression I am making on someone.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. I am afraid others will not approve of my partner	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. I am afraid that people will find fault with me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. Other people's opinions of my partner does not bother me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. When I am talking to someone, I worry about what they may be thinking about me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. I am usually worried about what kind of impression I make.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10. If I know someone is judging me, it has little effect on me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11. Sometimes I think I am too concerned with what other people think of me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12. I often worry that my partner will say or do the wrong things.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Read each of the following statements carefully and indicate how characteristic it is of you:

	1 = Not at all characteristic of me	2 = Slightly characteristic of me	3 = Moderately characteristic of me	4 = Very characteristic of me	5 = Extremely characteristic of me
1. I worry about what other people will think of me even when I know it doesn't make any difference.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. I am unconcerned					

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even if I know people are forming an unfavorable impression of me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. I am frequently afraid of other people noticing my shortcomings.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. I rarely worry about what kind of impression I am making on someone.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. I am afraid others will not approve of me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. I am afraid that people will find fault with me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. Other people's opinions of me do not bother me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. When I am talking to someone, I worry about what they may be thinking about me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. I am usually worried about what kind of impression I make.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10. If I know someone is judging me, it has little effect on me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11. Sometimes I think I am too concerned with what other people think of me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12. I often worry that I will say or do the wrong things.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Social Support

Let's turn now to the help and support you get from your family and friends. Thinking about your friends and family (other than your partner), please indicate the extent to which you agree or disagree with the following statements:

	1. Strongly disagree	2. Disagree	3. Agree	4. Strongly agree
1. There is really no one who understands what you are going through	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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2. The people close to you let you know that they care about you	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. You have a friend or relative in whose opinions you have confidence	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. You have someone who you feel you can trust	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. You have people around you who help you to keep your spirits up	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. There are people in your life who make you feel good about yourself	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. You have at least one friend or relative you can really confide in	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. You have at least one friend or relative you want to be with when you are feeling down or discouraged	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Role Captivity Measure

Here are some thoughts and feelings people sometimes have about themselves when they are in an intimate relationship with someone who has Asperger Syndrome.

How much does each statement describe your thoughts about your relationship?

	1. Not at all	2. Just a little	3. Somewhat	4. Very much
Wish you were free to lead a life of your own	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feel trapped by your partners behaviours	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Wish you could just run away	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Coping Humor Scale and UCLA Loneliness scale

Below you will find a list of seven statements. Please indicate the degree to which you agree or disagree with each statement:

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	1 = strongly disagree	2 = mildly disagree	3 = mildly agree	4 = strongly agree
1. I often lose my sense of humour when I'm having problems.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. I have often found that my problems have been greatly reduced when I tried to find something funny in them	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. I usually look for something comical to say when I am in tense situations.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. I have often felt that if I am in a situation where I have to either cry or laugh, it's better to laugh.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. I can usually find something to laugh or joke about even in trying situations.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. It has been my experience that humour is often a very effective way of coping with problems.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

The following statements describe how people sometimes feel. For each statement, please indicate how often you feel the way described:

How often do you feel?

	Never	Rarely	Sometimes	Always
1. That you are in tune with the people around you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. That you lack companionship?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. That there is no-one you can turn to?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. Alone?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. Part of a group of friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. That you have a lot in	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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common with the people around you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. That you are no longer close to anyone?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. That your interests and ideas are not shared by those around you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. Outgoing and friendly?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10. Close to people	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11. Left out?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12. That your relationships with others are not meaningful?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13. That no-one really knows you well?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14. Isolated from others?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
15. You can find companionship when you want it?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
16. That there are people who really understand you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
17. Shy?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
18. That people are around you but not with you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
19. That there are people you can talk to?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
20. That there are people you can turn to?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Communication Pattern Questionnaire-Short Version

Below are a list of four statements. Please indicate how likely is it that when issues arise:

	1. Very Unlikely	-	3. Unlikely	-	5. Somewhat unlikely	-	7. somewhat likely	-	9. Very likely
1. Both partners avoid discussing the problem.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. Both partners try to discuss the problem.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. Female tries to									

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start a discussion while male tries to avoid a discussion.

☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐

4. Male tries to start a discussion while female tries to avoid a discussion.

☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐

Below are a list of seven statements. Please indicate how likely it is that during a discussion of issues or problems:

	1. Very Unlikely	-	3. Unlikely	-	5. Somewhat unlikely	-	7. Somewhat likely	-	9. Very likely
1. Both spouses express feelings to each other.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. Both spouses blame, accuse, or criticize each other.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. Both spouses suggest possible solutions and compromises.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. Female pressures, nags or demands while male withdraws, becomes silent, or refuses to discuss the matter further.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. Male pressures, nags, or demands while the female withdraws, becomes silent, or refuses to discuss the matter further.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. Female criticizes while the male defends himself.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. Male criticizes while the female defends herself.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Marital satisfaction

Below you will find a list of statements. Please indicate the degree to which you agree or disagree with each statement:

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	1. Strongly disagree	2. Moderately disagree	3. Neither agree nor disagree	4. Moderately agree	5. Strongly agree
1. My partner and I understand each other perfectly.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. I am not pleased with the personality characteristics and habits of my partner.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. I am very happy with how we handle role responsibilities in our relationship.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. My partner completely understands and sympathizes with my every mood.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. I am not happy about our communication and feel my partner does not understand me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. Our relationship is a perfect success.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. I am very happy about how we make decisions and resolve conflicts.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. I am unhappy about our financial position and the way we make financial decisions.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. I have some needs that are not being met by my relationship.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10. I am very happy with how we manage our leisure activities and the time we spend together.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11. I am very pleased about how we express affection and relate sexually.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12. I am not satisfied with the way we each handle our responsibilities as parents.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13. I have never regretted my relationship with my	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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partner, not even for a moment.

14. I am dissatisfied about our relationship with my parents, in-laws, and/or friends.

☐☐☐☐☐

15. I feel very good about how we each practice our religious beliefs and values.

☐☐☐☐☐

Block 8

If you found any of these questions distressing please do talk to someone about it. You may ring Mrs Millar-Powell, a trained counsellor on 0425 284 355, or Dr Wayne Warburton on 9850 8643 to talk over any issues you may have. Dr Warburton can also be contacted for referral options (e.g., further counselling and support) should you wish to follow up on any of the issues raised for you while completing the questionnaire. Other options available are; Lifeline on: 13 11 14 (24hrs); or Salvo Care Line on: 1300 36 36 22 (24hrs). There is also a 24 hour, National Sexual Assault, Family & Domestic Violence Counselling Line: 1800 RESPECT (1800 737 732); or MensLine Australia: 1300 78 99 78.

Participant resources

opt in space for details regarding phone interview

Would you like to enter the prize draw for a set of four movie tickets?

Yes

No

Please enter your name and telephone number below so we can contact you if you win the prize:

Name

Telephone Number

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Thank you for taking the time to complete our online questionnaire. We now invite you to participate in a 30-45 minute phone interview about ASD/non-ASD intimate relationships. The de-identified interview will be recoded for transcription purposes. The purpose of the study is to investigate the nature of intimate relationships between couples where one of the partners has an Autism Spectrum Disorder (Aspergers) and the other partner does not. We are interested in your personal experience of the diagnosis, the positive aspects and challenges of ASD, and what, if any, are the strategies that have been helpful in your relationship.

Would you like to participate in a 30-45 minute phone interview about ASD/non-ASD intimate relationships?

Yes

No

Thank you for agreeing to participate in an interview, by providing your contact details in the next question you will be providing your consent to participate. Please download a copy of the Participant Information and Consent Form for the telephone interview for your records: [Mq picf human feb 2013](#)

No file chosen

All interview participants will be entered in the draw for one of two \$100 Coles gift cards that will be drawn at the end of the study.

Please list below your first name, telephone number, and email address:

Name

Telephone Number

Email Address

We will need to call you to schedule a time for the interview. Please indicate below when would you prefer to be contacted:

	9 am to 3 pm	4 pm to 8 pm	Anytime
Weekday	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Weekend	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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Thank you for participating in our survey, your contribution is greatly appreciated.

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Appendix D



Department of Psychology
Faculty of Human Sciences
MACQUARIE UNIVERSITY NSW 2109
Phone: +61 +61 (02 9850 9898)

Fax: +61 (02 9850 8062)
Email: psy_off@ mq.edu.au

Dr Wayne Warburton
Senior Lecturer

Online questionnaire participant Information and Consent Form

ASD-non ASD intimate relationships

You are invited to participate in an online anonymous survey. The purpose of the study is to investigate the nature of intimate relationships between couples where one of the partners has an Autism Spectrum Disorder (Aspergers) and the other partner does not. We are interested in your attitudes toward caregiving, coping, social support, and anxiety.

