

The Experience of Isolation and Loneliness in Young Adults with High-Functioning Autism.

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Abstract

ELIF ERIM MERKLER: The Experience of Isolation and Loneliness in Young Adults with High-Functioning Autism.

(Under the direction of Gary B. Mesibov, Ph.D.)

This study investigated the experience of isolation and loneliness in young adults with high-functioning autism. Thirty-seven high functioning autistic adults and 82 typically developing college freshmen were recruited through agencies serving individuals with autism and a local university. Participants completed measures assessing the presence of social relationships and feelings about those relationships, as well as overall mental health functioning. Results of the present study suggest that adults with high functioning autism are more isolated than their peers and that isolation from social networks and dyadic relationships leads to distress in this population. Interestingly, there were no group differences in the experience of distress associated with isolation. In addition, though adults with high functioning autism reported greater mental health difficulties than their peers, these difficulties were not directly associated with the experience of isolation. Limitations and clinical implications of the current study and directions for future work are discussed.

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Introduction

Generally, loneliness is defined as a mismatch between the need for social contact and existing social relationships (Perlman & Peplau, 1984). More specifically, two types of loneliness have been identified, social and emotional loneliness (Bukowski & Hoza, 1989; DiTomasso & Spinner, 1997; Furman & Robbins, 1985; Hoza, Bukowski, & Beery, 2000; Rubenstein & Shaver, 1982; Weiss, 1973; Weiss, 1984). Social loneliness refers to a negative state experienced as a result of group isolation, or the absence of a larger peer group or network of acquaintances, and emotional loneliness refers to a negative state experienced as a result of dyadic isolation, or the absence of specific dyadic or close interpersonal relationships. Research suggests that friendships, particularly close friendships, are important in reducing levels of both social and emotional loneliness and preventing feelings of anxiety and depression (DiTomasso & Spinner, 1997).

Given this definition of loneliness, individuals with autism are likely at risk for experiencing feelings of loneliness. Deficits inherent in the disorder impede the development and maintenance of friendships. The Diagnostic and Statistical Manual of Mental Disorders IV-Text Revision (2000) states as one of its criterion for autism a “failure to develop peer relationships appropriate to developmental level” (p.70). Many individuals with autism long to have friends (Wing, 1992). Thus, there appears to be a notable mismatch between their ability to make and maintain friendships and their desire to participate in some form of social relationship. In addition, high functioning individuals with autism are aware of their social deficits, leaving them vulnerable to depression (Capps et al., 1995; Wing 1992).

Previous research suggests that individuals with high functioning autism report that they are lonelier than their typically developing peers (Bauminger & Kasari, 2000; Merkler & Mesibov, 2002). However, findings also indicate that individuals with autism understand friendship and loneliness differently than their peers, calling into question the specific nature of what they are reporting when they say they are lonely. Specifically, because individuals with high functioning autism define and experience friendship differently from their peers, it is not clear whether reports of loneliness in this population refer simply to isolation without significant emotional impact (i.e., simply isolation) or to isolation with the experience of emotional distress (i.e., loneliness as it is experienced by the typical population).

The purpose of current study is to assess the experience of loneliness in the typical population, the limitations in autism that leave this population vulnerable to isolation, the ways in which these same limitations may affect the emotional response of individuals with high functioning autism to isolation, and the potential for mental health difficulties related to the experience of distress as a result of being isolated.

Defining Loneliness

What does it mean to be lonely? Perlman and Peplau (1984) describe loneliness broadly as an unpleasant experience resulting from a deficiency in the quantity or quality of one's network of social relationships. More specifically, they identify the mismatch between one's needs for social contact and one's existing social relationships as a potential contributor to feelings of loneliness. Weiss (1973, 1984), based on his observations, suggests that there are two different types of loneliness: one that stems from emotional isolation, characterized by the lack of close attachment found in dyadic relationships, and one that stems from social isolation, characterized by the lack of an accepting community. As he

describes them, both of these states of loneliness involve negative affect, the former a sense of emptiness, and the latter a feeling of exclusion.

Although originally based on interviews with and observations of two groups of adults (single parents and people who had recently moved to a new community), subsequent studies lend support to Weiss' theory. In their study, Rubenstein and Shaver (1982) attempted to examine loneliness in a more systematic way. To better understand the complex nature of the loneliness construct, they used factor analysis to investigate three different components of loneliness: feelings associated with loneliness, reasons for loneliness, and reactions to loneliness. Two of the factors that emerged regarding reasons for loneliness, *being unattached* and *alienation*, correspond to Weiss' emotional and social loneliness, respectively. Being unattached is the situation Weiss was studying when interviewing single parents, and alienation (e.g., feeling different, not fitting in, not being needed) is similar to the experience of those Weiss interviewed who had recently relocated.

Rubenstein and Shaver (1982) also identified four factors regarding feelings associated with loneliness: *desperation*, *depression*, *impatient boredom*, and *self-deprecation*. The authors argue that *desperation* and *impatient boredom* are conceptually similar to the feelings outlined by Weiss regarding emotional and social isolation. Weiss described the emotional state related to emotional isolation as the distress one might experience with the fear of abandonment. This description resembles items that load on Rubenstein's and Shaver's desperation factor (see below). Regarding social isolation, Weiss' description of this experience as a bored and restless feeling resembles Rubenstein's and Shaver's impatient boredom factor (see below). These similarities offer additional support for Weiss' observation that there are two main types of loneliness.

It is important to note that each of the factors identified by Rubenstein and Shaver (1982) involves some aspect of distress or negative affect. For example, *desperation* includes feeling panicked, helpless, afraid, and abandoned; *depression* includes feeling sad, empty, isolated, alienated and melancholy; *impatient boredom* includes feeling uneasy, angry, impatient, and bored; and *self-deprecation* includes feeling unattractive, stupid, ashamed, and insecure. Therefore, it would appear that, as it is experienced in the typical population, feeling lonely involves the presence of negative affect in conjunction with isolation.

The distinction between emotional and social loneliness is also found in literature investigating loneliness in children. Investigations into children's peer relationships have resulted in the identification of two different components, the larger peer group and individual dyadic relationships (Bukowski & Hoza, 1989; Furman & Robbins, 1985; Hoza, Bukowski, & Beery, 2000). Furman and Robbins indicate that a child's need for affection and intimacy are often met in close dyadic friendships and that needs for a sense of inclusion are met primarily through experiences within the peer group. In addition, they suggest that negative emotions are experienced when these needs go unmet.

In their study, Hoza, Bukowski, and Beery (2000) addressed the issue of whether deficits in group versus dyadic peer relationships are associated with different types of loneliness in children, emotional and social loneliness respectively. They developed a new self-report measure (Peer Network and Dyadic Loneliness Scale) designed to assess network (social) and dyadic (emotional) loneliness. Results from this study suggest that emotional and social loneliness are distinct, but related types of loneliness. The authors offer three findings in support of these assertions. First, factor analyses yielded a two-factor solution for

the PNDLS. Although several items had high loadings on both factors, all but one had its highest loading on the right factor. This finding seems to support the idea of two separate, but related loneliness constructs.

Second, Hoza et al. compared the PNDLS to a commonly used measure of loneliness in children, the Asher loneliness scale (Asher, Hymel, & Renshaw, 1984; Asher & Wheeler, 1985). The Asher loneliness measure assesses loneliness as a unidimensional construct, addressing “feelings of loneliness and social dissatisfaction” (p.1457). Children rate items on a 5-point likert rating scale. The items on the Asher et al. measure are diverse in nature assessing a range of experiences from loneliness (e.g., “I feel alone”) to self appraisals regarding social competence or peer status (e.g., “I’m good at working with other children” and “I am well-liked by the kids in my class”, respectively). In addition, items that make specific mention to friendship assess ease or difficulty of making friendships rather than characteristics such as closeness, level of caring, or emotional intimacy, which are closely related to Weiss’ original construct of emotional loneliness (Hoza et al., 2000). In comparing the two loneliness measures, Hoza et al. found that the Peer Network subscale of the PNDLS was more highly related to the Asher loneliness scale than the Peer Dyadic subscale. However, the Peer Dyadic scale also showed a moderate (but lower) correlation with the Asher loneliness scale.