The study is being conducted by Naomi Millar-Powell (naomi.millar-powell@students.mq.edu.au; 0425 284 355) to meet the requirements of Masters of Research under the supervision of Dr Wayne Warburton (wayne.warburton@mq.edu.au; 02 9850 8643) of the Department of Human Sciences (Psychology), and Dr Julie Peterson (reception@otherhalf.com.au; 02 9880760) an associate supervisor and clinical psychologist. If you decide to participate you will be asked to answer some questions about caregiving, coping, social support, and anxiety. At the end of the survey you will be invited to participate in a telephone interview about living with ASD. The interview is entirely optional and you should only submit your name and contact details if you wish to participate.

Any information or personal details gathered in the course of the study are confidential, except as required by law. No individual will be identified in any publication of the results as all of the participant's responses are de-identified. Only Dr Warburton, Dr Peterson, and Mrs Millar-Powell will have access to the data. A summary of the results of the data will be made available to you on the website where you accessed this study or on the notice board in the psychologist's office where you read the advertisement. Alternatively, you may contact Naomi Millar-Powell on the phone number or email address listed above and request a copy to be posted to your home.

As a token of our appreciation of your time you will have an opportunity to enter a prize draw to win a set of five movie tickets valued at approximately \$100, which will be drawn at the end of the study.

Participants are unlikely to find the questions distressing; however, should you become upset whilst completing the study you should let the researcher know immediately. If you become upset after leaving the study, you can contact Dr Warburton (a registered psychologist) during working hours, as well as the Macquarie University Campus Wellbeing counselling service (9850 7497), the Salvation Army Care Line (1300 36 36 22), or Lifeline (13 11 14).

Participation in this study is entirely voluntary: you are not obliged to participate and if you decide to participate, you are free to withdraw at any time without having to give a reason and without consequence. Should you have any questions regarding the study please feel free to contact Naomi Millar-Powell on 0425 284 355.

The ethical aspects of this study have been approved by the Macquarie University Human Research Ethics Committee. If you have any complaints or reservations about any ethical aspect of your participation in this research, you may contact the Committee through the Director, Research Ethics (telephone (02) 9850 7854; email ethics@mq.edu.au). Any complaint you make will be treated in confidence and investigated, and you will be informed of the outcome.

I have read and understand the information above and any questions I have asked have been answered to my satisfaction. I agree to participate in this research, knowing that I can withdraw from further participation in the research at any time without consequence. I have been given a copy of this form to keep.

PARTICIPANT'S COPY

Appendix E

Participant resource pack

1800 RESPECT (1800 737 732): 24 hour, National Sexual Assault, Family & Domestic Violence Counselling Line for any Australian who has experienced, or is at risk of, family and domestic violence and/or sexual assault.

To find contact details and links to more organisations refer to the Domestic Violence Resource Centre www.dvrcv.org.au

Relationships Australia

Phone: 1300 364 277 (cost of a local call)

Online counselling is also available at www.relationshiphelponline.com.au

Lifeline

Phone: 13 11 14 (statewide)

24 hour telephone counselling service

www.lifeline.org.au

Salvo care line

Phone: 1300 36 36 22

www.salvos.org.au

Support groups for partners of individuals with ASD

Aspia- Asperger partners support group, Sydney

Email: For all enquiries, please contact us by email -- info@aspia.org.au

Mobile: 0432 507 828

Queensland Asperger Partners' Support Group (QAPS), Brisbane

Asperger Partners' Support Group

Email: qaps.group@gmail.com

Mobile: 0418 761 652

Toowoomba Asperger Partners' Support (TAPS)

Contact: Sheena

Mobile: 0418 790 216

Email: the.taps.group@gmail.com

Northern Rivers (Tweed Heads) Partner Support

Contact: Debbie

Phone: (02) 6676 0483

Email: northernriversasdnetwork@gmail.com

Perth Partner Support

Contact: Roz

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Ph: (08) 9284 5252

Email: rozsdesk@inet.net.au

Melbourne Partner Support

Contact: Melissa

Web: www.aspartneraus.org

Email: admin@aspartneraus.org

Aspergers Victoria

Blackburn, Melbourne

Web: www.aspergersvic.org.au/partners

Support Groups for Adults with Asperger's Syndrome

Aspect's Adult Social Group

For adults with Asperger's or high-functioning autism

Contact: Caroline

Mobile: 0409 603 582

Email: adultsocialgroup@autismspectrum.org.au

More information: www.autismspectrum.org.au/adultsocialgroups

Sydney - North Shore

Asperger Adult Group

Contact: Jeroen Decates

Monthly Saturday afternoon sessions, attendance is only possible by contacting Jeroen beforehand.