Third, Hoza et al. also compared the PNDLS and the Asher loneliness scale to children’s sociometric ratings of peers. When two children nominated each other as best friends, this was considered mutual best friendship because both members of the dyad attributed similar levels of importance to the relationship. Social preference was assessed by averaging received liking scores (e.g., nominations of friendship), which appears to represent

connection with a larger peer network. Additional support for the different types of loneliness is evidenced by higher correlations of both the Peer Network scale and the Asher scale to social preference than to mutual best friendship, as well as a higher correlation of the Peer Dyadic subscale to mutual best friendship than social preference. Thus, taken together, these three findings offer additional support to Weiss' model of emotional and social loneliness and extend it to include the experiences of children.

In addition to identifying two main types of loneliness, the literature on loneliness in typically developing adults addresses the role of different types of interpersonal relationships in the experience of loneliness. In his work, Weiss identified six main social provisions that are met through relationships and necessary for well-being: attachment, social integration, reliable alliance, guidance, reassurance of worth, and opportunity for nurturance (Weiss, 1974). Because no relationship is able to meet all of these needs, a number of different relationships must be maintained. In their study, DiTomasso and Spinner (1997) examined the link between relationships that meet these social provisions and the experience of loneliness and mental health difficulties in college students. They examined what they labeled as 'emotional loneliness' and 'social loneliness', but defined these constructs differently. They refer to emotional loneliness with respect to family and romantic relationships and social loneliness with respect to peer relationships, including both groups of friends and dyadic friendships.

DiTomasso and Spinner's findings (1997) show that attachment played a critical role in the experience of emotional loneliness (loneliness reported with regard to family and romantic relationships). Specifically, lower levels of attachment were associated with higher

levels of emotional loneliness. In addition, they found that lower levels of social integration were associated with higher levels of social loneliness (related to peer relationships).

Two other findings from this study stand out as particularly important when considering potential differences between typically developing adults and those with a diagnosis of autism. First, those who received more guidance and attachment from others reported less social loneliness, independent of their degree of social integration. Therefore, it appears that, in the typical population, the level of adjustment to social isolation (absence of peers) varies based on the availability of closer dyadic relationships. An important implication stemming from this finding is that although emotional (related to family and romantic relationships) and social (related to peer relationships) loneliness are distinct types of loneliness that apply to separate domains of life, they are still related concepts (DiTomasso & Spinner). The second important finding relates to mental health functioning. DiTomasso and Spinner (1997) found that social loneliness was the best predictor of both depression and anxiety, as measured by the Symptom Checklist-90. This finding suggests that friendship (dyadic and peer network) has a particularly important value, and the inability to form stable and lasting social relationships may be a better predictor of loneliness and mental health problems than the absence of lasting family or romantic relationships.

In summary, the literature on loneliness distinguishes between dyadic relationships and group, or social network, relationships (Bukowski & Hoza, 1989; DiTomasso & Spinner, 1997; Furman & Robbins, 1985; Hoza, Bukowski, & Beery, 2000; Rubenstein & Shaver, 1982; Weiss, 1973; Weiss, 1984). Both types of loneliness involve two main components, isolation and negative affect. However, there is some question as to whether individuals with autism recognize or experience the negative affect component of loneliness (Bauminger &

Kasari, 2000; Merkler & Mesibov, 2002). Therefore, this project will distinguish between the two components of loneliness, isolation and negative affect, in two different contexts, dyads and social networks, to identify four aspects of loneliness. Dyadic and social network *isolation* refer to the absence of intimate dyadic relationships or social peer networks, respectively. Dyadic and social network *loneliness* occur when the absence of these relationships leads to the experience of distress, or negative affect. The goal of this study is to demonstrate that because of differences in understanding social relationships and difficulty in establishing interpersonal relationships, adults with autism experience isolation and loneliness differently than their typically developing peers.

Risk Factors for Autism

Are individuals with autism at risk for loneliness? Perlman and Peplau (1984) note that those who are different from their peers may have fewer opportunities to develop relationships and therefore may be more susceptible to feelings of loneliness. They cite, as an example, age and cultural differences; however, the same is likely to be true for individuals who have developmental disabilities. For individuals with autism, cognitive and social deficits interfere with their ability to make and maintain friendships (Bacon, Fein, Morris, Waterhouse, & Allen, 1998; Bauminger, Shulman, & Agam, 2003; Fullerton, Stratton, Coyne, & Gray, 1996; Hauck, Fein, Waterhouse, & Feinstein, 1995; Rieffe, Terwogt, & Stockmann, 2000; Sacks, 1994; Serra, Minderaa, van Geert, & Jackson, 1999; Sigman, Kasari, Kwon, & Yirmaya, 1992). These deficits also influence the autistic individual's experience and understanding of social situations, which makes it unclear whether they are at increased risk for experiencing loneliness (Bauminger & Kasari, 2000; Capps, Sigman, Yirmiya, 1995; Merkler & Mesibov, 2002). However, what is clear is that

these deficits leave them at risk for both social network and dyadic isolation. In social situations, they have difficulty monitoring other people's thoughts, desires, and beliefs, and the inability to do so interferes with their ability to respond to others in socially acceptable ways (Bauminger, Shulman, & Agam, 2003; Boucher, 1989; Bowler, 1992; Klinger & Dawson, 1996; Leekam, Baron-Cohen, Perrett, Maarten, & Brown, 1997; Ozonoff & Miller, 1995; Rieffe, Terwogt, & Stockmann, 2000; Serra, Minderaa, van Geert, & Jackson, 1999). This monitoring weakness, in turn, decreases peer acceptance and interferes with the development of friendship.

The difficulties outlined above leave adults with autism at risk for isolation not only because they set individuals with autism apart from the typically developing population, but also because they severely affect the ability to develop social relationships. Hoza et al. (2000) suggest that dyadic and social network loneliness, although distinct types of loneliness, are related concepts. In addition, findings from DiTomasso and Spinner (1997) suggest that meaningful peer relationships, whether dyads or social networks, are important in preventing both types of loneliness, as well as potential subsequent mental health difficulties. Unfortunately, it is in the area of peer relationships that individuals with autism struggle most. Therefore, as a group, individuals with autism appear to be at risk for experiencing both dyadic and social network isolation. Their vulnerability stems from an inability to make and maintain friendships, which results from cognitive and social difficulties associated with the diagnosis of autism. Discussed below are the social impairments found in autism that are likely to interfere with the development and maintenance of social relationships.

Initiation

People who have problems socializing are likely at risk for being lonely. These problems include difficulty initiating social interactions, such as introducing themselves and making arrangements to initiate social activity (Horowitz & Anderson, 1982). Initiation is difficult for individuals with autism in any context and especially in the context of social interactions. In autism, these difficulties begin interfering with the ability to make and maintain friendships in early childhood and continue to do so throughout the course of development. In a study of initiation, Hauck, Fein, Waterhouse, and Feinstein (1995) investigated initiation behavior in autistic children as compared to mentally retarded peers. Results from this study demonstrated that individuals with autism initiated interactions with peers one third as often as retarded children. Not only did the quantity of initiation toward peers differ, but the quality did as well. When initiating to peers, children with autism tended to give information and greet, whereas retarded children sought information and initiated play with their peers. The autistic child's tendency to engage in routinized interactions is evident in their manner of initiating peer interactions. They more often engage in interactions that are routinized and self-absorbed rather than those that are imitative or reciprocally interactive, whereas their mentally retarded peers are more likely to engage in the latter.

Although the sample size from this study was small, the results did indicate that frequency of social initiation was predicted by verbal ability. This finding is confirmed in a subsequent study by Bauminger, Shulman, and Agam (2003) in which high functioning children with autism were more socially involved than their lower functioning peers with autism. Whereas Hauck and her colleagues found that lower functioning children with autism

initiated at 1/3 the rate of mentally retarded peers, Bauminger and her colleagues found that high functioning children with autism initiated and responded to peers at half the rate of typically developing peers. Nevertheless, high functioning children with autism participated less in peer interactions than their typically developing peers. In addition, the quality of initiations by high functioning children with autism was different when compared to their peers. Children with autism had significant difficulty with combined and complex social behaviors (e.g., smile combined with eye contact, sharing, and social communication). They were more likely to engage in functional communications (e.g. communication with the intention of meeting a personal need) than the typical children, suggesting that such interactions may be easier for them than social engagement with peers. These results indicate that, although high functioning individuals with autism may initiate interactions with peers, their initiations are likely to be functional in nature and/or stilted, awkward, unusual and bizarre. Such limited and inept approaches are likely to make individuals with autism look odd and clumsy in social interaction and limit their ability to successfully initiate interactions with peers. Normally developing children may perceive their autistic peers as different and, as a result, evaluate them negatively (Raupp, 1985). Similarly, typically developing adults may evaluate peers with autism in a negative way based on awkward social interactions.