Ph: 0402 028 588

Email: info@jdpsy.org

Sydney - West

Adults with Asperger's Group

Burwood

Contact: Eleanor Gittins

Ph: 0408 954 358

Email: janetgittins@hotmail.com

Melbourne - Werribee Asperger Support Group

Asperger Adults 18+

Phone: Catriona on 0438 596 662

Web: aspergers.silverviper.com

Individuals working with ASD-NT intimate relationships

New South Wales

Sydney

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ASD-NT INTIMATE RELATIONSHIPS

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JEROEN DECATES

Clinical Psychologist (Male)

3/3 Railway Avenue

Wahroonga

Web: www.jdpsy.org

Email: info@jdpsy.org

Ph: 0402 028 588

ELEANOR GITTINS

Registered Psychologist

Sutherland

Email: janetgittins@hotmail.com

Ph: 0408 954 358

STEVE DEN-KAAT

Clinical Psychologist

Diverse Minds Psychology Clinic

Erskineville NSW

Web: www.diverseminds.com.au

Ph: 02 9519 1519

Email: admin@diverseminds.com.au

CAROL GRIGG

Phone or Skype counselling for partners

OAM, Dip. Counselling, Member ACA Level 1, Grad Memb AIPC

After hours available

Ph: 0408 817 828

Web: www.carolgriggcounselling.com.au

LIZ PASH

Grief Counsellor

Epping (Sydney)

Liz is a Social Worker, Counsellor and Educator, with understanding of relationships affected by Asperger's Syndrome

Ph: 0498 964 275

Email: lizlpash@hotmail.com

Dr JULIE PETERSON

Clinical Psychologist

Embracing The Other Half Psychology Clinic

55 Grandview Street, Pymble

Web: www.otherhalf.com.au

Ph: (02) 9988 0760

Email: reception@otherhalf.com.au

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ASD-NT INTIMATE RELATIONSHIPS

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NOËL BOYCOTT

Registered Psychologist
Coolooli Centre,
137 Princes Highway, Milton NSW 2538
Email: nboycott@bigpond.com
Ph: 0402 058 899

GUDULA DORNSEIFER

Relationship Counsellor & Mediator, Goodwill Relations
Rozelle: (02) 9810 6808
City: (02) 9290 3621
Mobile: 0419 406 103
Email: gudula@goodwillrelations.com.au
Web: www.goodwillrelations.com.au

DEBRA ENDE

Clinical Psychologist
Suite 2, Level 1
2 Knox Lane
Double Bay NSW 2028
Ph: 0414 879 960

LIZ DORE

Counsellor and Educator
Relationships and Stuff
Web: www.relationshipsandprivatestuff.com
Email: lizdore@bigpond.com
Ph: 0416 122 634

Service includes relationships and sexuality counselling, social skills training, individual/group education for teenagers and adults.

RENEE FERRIS

Psychologist
Assist Psychology
Penrith: 0400 670 108
Blaxland Ph: (02) 4731 8111 & 0400 670 108
Web: www.assistpsychology.com.au
Email: assistpsychology@gmail.com

HARRY MAYR

Concord West and Penrith
Ph: (02) 4731 6516
Ph: 0412 316 656

Sydney Psychiatrist

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Dr CHRISTOPHER CANARIS
Ashfield
Ph: (02) 8922 9001

Queensland

Brisbane Psychologists

Prof. TONY ATTWOOD
Petrie
Web: www.tonyattwood.com.au
Ph: (07) 3285 7888

Dr MICHELLE GARNETT
Clinical Psychologist
Minds and Hearts, Specialist clinic for Autism and Asperger's Syndrome
West End, Brisbane
Ph: (07) 3844 9466
Email: info@mindsandhearts.net
Web: www.mindsandhearts.net

JENNIFER BOSTOCK-LING
Registered Psychologist MAPS
Humpybong Place
1/120 John Street
Redcliffe, Queensland 4020
Ph: (07) 3883 1111
Mob: 0411 824 944

RACHAEL LEE HARRIS
Registered Psychotherapist ARCAP
25 Bantry Ave, Burpengary Qld 4505
Mob: 0449 504 738
Email: rlharrispsy@gmail.com
Web: rlharrispsy.com
Skype sessions available for interstate clients. Rachael specialises in all aspects of ASC,
including Relationship Counselling, Anger/Anxiety Management, Meditation for Emotional
Resilience and Asperger Women's Retreats.