Social Rules

The deficits inherent in autism become most evident as they reach adolescence, making it increasingly difficult for individuals with autism to make and maintain friendships. Adolescence is the stage during which typically developing children develop skills in abstract thinking. Rules that govern behavior become increasingly subtle and complex (Fullerton et

al., 1996). Adolescents begin to use language that is more sophisticated, including sarcasm and cynicism. Individuals with autism have difficulty reading vocal and facial expressions, which might distinguish a serious from a sarcastic comment, and are likely to miss the subtle meanings of the more complex speech patterns that their peers now utilize (Fullerton et al.). They interpret what they hear literally, which is likely to result in teasing and rejection.

Individuals with autism also have difficulty interpreting subtle gestural cues, and they do not always respect their peers' personal space boundaries (American Psychiatric Association, 2000). Teenagers tend to hang out in groups and indicate receptivity to others' nonverbal cues. Autistic adolescents have difficulty reading nonverbal cues and may approach others too closely. They do not understand the new contexts of friendship. Early and middle childhood friendship involves doing things together; however, adolescent friendship involves standing or sitting around and "hanging out" (Fullerton et al., 1996). In addition, social rules are no longer completely consistent. For example, it may be acceptable to approach one kind of group, such as an organized club, but not another, such as a gang or a clique of friends. As a result of not understanding or being able to identify these subtle rule changes, individuals with autism may offend their peers by walking or standing too close or making an inappropriate initiation of interaction (Fullerton et al.).

Temple Grandin, a high functioning woman with autism, illustrates her difficulties developing friendships in the following passage:

I couldn't figure out what I was doing wrong. I had an odd lack of awareness that I was different. I thought the other kids were different. I could never figure out why I didn't fit in (Sacks, 1994, p.116).

She further explains that she seemed to be devoid of the implicit knowledge of social conventions that "every normal person" (p.116) acquires. Sacks describes her experience of

social interaction eloquently, “ Something was going on between the other kids, something swift, subtle, constantly changing – an exchange of meanings, a negotiation, a swiftness of understanding so remarkable that sometimes she wondered if they were all telepathic” (p.116). Even though, as an adult, she is presently aware these social signals exist, Grandin admits that she herself cannot perceive them, participate in them, or conceive of the complex states of mind behind them.

Joint Attention and Theory of Mind

In the literature on typical development, joint attention is thought to be a precursor to theory of mind abilities, or understanding other people, and communicative intent (Bates, 1979; Tomasello, 1995). Joint attention is defined as the use of nonverbal behaviors to share a focus of attention with another person (Klinger & Dawson, 1996). These behaviors include eye contact, gaze following and physical gestures, such as pointing. Whereas joint attention abilities allow an individual to share experiences with another person through non-verbal cues, theory of mind involves the ability to understand that others have beliefs, desires, and intentions different from one’s own (Klinger & Dawson, 1996). Therefore, an inability to understand non-verbal communications may suggest an inability to understand that different people have different thoughts and beliefs.

It has been strongly argued that children with autism have significant deficits in joint attention and theory of mind, leading to difficulty understanding the perspective of others (Baron-Cohen, 1995; Baron-Cohen, 1991; Baron-Cohen, Leslie, & Frith, 1985; Carrutehrs, 1996; Frith, 1989; Leslie, 1987; Mundy, Sigman, & Kasari, 1994; Perner, Frith, Leslie, & Leekam, 1989). However, there has been increasing support in the literature identifying high functioning individuals with autism as having appropriately developed joint attention and

theory of mind skills as evidenced by performance on structured laboratory tasks, but failing to apply these skills when in natural situations (Bauminger, Shulman, & Agam, 2003; Boucher, 1989; Bowler, 1992; Leekam, Baron-Cohen, Perrett, Maarten, & Brown, 1997; Ozonoff & Miller, 1995; Rieffe, Terwogt, & Stockmann, 2000; Serra, Minderaa, van Geert, & Jackson, 1999). For example, children with high functioning autism are as accurate as their typically developing peers at identifying the target of another person's gaze when asked; however, they are much less likely to spontaneously follow that person's gaze by looking in the same direction (Leekam et al.). In addition, children with high functioning autism appear as competent as their peers at identifying and inferring other people's emotional states and have the ability to understand social situations, but are much less likely to spontaneously apply this knowledge when describing or interacting with another person (Bauminger et al.; Rieffe et al.; Serra et al.)

Difficulty applying joint attention and theory of mind skills can have serious implications for the social competence of high functioning individuals with autism. High functioning individuals with autism struggle to read situational cues when engaged in conversation. They are not easily able to read nonverbal signals, or hints, provided by their partner. In addition, they have difficulty organizing their thoughts and expressing them verbally, which may lead them to respond to their conversational partner with irrelevant information or shift topics abruptly with no readily apparent transition (Tager-Flusberg & Anderson, 1991). In fact, frequently in conversation, people with autism talk incessantly about a specific area of interest and will remain unaware that their conversational partner is not interested in that same topic. They are not able to monitor others' level of interest (Fullerton et al., 1996). Due to these difficulties, it is not uncommon for an individual with

autism to perseverate on a special topic of interest without reading or noticing nonverbal cues that suggest boredom in their conversational partner, such as eye rolling, gaze shifting, or fidgeting. Focusing too much on one's self and one's own topics of interest may lead to an appearance of being self-centered, further inhibiting the individual with autism from connecting socially with peers.

These joint attention and theory of mind deficits become increasingly apparent as children reach adolescence and continue into adulthood. In adolescence, typically developing peers notice that the individual with autism is boring, longwinded, or weird. Peers are insecure about fitting into cliques and may ostracize those who are different because they feel vulnerable and do not want to be shunned themselves for being associated with someone who is different (Fullerton et al., 1996). Even as adults, individuals with autism likely find it difficult to interact with peers due to their difficulties with joint attention and theory of mind, thus, making it difficult for them to participate in social networks or maintain meaningful interpersonal relationships.

Emotional Understanding and Empathy

In their second year, typically developing children are able to identify simple emotions such as happiness or sadness (Harter & Whitesell, 1989; Seidner, Stipek, & Feshback 1988). Later in their preschool years, these children begin to develop an understanding of complex, socially based emotions such as pride, shame, and embarrassment. The development of more complex and socially based emotions requires the ability to understand intentions, responsibility, and social norms (Sigman & Capps, 1997; Bosacki & Moore, 2004). It is through comparison of one's own behavior with accepted social norms that one begins to experience and understand these complex emotional states.

On a more basic level, development of these emotions requires an understanding of self. The most frequently used method for assessing understanding of self involves showing children their reflection in the mirror and putting a spot on their nose. If the child makes an effort to rub the spot off, it is believed that he/she has an understanding of self. Whereas children with autism do recognize themselves in the mirror, they do not demonstrate the same self-conscious emotions as their typically developing peers (Dawson & McKissik, 1984; Ferrari & Matthews 1983; Spiker & Ricks, 1984). In addition, their cognitive and social deficits interfere with their ability to interpret and understand social norms. Therefore, children with autism are likely to have more difficulty understanding complex social emotions than simple emotional states.

It is believed that an understanding of self and complex social emotions is necessary for the development of empathy. Therefore, it seems that, because of their cognitive and social deficits, children with autism are less likely to demonstrate empathy than their typically developing peers. In fact, research has demonstrated this to be true (Sigman, Kasari, Kwon, & Yirmaya, 1992; Bacon, Fein, Morris, Waterhouse, & Allen, 1998). Sigman et al. investigated empathic responses of typically developing children, children with mental retardation, and children with autism in two laboratory situations. In one setting, parents feigned illness and, in the other, they pretended to hurt themselves while playing with a toy hammer and cried out in pain. Whereas typically developing children and those who were mentally retarded appeared upset at their parents' distress, made eye contact, and tried to offer comfort, children with autism generally appeared uninterested, rarely made eye contact, and continued to play without interruption.

In a similar study, Bacon et al. (1998) found that both high and low functioning children with autism demonstrated lower rates of social referencing when presented with an orienting stimulus (a loud animal-like sound) than mentally retarded, developmentally language-disordered, and normal control participants. Unlike normal control participants, children with autism did not look to the adult in the room to gauge their response to the orienting stimulus based on that adult's emotional state. Findings also indicated that autistic children were not likely to engage in prosocial behavior. When they did respond prosocially, it was not a spontaneous response but the result of a prompt. For example, an experimenter displayed concern about a lost pen that was placed where the child could see it, but not where it was obvious to the experimenter. The high functioning autistic children were not likely to respond until asked to help find the pen. Failure of autistic individuals to respond to the emotions of others, including distress, may lead peers to judge them harshly as self-absorbed or cold and indifferent (Travis & Sigman, 1998). Subsequently, individuals with autism are not likely to be accepted by their peers.

Loneliness and Autism

It is clear that the social and cognitive deficits inherent in autism interfere with their ability to relate to peers and establish meaningful friendships. Literature addressing the experience of loneliness in typically developing individuals identifies the loneliness experienced in the absence of peer relationships as the best predictor of increased levels of anxiety and depression (DiTomasso & Spinner, 1997). However, individuals with autism define friendship and understand complex social emotions, such as loneliness, differently than their peers. Therefore, it is not clear whether this connection, which holds for typically developing individuals, also holds for individuals with autism.

Capps, Sigman, and Yirmiya (1995) suggest that high functioning autistic individuals are aware of their deficits in social functioning and how those deficits isolate them. They found that highly intelligent autistic children's perceived social competence was lower than that of both typically developing and other autistic children. That is, higher functioning autistic children viewed themselves as less socially competent than both typically developing and other autistic children. The authors suggest that perhaps higher functioning autistic people are better able to read others' emotions and, therefore, acquire greater awareness of qualities that differentiate them from their typically developing peers. These individuals may understand others' appraisals of their limitations and may accurately see themselves and their own abilities.

In this study, parents of high functioning autistic children reported that their children showed more negative emotions than was reported by parents of comparison children. Parents of highly intelligent autistic children report that their children are better able to function in the social world than those who are more severely affected by the disorder. However, recall that these children do *not* perceive themselves as socially competent. It is possible that awareness of their deficits leads to behavior reported by parents as more socially adaptive, while at the same time it leads the children to focus on their limitations to a greater extent than the abilities reported by their parents. In addition, high functioning autistic children are likely to be included in regular education programs, which may increase the child's awareness of social limitations while it increases the parents' sense that their child is better socially adjusted. These children are also likely to engage in social interaction that, for the child, may highlight limitations whereas, for the parents, it may underscore greater social adjustment (Capps et al.).

Responses to some of the items of the perceived self-competence scale used in this study left the researchers concerned about low self esteem and distress in the group of high functioning autistic children (Capps et al., 1995). For example, individuals with high functioning autism were likely to endorse items such as, “some kids wish that more people liked them,” “some kids find it hard to make friends,” and “some kids are not very popular.” The scale does not measure self-esteem or depression, but the responses clearly indicate feelings of isolation and rejection. The increased capacity for emotional understanding that is evident in high functioning autistic individuals is likely to expand their frame of reference and result in social comparisons. This ability heightens the importance of social functioning on self-esteem, which may lead to feelings of isolation and depression in autistic individuals who recognize their deficits. High functioning individuals with autism are thus vulnerable to depression due to their recognition of poor performance in social situations (Wing, 1992).

Findings from studies investigating loneliness and friendship in children with high functioning autism provide support for Capps et al.’s observations that children with autism may be prone to experiences of isolation and rejection. Bauminger and Kasari (2000) and Merkler and Mesibov (2002) found that children with autism reported feeling lonelier (on measures of loneliness not designed to assess isolation and negative affect separately) than their typically developing peers. However, it is important to note that, in these studies, children with autism appeared to understand the concept of loneliness differently than their peers. Bauminger and Kasari found that children with autism defined loneliness predominantly on the dimension of being alone, whereas typically developing children were more likely to provide a complete definition of loneliness that included both absence of others and negative affect. Thus, children with autism predominantly defined loneliness as

isolation. Similarly, Merkler and Mesibov found that children with high functioning autism were less likely to understand that a person could feel lonely when around other people (e.g., not isolated). These findings suggest that although individuals with autism report that they are lonelier (on conventional loneliness measures) than their typically developing peers, their experience of loneliness may be quite different. Whereas loneliness that is described and reported by typically developing individuals involves the experience of negative affect (Bauminger & Kasari; Merkler & Mesibov; Rubenstein & Shaver, 1982), when reported by individuals with autism this may not be true. It is not clear whether individuals with autism are reporting matter-of-factly that they are more isolated than their peers or whether they are reporting isolation that is accompanied by negative affect, otherwise known as loneliness. That is, individuals with autism may report that they are lonely because they are isolated, without experiencing the negative emotions commonly associated with loneliness such as helplessness, fear, sadness, alienation, and anger (Rubenstein & Shaver, 1982).

Also of note, Bauminger and Kasari and Merkler and Mesibov used the Asher loneliness scale (Asher, Hymel, & Renshaw, 1984; Asher & Wheeler, 1985), which does not reflect the two types of loneliness identified by the loneliness literature, dyadic and social network loneliness (Bukowski & Hoza, 1989; DiTomasso & Spinner, 1997; Furman & Robbins, 1985; Hoza, Bukowski, & Beery, 2000; Rubenstein & Shaver, 1982; Weiss, 1973; Weiss, 1984). In fact, the Asher scale appears to be more strongly related to social network loneliness than to dyadic loneliness (Hoza et al., 2000). Therefore it is not clear what kind of loneliness individuals with autism are reporting, dyadic loneliness or peer network loneliness. Given their significant social deficits, it is likely that individuals with autism are

isolated from both peer networks and more intimate dyadic relationships. What is less clear is how this isolation affects them emotionally.

Understanding perceptions of friendship in individuals with high functioning autism may provide greater insight into the type(s) of loneliness these children are most likely to experience. In their studies, Bauminger and Kasari and Merkler and Mesibov also found that children with high functioning autism less frequently identified affective dimensions of friendship as important than their typically developing peers did. Typically developing children identified characteristics such as emotional sharing (e.g., sharing secrets or private information), trust, and helping behaviors (e.g., a friend would help in a time of need) as important for friendship more frequently than did autistic children. In addition, Bauminger and Kasari found that parents of high functioning children with autism described friendships that were centered around games with little interaction and interactions that were rarely initiated by the autistic children. Given that they value different aspects of friendship than do their typically developing peers, the absence of those friendships may affect individuals with autism differently. Individual dyadic relationships are more likely to center around characteristics not strongly endorsed by individuals with high functioning autism such as intimacy, support, and trust; whereas, social network relationships are more likely to center around characteristics that are valued by individuals with high functioning autism, including less intimate interpersonal interactions and more focus on common activities. Therefore, if individuals with high functioning autism describe friendships that center around common interests and place less emphasis on intimacy, they may be more likely to experience distress in relation to isolation from a peer network than isolation from intimate dyadic relationships. Perhaps they are able to meet their social needs through casual acquaintances who share

similar interests, without forming more intimate interpersonal bonds. This would be consistent with reports of loneliness on the Asher scale, which more highly correlates with peer network loneliness.

In summary, individuals with high functioning autism are often in positions that leave them vulnerable to the experience of isolation and maybe loneliness, as well. Their deficits are likely to interfere with their ability to make and maintain friendships and they may compare their abilities to typically developing peers, leading to greater awareness of these deficits. In fact, children with high functioning autism have reported feeling lonelier than their typically developing peers. Nevertheless, research shows that these children define friendship and understand loneliness differently; therefore, their reports of loneliness may be more accurately described as isolation. Furthermore, it is not clear what type of loneliness or isolation is experienced by individuals with autism. Although their difficulties with social functioning suggest that they are more isolated than their peers with regard to both dyadic and peer network relationships, their conceptualization of friendship suggests that they may be more likely to experience negative affect in relation to the absence of a peer network than the absence of a close dyadic relationship.

Overview and Hypotheses

Loneliness is commonly described as a negative affective state experienced as a result of dyadic or social network isolation (Bukowski & Hoza, 1989; DiTomasso & Spinner, 1997; Furman & Robbins, 1985; Hoza, Bukowski, & Beery, 2000; Rubenstein & Shaver, 1982; Weiss, 1973; Weiss, 1984). Social network isolation is characterized by the absence of a larger peer group or network of acquaintances, and dyadic isolation is characterized by the absence of close interpersonal relationships. Deficits inherent in autism interfere with an

individual's ability to make and maintain friendships, leaving individuals with this disorder at risk for both social network and dyadic isolation. However, it is not clear whether the experience of isolation leads to a negative affective state in individuals with high functioning autism. Similarly it is not clear whether individuals with autism are more vulnerable to mental health difficulties as a result of negative affect experienced in conjunction with increased isolation, as would be true for their typically developing peers (DiTomasso & Spinner, 1997). Therefore, this study will address the experience of isolation and feelings of loneliness in individuals with high functioning autism. Findings from this study are expected to contribute to a better understanding of the experiences of adults with high functioning autism and to help guide service provision for this population. The aims of the study are as follows.