Toowoomba

IAN COLLETT
Psychologist
Ian Collett Psychology Services
114 Russell Street

CAREGIVER BURDEN AND RELATIONSHIP SATISFACTION IN
ASD-NT INTIMATE RELATIONSHIPS

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Toowoomba
Ph: (07) 4638 9526

Victoria

Melbourne Psychologists

GAYLE VERMONT
Psychologist
Ph: 0412 113 105

DR JANINE MANJIVIONA
Clinical Psychologist
Ph: (03) 9891 6835

LIZ PLAIL
Psychologist
Cardinia Medical Centre
180 Princes Highway
Pakenham VIC 3810
Ph: 0409 029 496

SHARYN GROCH
Psychologist
Level 1, 173 Burke Rd
Glen Iris VIC 3146
Ph: (03) 9500 9968

KEVIN O'NEILL
Psychologist
The Social Learning Studio
1/530 Mt Alexander Road
Ascot Vale VIC 3036
Ph: (03) 9326 1980
Mob: 0438 514 237
Email: kevinaoneill@optusnet.com.au
Web: www.sociallearningstudio.com

Western Australia

Perth

ROZ MACNISH
Relationships Therapist

Email: rozsdsk@iinet.net.au
Phone: (08) 9284 5252

Books

Book Suppliers

FOOTPRINT BOOKS are a Sydney-based book distributor, representing leading global publishers and offering a comprehensive range of titles related to Asperger's Syndrome and Autism. Register and receive updates on new and upcoming releases at www.footprint.com.au.



Phone: (02) 9997 3973
Email: info@footprint.com.au

RESOURCES AT HAND

Web: www.resourcesathand.com.au
Ph: (07) 3880 0862

BOOK-IN-HAND offer a comprehensive range of books on Asperger's Syndrome and Autism.
Web: www.bookinhand.com.au
Phone: 1800 505 221
Mobile users please call: (07) 3885 8525

Other Recommended Books

1. *The Complete Guide to Asperger's Syndrome* by Tony Attwood
2. *Asperger's Syndrome, a Guide for Parents & Professionals* by Tony Attwood
3. *The Asperger Couple's Workbook: Practical Advice and Activities for Couples and Counsellors* by Maxine Aston
4. *Counselling for Asperger Couples* by Barrie Thompson
5. *22 Things a Woman must know if she loves a man with Asperger's Syndrome* by Rudy Simone
6. *Solutions for Adults with Asperger's Syndrome: Maximizing the Benefits, Minimizing the Drawbacks to Achieve Success* by Juanita Lovett
7. *Asperger's Syndrome from the Inside Out: A supportive and practical guide for anyone with Asperger's Syndrome* by Michael John Carley
8. *Making Sense of Sex: A Forthright Guide to puberty, sex and relationships for people with Asperger's Syndrome* by Sarah Attwood
9. *Asperger's Syndrome and Sexuality from Adolescence through Adulthood* by Isabelle Henault