Aim 1: Measure Development

It is not clear whether increased reports of loneliness within the autism population refer to loneliness as it is experienced in the typical population, including both isolation and negative affect, or simply to increased rates of isolation, without any experience of negative affect. Therefore, the first aim of this study is to develop a measure that separately assesses the two main components of loneliness, isolation and negative affect. To investigate the feasibility and psychometric properties of this measure, the Isolation and Affect measure, three pilot studies will be conducted.

Pilot study 1 is designed to establish the feasibility of the newly developed Isolation and Affect measure by addressing the following questions: Are the measure's directions, practice items, and response format easily understood by adults with high functioning autism? Pilot study 2 is designed to examine the reliability (internal) and validity

(convergent, divergent, and construct) of the Isolation and Affect measure. Pilot study 3 involves two main goals. Data from this study will be used with that from pilot study 2 to examine reliability and validity of the Isolation and Affect measure. In addition, this study is designed to establish feasibility of the measure with respect to typically developing young adults (e.g. are the measure's directions, practice items, and response format appropriate for typically developing young adults).

Aim 2: Testing Hypotheses.

The second aim of this study is to use the Isolation and Affect measure in samples of high functioning autistic and typically developing individuals to test the following hypotheses.

Hypothesis 1: Individuals with autism will be more likely to report the experience of isolation, both with regard to dyadic relationships and social network membership, than their typically developing peers. This finding is expected because deficits in autism interfere with the ability to make and maintain friendships and social relationships, which are necessary in the prevention of isolation.

Hypothesis 2: Individuals with autism understand friendship differently than their typically developing peers and therefore may react to isolation differently. They place less value on intimacy in friendship (a characteristic that is often present in typical dyadic relationships) than typically developing peers, but appear to understand their differences through social comparison (often occurring in group settings), which is an awareness that has been identified as a risk factor for emotional distress in this population. Therefore, it is expected that individuals with high functioning autism will express greater distress resulting

from increased isolation from peer networks (or group membership) compared to distress resulting from isolation from dyadic friendships.

Hypothesis 3: Related to the previous hypothesis, I predict that individuals with autism will experience similar levels of distress as compared to their typically developing peers with regard to social network isolation. In contrast, they are likely to experience less distressed as compared to their peers with regard to dyadic isolation.

Hypothesis 4: Given the importance of dyadic friendships in the typically developing population, it is likely that for typically developing adults, levels of adjustment will vary based on the interaction between membership in a peer network and dyadic relationships. That is, the presence of a close dyadic relationship is likely to decrease the distress felt in response to the absence of a peer network. Similarly, membership in a peer network might lessen distress felt in response to the absence of a close dyadic peer relationship. However, this interaction may not hold for adults with autism because they may place less importance on close dyadic peer relationships. That is, they are less likely to be distressed by the absence of dyadic relationships and therefore, the presence of such relationships may not lessen the distress experienced in response to the absence of a peer network.

Hypothesis 5: In typical development, the understanding of complex emotions, which tend to be socially based (e.g. pride, shame, guilt, embarrassment), is accompanied by increased social understanding. Understanding these emotions requires an understanding of social norms. Therefore, individuals with autism, who demonstrate clear deficits in the understanding of social norms, may be less likely to understand or identify the experience of complex emotions. Loneliness is one of those emotions that can be described as a complex emotion with social underpinnings. Due to difficulties outlined above, adults with high

functioning autism are more likely to report distress as anger or sadness, rather than as loneliness. Thus, if previous predictions are accurate, individuals with high functioning autism are more likely to experience distress in relation to peer network isolation and are more likely to report that stress as anger or sadness than as loneliness. Furthermore, typically developing adults are likely to endorse higher rates of loneliness in response to both social network and dyadic isolation compared the adults with high functioning autism, who are more likely to report their distress as anger or sadness.

Hypothesis 6: This study will also investigate mental health functioning in individuals with high functioning autism. Typically developing adults are more likely to experience anxiety and depression as a result of isolation from peers (DiTomasso & Spinner, 1997). However, previous studies have not addressed the links between isolation, loneliness, and mental health in individuals with autism. Therefore, this study will investigate whether connections between isolation and mental health difficulties that exist for the typical population also exist for adults with high functioning autism. I predict that both adults with high functioning autism and their typically developing peers will experience increased levels of mental health difficulties with increased levels of social network isolation. Furthermore, it is expected that, for both groups, this relationship between isolation and mental health functioning will be mediated by the experience of distress. This same pattern of mediation is expected to hold true for typically developing adults with regard to dyadic isolation; however, I predict that the relationship between dyadic isolation and mental health functioning is less likely to exist in the autism population because adults with autism place less emphasis on the importance of intimate dyadic relationships.

Method

Participants

Pilot studies

Three pilot studies were run, two to assess the feasibility of the Isolation and Affect Measure and one to assess the reliability and validity of the measure. Participants for pilot study 1, designed to investigate feasibility of the Isolation and Affect measure regarding adults with high functioning autism, were 3 Caucasian adults with high functioning autism aged 27, 34, and 41. Adults with autism were recruited through an adult social group run at Division TEACCH. Though efforts were made to recruit minority participants, the race, ethnicity, and gender of the members of the group limited access to minorities in these areas.

Pilot studies 2 and 3 included 105 college freshmen from the University of North Carolina at Chapel Hill. Responses from these participants were used to investigate the reliability and validity of the Isolation and Affect Measure in pilot study 2. In addition, for pilot study 3, 5 of these participants completed feedback forms for the purpose of assessing the feasibility of the measure when used with college freshmen. Participants included 33 men (31%) and 72 women (69%) aged 17-19, with the exception of two participants who were 21 and 34 years old. Seventy-eight (74%) participants were Caucasian, 14 (13%) African American, 8 (8%) Hispanic, 2 (2%) American Indian, 8 (8%) Asian, and 1 (1%) Indian. Regarding parents' education levels, 78 participants had fathers who had completed a bachelor's degree or advanced degree and 79 had mothers who had completed a bachelor's degree or advanced degree.

College freshmen were chosen as a comparison group for two main reasons. First, the Isolation and Affect measure required validation on a group of typically developing individuals to determine that the measure assessed isolation and negative affect in the typical population before it was used to assess these dimensions in the autism population. Second, it was important to determine whether the Isolation and Affect measure discriminated between those who were isolated and those who were not, and college students have been identified by previous literature as an appropriate population for the study of loneliness in several different contexts (Diamante & Windholz, 1981; DiTomasso & Spinner, 1997; Hansson & Jones, 1981; Jackson, Fritch, Nagasaka, & Gunderson, 2002; Jackson, Soderlind, & Weiss, 2000; Medora & Woodward, 1986; Ponzetti, 1990; Wilbert & Rupert, 1986). In fact, Medora and Woodward identify late adolescent college students as the 6th most lonely group compared to other previously studied groups, including college freshmen, who rank as the 3rd most lonely group following low-income adolescent single mothers and alcoholics. For these reasons, college students were an appropriate group for examining the psychometric properties of the Isolation and Affect measure. In addition, because they are typically developing and vulnerable to the experience of isolation, this population was an appropriate comparison group for the subsequent study, which compared responses to isolation in members of the typically developing population and the high functioning autism population. A comparison group of learning disabled students was considered; however, because learning disabled students are likely to react similarly to isolation as typical college students and because IQ was controlled, the inclusion of a learning disabled group did not appear to contribute additional information to the study.

Full Study

Participants included 37 adults with high-functioning autism from across the state of North Carolina and 82 college freshmen at the University of North Carolina at Chapel Hill. Participants with autism were diagnosed by licensed psychologists unassociated with the current study and recruited through the Neurodevelopmental Disorders Research Center Subject Registry Core. They ranged in age from 18-52 ($M = 29.65$, $SD = 10.19$) and included 30 (81%) males and 7 (19%) females. College freshmen ranged in age from 17-19 ($M = 18$, $SD = 0.33$) and included 26 (32%) males and 56 (68%) females. Regarding ethnicity, participants with autism included 33 (89%) Caucasian, 1 (3%) African American, 1 (3%) Asian, and 2 (5%) Indian. College freshmen included 68 (83%) Caucasian, 8 (10%) African American, 3 (4%) Hispanic, and 4 (5%) Asian. Cognitive ability was assessed using the BETA III (Kellogg & Morton, 1999), described below. Participants with autism had IQ scores that ranged from 69-118 ($M = 93.13$, $SD = 12.59$) and college freshmen had scores that ranged from 84-139 ($M = 107.45$, $SD = 11.41$). Socioeconomic status was assessed using parents' degree of education. In participants with autism, 25 (71%) had fathers and 23 (64%) had mothers with a college degree or higher. Regarding college freshmen, 65 (79%) had fathers and 62 (76%) had mothers with a college degree or higher.

Measures

Pilot study 1 included only the Isolation and Affect measure. Pilot studies 2 and 3 included the Brief Symptom Inventory (BSI), a demographic questionnaire, the Isolation and Affect measure, the intimacy and companionship subscales of the Network Relationships Inventory (NRI), the Positive and Negative Affective Schedule (PANAS), and the Social and Emotional Loneliness Scale for Adults (SELSA). The full study included the Brief Symptom

Inventory, a demographic questionnaire, the Isolation and Affect measure, and the Beta III. Items from the Isolation and Affect Measure, NRI, PANAS, and SELSA are listed in the Appendix.

Brief Symptom Inventory

The Brief Symptom Inventory (BSI) (Derogatis, 1993) is a 53 item self-report measure of clinical symptomatology. It is composed of nine factors: somatization, obsessive compulsive, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid ideation, and psychoticism. The BSI has been found to show good internal consistency, with Alpha coefficients ranging from .71-.85 (Croog et al., 1986; Derogatis, 1993; Aroian & Patsdaughter, 1989), and test-retest reliability, with coefficients ranging from .68-.90 (Derogatis, 1993). The BSI also shows good convergent validity when compared to the MMPI, as well as construct, and predictive validity (Derogatis, 1993). For the purposes of this study, the BSI's Global Severity Index was used as a measure of overall mental health functioning.

Isolation and Affect Measure

Most scales designed to assess loneliness naturally do so by asking questions that address the two components of loneliness, isolation and negative affect, without distinguishing between the two. However, for the purposes of this study it was necessary to create a measure that assessed these components separately. In addition, it was necessary to evaluate these components of loneliness in the context of both the social peer network and more intimate dyadic relationships. The questions for the Isolation and Affect measure were based on the Peer Network and Dyadic Loneliness Scale (PNDLS) constructed by Hoza, Bukowski, and Beery (2000). The PNDLS is designed to measure both social network and

dyadic loneliness. Designed for children, it presents participants with pairs of sentences describing children who differ according to a specific characteristic of interest and asks them to choose which child is more like them.

Questions for the new measure were modified such that they were worded appropriately for adults. Participants were asked to answer each question on a 5-point Likert scale and then rate the intensity of five emotions (happiness, sadness, anger, anxiety and loneliness) on a scale of 1 (not at all) to 5 (most intense) based on their response to the question. The Isolation and Affect Measure includes a total of 4 subscales: dyadic isolation, dyadic distress, social network isolation and social network distress. Scores for each of the isolation subscales are calculated by averaging responses to the individual items that compose them. Scores for each of the distress subscales are calculated by summing individual emotion ratings for each item (with happiness reverse scored) and then averaging those responses across all items in each subscale.

Network Relationships Inventory (companionship and intimacy subscales)

The companionship and intimacy subscales of Furman and Buhrmester's Network Relationships Inventory (NRI) (1985) ask participants to rate each of six questions (3 companionship, 3 intimacy) with regard to eight specific people on a 5-point scale (1 = little/none, 5 = extremely much) how much time they spend with others and how much they confide in others. To prevent excessive length and repetitiveness among the different measures used in this study, participants were asked to rate levels of companionship and intimacy with regard to only 4 people (parents, sibling, friend, boy/girl friend). Only friend ratings were used in comparison with the Isolation and Affect measure. They were averaged within subscales (companionship and intimacy). Friend ratings are of particular importance

because the Isolation and Affect Measure is assessing affect in relation to the presence or absence of dyadic or social network friendships.

Buhrmester and Furman (1987) calculated internal consistency reliability coefficients (Cronbach's alpha) for each of these subscales. Coefficient alphas for the companionship and intimacy subscales were computed separately for each of the 16 scales and ranged from .77-.95 for the oldest children participating in their study (8th graders). They also examined intercorrelations among scales to examine interrelations between the companionship and intimacy scales. They found that for these measures, coefficients ranged from $r = .41$ to $r = .73$, all $p < .05$. These findings suggest that the different subscales were positively correlated but, given that the correlations were moderate in size, the scales appear to measure distinguishable constructs.

The Positive and Negative Affect Schedule

The Positive and Negative Affective Schedule (PANAS) is comprised of two 10-item mood scales that have been shown to be highly internally consistent, largely uncorrelated, and stable at appropriate levels over a 2-month period (Watson, Clark, & Tellegen, 1988). The scales can be administered with a variety of instructions, asking participants to rate their mood in different periods of time: at the moment, today, past few days, past few weeks, the past year, and in general. For the purposes of this study, the PANAS instructions asked participants to rate their general mood.

With the instruction to rate general mood, Watson et al. found internal consistency reliability (Cronbach's alpha) for positive affect (PA) was .88 and for negative affect (NA) was .87. The correlation between these two scales was low, at $-.17$. Alpha reliabilities remained relatively stable across college student, adult and psychiatric inpatient samples

(Watson et al.). Test-retest reliability was strongest for the PA and NA scales when instructions asked participants to rate mood over a longer period of time. Therefore, stability coefficients were highest for general ratings at .68 for PA and .71 for NA. Watson et al. argue that these coefficients of the general ratings are high enough to suggest that they may be used as a trait measure of affect.

To examine scale validity, Watson et al. subjected ratings from the original 60 mood descriptors to a principal factor analysis with squared multiple correlations. Two dominant factors emerged, together accounting for two-thirds of the common variance. These two factors were then rotated to orthogonal simple structure according to the varimax criterion. The authors then correlated the estimated factor scores with the PANAS PA and NA scales. For general ratings, the convergent correlation was .94 for PA and .93 for NA. Divergent correlations were low, at -.08 for PA and -.12 for NA. Regarding item validity, each of the 20 final items was chosen because it was a relatively pure factor marker (average loading of .40 or greater on relevant factor and secondary loading of not greater than | .25 |). Therefore, the two dimensions accounted for almost all of the common variance. All of the descriptors have strong primary loadings (.50 or above) on the appropriate factor and low secondary loadings.

The Social and Emotional Loneliness Scale for Adults

The Social and Emotional Loneliness Scale for Adults (SELSA) is a measure that assesses loneliness with regard to romantic relationships, family relationships, and social relationships (DiTomasso & Spinner, 1993). A principal components analysis with varimax rotation was conducted by the authors and yielded the three subscales listed above, which accounted for 52.4% of the variance. All three subscales demonstrated good internal

consistency, ranging from .89 to .93. To examine concurrent and discriminant validity of the SELSA subscales, DiTomasso and Spinner compared them to the UCLA Loneliness Scale (Russell, Peplau, & Cutrona, 1980). They found that the romantic scale of the SELSA was most highly correlated (.69) with the item from the UCLA Loneliness measure that assessed emotional (dyadic) loneliness, and was only weakly correlated with the item from the UCLA measure that assessed social (social network) loneliness (.14). Correlations for the social loneliness subscale of the SELSA had the reverse pattern, correlating more highly with the social loneliness item from the UCLA measure and only weakly with the emotional loneliness item from the UCLA measure.

DiTomasso and Spinner found that all of the SELSA subscales correlated significantly with the UCLA Loneliness measure, with the social subscale demonstrating the highest correlation (.79) and the family and romantic subscales showing more moderate correlations (.37 and .40, respectively). Further support was found when they compared the SELSA subscales to number of dates and current romantic involvement. Romantic loneliness was significantly correlated with number of dates (.46). That is, greater romantic loneliness was associated with lower dating frequency. In comparison, neither family loneliness nor social loneliness correlated significantly with number of dates. Similarly, romantic involvement was related to lower levels of romantic loneliness (.81), but was only weakly associated with family loneliness (.13) and social loneliness (.08).

The Beta III

The Beta III (Kellog & Morton, 1999) was used to screen the intellectual functioning of study participants. It allows for a quick estimate of participant's abilities in a group format, using minimal language. Its emphasis on nonverbal assessment is ideal for

participants with autism who may have difficulty processing language or expressing themselves verbally. Test-retest reliability was assessed using three different age groups: 16-24, 25-54, and 55-89. Coefficients for these groups ranged from .82-.90, but all increased to .90 and .91 after correcting for restriction of range. Analyses of validity included comparison to the WAIS-III, which yielded coefficients of .67 Verbal IQ, .80 for Performance IQ, and .77 for Full Scale IQ (Kellog & Morton).