10. *Aspergers in Love* by Maxine Aston, Jessica Kingsley Publishers (JKP)
11. *Asperger Employment Workbook* by Roger N Meyer, JKP
12. *The Other Half of Asperger Syndrome* by Maxine Aston
13. *Asperger's Syndrome and Adults ... Is Anyone Listening? Essays and Poems by Partners, Parents and Family Members of Adults with Asperger's Syndrome* by Karen E Rodman, JKP
14. *Asperger Syndrome & Long-Term Relationships* by Ashley Stanford, JKP
15. *An Asperger Marriage* by Gisela & Christopher Slater-Walker, JKP
16. *The Essential Difference* by Simon Baron-Cohen, Penguin Books
17. *Asperger Syndrome in the Family: Redefining Normal* by Liane Holliday Willey, JKP
18. *Living and Loving with Asperger Syndrome: Family Viewpoints* by Patrick, Estelle & Jared McCabe
19. *Build your own Life: A Self-Help Guide for Individuals with Asperger's Syndrome* by Wendy Lawson, JKP
20. *Beyond the Wall: Personal Experiences with Autism and Asperger Syndrome* by Stephen Shore
21. *Discovering my Autism* by Edgar Schneider
22. *Living the Good Life with Autism* by Edgar Schneider
23. *Through the Eyes of Aliens: A book about Autistic People* by Jasmine Lee O'Neill
24. *My Life with Aspergers* by Australian author Megan Hammond, New Holland Publishers
25. *Confessions of an Unashamed Asperger* by Australian author Ron Hedgcock, currently available as an ebook
26. *Life with a Partner or Spouse with Asperger Syndrome: Going over the Edge?* Practical steps to saving you and your relationship, by Kathy J Marshack, Autism Asperger Publishing Company
27. *The Aardvark's Wife* An intimate view into the life and challenges of an Asperger Marriage, by Carolyn Woods, Woods Media.
28. *Look me in the eye* by John Elder Robison www.johnrobison.com
29. *Be different: Adventures of a free-range Aspergian with practical advice for Aspergians, misfits, families & teachers* by John Elder Robison www.johnrobison.com
30. *Connecting with your Asperger partner: Negotiating the maze of intimacy* by Louise Weston, JKP Publishers
31. *The Partner's Guide to Asperger Syndrome* by Susan J. Moreno, Marci Wheeler and Kealah Parkinson. Foreword by Tony Attwood. Jessica Kingsley Publishers
32. *What Men with Asperger Syndrome want to know about Women, Dating and Relationships* by Maxine Aston
33. *Troubleshooting Relationships on the Autism Spectrum: A user's guide to resolving relationship problems* by Ashley Stanford
34. *Out of Mind - Out of Sight: Parenting with a Partner with Asperger Syndrome* by Kathy Marshack

Appendix E

**Preamble and Questions for semi-structured phone interviews ASD-NT intimate
relationships**

Questions for participants for NT partners

Hi xxx, thank you for taking the time to participate in this research project. Before we begin, I need to remind you that this interview is being recorded. Also, you can end the interview at any time without consequence. Similarly, if you are uncomfortable answering any question please feel free to ask me to move on to the next question.

Is there anything you would like me to clarify before we begin?

1. Do you have any children from this relationship? Age(s)?
2. (Yes) Do they live at home? Have any of your children been diagnosed with Autism Spectrum Disorder?
3. What circumstances led to your partner being diagnosed with Aspergers?
4. What emotions did you experience after your partners diagnosis?
5. Do you remember any particular thoughts after the diagnosis?
6. Has the diagnosis changed your thoughts or feelings about your partner? (e.g., your expectations of your partner)
7. Often we focus on Aspergers as a disability; however, some people feel that this is an inappropriate label. What are your thoughts on this?
8. Can you bring to mind any of the positive aspects of having a partner with Aspergers?
9. What are some of the negative aspects of having a partner with Aspergers?
10. Do you or partner have strategies for dealing with social situations or relational needs, for example, purposively taking breaks when eating to engage in small talk, or scheduling daily connecting time? If so, has it been beneficial for your relationship?
11. Does your partner have a special interest?
12. How do you feel about their special interest?

Questions for participants with ASD

Hi xxx, thank you for taking the time to participate in this research project. Before we begin, I need to remind you that this interview is being recorded. Also, you can end the interview at any time without consequence. Similarly, if you are uncomfortable answering any question please feel free to ask me to move on to the next question.

Is there anything you would like me to clarify before we begin?

1. I'd like to begin with some questions about your health. Do you have any chronic conditions?
2. I notice in your responses you have xx children, do they live at home? Have any of your children been diagnosed with Autism Spectrum Disorder?
3. What circumstances led to you being diagnosed with Aspergers?
4. Do you remember any particular thoughts after the diagnosis?
5. Has the diagnosis changed your thoughts or feelings about yourself?
6. Often we focus on Aspergers as a disability; however, some people feel that this is an inappropriate label. What are your thoughts on this?
7. Can you bring to mind any of the positive aspects of having Aspergers?
8. What are some of the negative aspects of having Aspergers?
9. Do you have any strategies for dealing with social situations or relational needs, for example, purposively taking breaks when eating to engage in small talk, or scheduling daily connecting time? If so, has it been beneficial for your relationship?
10. Do you have a special interest?
11. How does your partner feel about your special interest?