Procedure

Pilot studies

Pilot study #1. Three adults with high functioning autism between the ages of 27 and 41 were recruited through an adult social group run by Division TEACCH. They were scheduled for an individual 60 minute appointment in a private room at the TEACCH clinic. After providing informed consent, each participant completed the Isolation and Affect measure and provided feedback regarding clarity of directions and format. Feedback from participants resulted in minor wording changes to the Isolation and Affect Measure.

Pilot Study #2. Ninety-five undergraduates were recruited through the UNC Chapel Hill Psychology Department's Participant Pool. Each testing session was comprised of groups including up to 25 participants. Participants received one PSYC10 credit hour for their participation.

Each session began with the PI or trained project staff providing information on the procedures for the study and its purpose. At that time, project staff asked students to space themselves out to ensure privacy of questionnaire responses. After providing informed consent and having an opportunity to ask questions, students completed a series of measures including a Demographic Questionnaire, the Social and Emotional Loneliness Scale for

Adults (SELSA), the Brief Symptom Inventory (BSI), the Positive and Negative Affective States (PANAS), the intimacy and companionship subscales of the Network Relationships Inventory (NRI), the Marlowe-Crowne Social Desirability Scale, and the Isolation and Affect measure.

Pilot study # 3. Five college freshmen were recruited through the UNC Psychology Department's Participant Pool. They were each scheduled for an individual 90 minute appointment. After providing informed consent, they completed the same battery of measures as listed for pilot study #2. All the procedures from pilot study #2 were followed. In addition, following completion of the measures, each of the 5 undergraduates answered questions and provided feedback about the clarity of directions and measure items.

Full study

Thirty seven participants with high functioning autism were recruited from across the state of North Carolina through Division TEACCH, using both the clinic's database and the Neurodevelopmental Disorders Research Center Subject Registry Core. Eighty two typically developing participants were recruited through the UNC Psychology Department's Participant Pool. Participants in the full study were scheduled for a 60-75 minute appointment. Most participants met in groups ranging from 2-20 people; however, due to scheduling difficulties, some participants with autism completed measures in an individually scheduled session. After providing informed consent and having an opportunity to ask questions, they completed the following set of measures: the Brief Symptom Inventory, a demographic questionnaire, the Isolation and Affect measure, and the Beta III. Undergraduate participants received course credit and debriefing as outlined by the Participant Pool guidelines.

Results

Power Analysis

In order to demonstrate that this study design had adequate power, a power analysis was run on the most complex Regression models within the hypotheses of interest. For between group analyses, this model consists of three predictors and an interaction term (gender, autism, isolation, and the interaction between autism and isolation). In order to detect a large to moderate effect size ($f^2 = 0.35, 0.15$; Cohen, 1988), with desired power of .80 at an alpha level of .05, a sample size of 64 (large) to 132 (moderate) is necessary. Thus, the total sample of 119 falls within this range to meet these power requirements. Analyses within groups also include one model with three predictors and an interaction term. For the typically developing group, the sample of 82 falls within the range designated above. However, for the autism group, the sample of 37 does not fall within this range. Therefore, analyses with three predictors and an interaction term for this group are exploratory in nature and only likely to detect a large effect size. Of the remaining within group analyses, the most complex involves three predictor variables (gender, social network isolation, and dyadic isolation). In order to detect a large effect size ($f^2 = 0.35$; Cohen, 1988) with desired power of .80 at an alpha level of .05, a sample size of 31 is necessary. Thus, the current individual group sample of 37 meets the minimum power requirements for all other within group analyses.

Regarding effect size, it was not possible to rely on literature to determine an appropriate effect size because there is no existing literature on the experience of isolation

and loneliness in adults with high functioning autism. Given the population of interest, it would be difficult to attain the number of participants necessary to detect small to moderate effect sizes. Many studies in this field have sample sizes that range from 10 to 22 participants (Bauminger, Shulman, & Agam 2003; Bauminger, Shulman, & Agam 2004; Downs & Smith, 2004; Rieffe, Terwogt, & Stockmann, 2000; Travis, Sigman, & Ruskin, 2001). Furthermore, because the deficits inherent in high functioning autism are pervasive and severe, it is reasonable to expect a larger effect size.

Measure development

To assess the Isolation and Affect measure's internal reliability, confirmatory factor analysis was used to look at within scale dimensionality. When conducting confirmatory factor analysis, the scale of the latent variables must be set by setting one of the factor loadings to 1. The two scale dimensions of interest, both within dyadic peer relationships and social network relationships, were isolation and distress.

The findings of confirmatory factor models for social network and dyadic isolation can be found in Figures 1 and 2, respectively. The model level for these subscales is a poor fit, suggesting that there may be other items that reflect social network and dyadic isolation; however, the equation levels show a good fit with R^2 ranging from .648 to .937 for social network isolation and from .729 to .959 for dyadic isolation. Additionally, all factor loadings for both subscales are statistically significant at the .05 level. Each item included in the subscales reflects participants' underlying social network and dyadic isolation. Further evidence that the items in each subscale jointly represent social network and dyadic isolation is found in the subscale's Cronbach's alpha values of .969 and .973, respectively. The

internal consistency reliability of these measures is very high. Therefore, they were used in this form for the full study.

The findings of confirmatory factor models for social network and dyadic distress can be found in Figures 3 and 4, respectively. As seen with the isolation subscales, the model level is a poor fit, suggesting that there may be other items that reflect social network and dyadic affect; however, the equation levels show a good fit with R^2 ranging from .525 to .837 for social network affect and from .713 to .915 for dyadic affect. Additionally, all factor loadings for both subscales are statistically significant at the .05 level. Each item included in the subscales reflects participants' underlying social network and dyadic affect. Further evidence that the items in each subscale jointly represent social network and dyadic affect is found in the subscale's Cronbach's alpha values of .969 and .982, respectively. The internal consistency reliability of these measures is very high. Therefore, they were used in this form for the full study.

To assess convergent, divergent, and construct validity, a series of correlations were run to examine the relationships between subscales of the Isolation and Affect measure and the following measures: the intimacy and companionship subscales of the Network Relationships Inventory (NRI), the anxiety and depression subscales of the Brief Symptom Inventory (BSI), the Social and Emotional Loneliness Scale for Adults (SELSA), and the Positive and Negative Affective States scale (PANAS). In order to compare these different correlations, r to z transformations were used. As predicted, the negative correlation between the isolation subscales of the Isolation and Affect measure and the companionship and intimacy scales of the NRI was stronger than the correlation between the isolation subscale of the Isolation and Affect measure and the anxiety and depression subscales of the BSI. Thus,

greater levels of isolation, as measured by the Isolation and Affect measure, were significantly correlated with lower levels of companionship and intimacy, as measured by the NRI. The isolation subscales of the Isolation and Affect measure were not significantly correlated with either the anxiety or depression subscales of the BSI. The correlations can be found in Table 1.

Regarding the distress subscales of the Isolation and Affect measure, significant correlations were found with all three subscales of the SELSA (family, romantic, and friendship) and with the affect subscales of the PANAS. However, the correlation between the distress subscales of the Isolation and Affect measure and the friendship subscale of the SELSA is notably stronger than the correlations between the distress subscales of the Isolation and Affect measure and the remaining subscales of the SELSA and PANAS. Thus, the distress experienced with regard to isolation from social network and dyadic peer relationships is most strongly correlated with loneliness resulting from the absence of supportive friendships as compared to loneliness resulting from the absence of supportive family or romantic relationships, as well as compared to general affective state. The correlations can be found in Table 2. Overall, the combined results from these comparisons lend support for construct validity in the Isolation and Affect measure.

Hypothesis Testing

Prior to testing the following hypotheses, preliminary regression analyses were run to determine whether possible control variables (i.e., gender, age, ethnicity, socio economic status, and IQ) were associated with each outcome variable (isolation, affect, and mental health). Due to differences in group demographics, it was not possible to control for age and IQ variables because membership in the groups defined them. While there was variability in

age range in the autism group (18-52), age range in the control group was restricted (17-19). Age was not associated with outcome variables in the autism group, but the association between age and outcome variables in the control group could not be tested due to restriction in range. Similarly, differences in IQ scores between groups defined the groups, such that the autism group had a lower mean and range in scores (mean 93, range 69-118) than their peers (mean 107, range 84-139). Within individual groups, IQ was not associated with outcome variables. Regarding the remaining control variables, gender was the only one that yielded a significant relationship with each of the outcome variables. Therefore, gender was included as a covariate in the analyses listed below.

Descriptive statistics for each outcome variable by group and for the entire sample are in Table 3. The autism group was higher than their typically developing peers on all dependent variables. This will be explored further in the hypothesis testing sections below. Skewness and Kurtosis values suggest the presence of outliers for many of the outcome variables; therefore, analyses were run both with the entire sample and without outlying data points. For most analyses, the exclusion of outlying data did not change outcomes. Analyses that did demonstrate a change in outcome with the removal of outlying data points are discussed, as relevant, below.

Hypothesis 1: Individuals with autism are more isolated than their typically developing peers.

To test the first hypothesis, two regressions were run on the full sample. The first was run to examine autism and gender effects on social network isolation and the second was run to examine autism and gender effects on dyadic isolation. The results of the regressions can be found in Table 4. As expected, autism was a significant predictor of both social

network, $b = .904$, $p < .05$, and dyadic, $b = .805$, $p < .05$, isolation, suggesting that adults with autism are more isolated than their typically developing peers.

Hypothesis 2: Adults with autism will experience greater distress with regard to isolation from a social network than from a dyadic relationship.

To test this hypothesis, two regressions were run looking at the effects of isolation on social network and dyadic affect in the autism group only. The first regression examined the effects of gender, social network isolation, and dyadic isolation on social network distress. The second regression examined the effects of the same predictors on dyadic distress. A summary of the findings for these analyses can be found in Table 5. Results indicate that social network isolation was a significant predictor of social network distress ($b = 2.531$, $p < .05$) and that dyadic isolation was a significant predictor of dyadic distress ($b = .965$, $p < .05$). The scales for each isolation measure are the same, which allowed for comparison of the coefficients for the significant predictors (social network and dyadic isolation) from each separate regression equation. A comparison between the relationships of social network isolation and distress versus dyadic isolation and distress was conducted to determine whether one relationship was stronger than the other. Results indicate that the relationship between social network isolation and social network distress was stronger than the relationship between dyadic isolation and dyadic distress, $t = 2.57$, $p < .05$. Thus, as expected, it appears that adults with autism are more distressed in the absence of social network relationships than in the absence of dyadic relationships.

Exploratory analyses were run to examine differences in rates of distress in the typically developing comparison group. Interestingly, when outlying data were removed, results for this group were comparable to those found in the group of adults with autism.

Social network isolation was a significant predictor of social network distress ($b = 1.976$, $p < .05$) and dyadic isolation was a significant predictor of dyadic distress ($b = .690$, $p < .05$). Comparison of the coefficients indicated that the relationship between social network isolation and social network distress was stronger than the relationship between dyadic isolation and dyadic distress, $t = 2.77$, $p < .05$. These additional findings can be found in Table 5.

Hypothesis 3: Adults with autism will experience similar levels of distress as compared to their typically developing peers with regard to social network isolation. In contrast, they are likely to experience less distress as compared to their peers with regard to dyadic isolation.

Two regressions were run on the full sample to test this hypothesis. The first examined the effects of autism, gender, social network isolation, and the interaction between social network isolation and autism on social network affect. The second examined the effects of autism, gender, dyadic isolation and the interaction between dyadic isolation and autism on dyadic affect. Results, shown in Table 6, indicate that although isolation was a significant predictor of distress in both models, the interaction term was not significant in either model. This suggests that, contrary to expectations, there are no differences between adults with autism and their typically developing peers with regard to the experience of distress relating to either social network or dyadic isolation.

Hypothesis 4: Typically developing adults will experience different levels of distress based on the interaction between membership in peer network and dyadic relationships. That is, the presence of one type of relationship is likely to decrease the distress felt in response to the absence of the other. This interaction may not hold for adults with autism, who may place less importance on the absence of dyadic relationships.

To test this hypothesis, it was necessary to look at the effects of isolation on distress for each group separately. Therefore, for both adults with autism and for typically developing peers, two regressions were run. The effects of gender, social network isolation, dyadic isolation, and the interaction between isolation measures were examined first on social network distress and then on dyadic distress. A summary of the results can be found in Table 7. As predicted, the interaction terms were not significant predictors of distress in adults with autism. Note, the sample size for this group is 37, which would make it difficult to detect anything smaller than a large effect size in a model with three predictors and an interaction term. In the comparison sample, social network isolation was a significant predictor of social network distress ($b = 2.051, p < .05$), but the interaction term between social network and dyadic isolation was not. When outlying data was removed from the equation (results not shown in Table 7), both social network isolation ($b = 2.735, p < .05$) and dyadic isolation ($b = 1.661, p < .05$) were significant predictors, but the interaction term remained a non significant predictor.

Regarding dyadic distress in the typically developing group, both types of isolation and their interaction term were significant predictors. To interpret the effects of social network isolation and dyadic isolation, it was necessary to look at the effect of each variable dependent on the other variable in the interaction term. At 1.0, the lowest level of dyadic isolation, distress increased .681 with each one point increase in social network isolation. At the mean level of dyadic isolation, 1.57, distress increased .240 with each one point increase in social network isolation. However, as levels of dyadic isolation increased further, distress began to decrease with each one point increase in social network isolation. For the majority of the college freshmen (80%), social network isolation continued to contribute to increased

levels of distress, even as dyadic isolation increased and the impact of social network isolation on distress decreased. However, for those college freshmen experiencing higher levels of dyadic isolation, higher levels of social network isolation were actually related to a decrease in levels of distress. This pattern also holds when looking at the impact of dyadic isolation conditional on levels of social network isolation. When social isolation was at its lowest value, 1.0, distress increased 1.442 with every one point increase in dyadic isolation. At the mean, 1.69, distress increased .908 with every one point increase in dyadic isolation. However, at higher levels of social network isolation, distress decreased with increased levels of dyadic isolation. For the majority of college freshmen (93%), dyadic isolation continued to contribute to increased rates of distress, even as social network isolation increased and the impact of dyadic isolation on distress decreased. However, for those college freshmen experiencing higher levels of social network isolation, higher levels of dyadic isolation were actually related to a decrease in levels of distress. Overall, results do not support the hypothesis that the presence of one type of relationship (social network or dyadic) lessens the distress felt in the absence of the other relationship.

Hypothesis 5a: Adults with autism are more likely to report distress as sadness and anger, rather than as loneliness.

To test this hypothesis a series of regressions were run on the autism group examining the effects of gender and social network isolation on the following outcome variables: social network sadness, social network anger, and social network loneliness. Regressions were also run examining the effects of gender and dyadic isolation on the following outcome variables: dyadic sadness, dyadic anger, and dyadic loneliness. Results are presented in Table 8.

Social network isolation was a significant predictor of all three individual emotion outcome variables. Social network isolation coefficients from the regressions equations with outcome variables social network sadness and social network anger were each compared to the social network coefficient from the regression equation with outcome variable social network loneliness. Contrary to expectations, the comparisons did not yield any significant differences in the strength of these relationships. Thus, with regard to social network isolation and distress, adults with autism rated comparable levels of sadness and anger as compared to loneliness in relation to the experience of isolation.

As with social network isolation, dyadic isolation was a significant predictor of all three individual emotion outcome variables. Dyadic isolation coefficients from regression equations with outcome variables dyadic sadness and dyadic anger were each compared to the dyadic isolation coefficient from the regression equation with outcome variable dyadic loneliness. Again, as with social network isolation, the comparisons did not yield any significant differences in the strength of these relationships. Thus, with regard to dyadic isolation and distress, adults with autism rated comparable levels of sadness and anger as compared to loneliness in relation to the experience of isolation.

Hypothesis 5b: Typically developing adults are more likely to endorse higher rates of loneliness in response to isolation compared to adults with autism, who are more likely to report their distress as anger or sadness.

To test this hypothesis, two series of regressions were run on the entire sample. One series examined the effects of gender, autism, social network isolation, and the interaction between social network isolation and autism on the following outcome variables: social network sadness, social network anger, and social network loneliness. The second series of

regressions examined the effect of gender, autism, dyadic isolation, and the interaction between dyadic isolation and autism on the following outcome variables: dyadic sadness, dyadic anger, and dyadic loneliness. Table 9 shows the results of these regressions.

Social network isolation was a significant predictor in all three regression equations; however, none of the interaction terms were significant when analyses were run using the full data set. These interaction terms also remained non significant when outlying data was removed. Similarly, when using the full data set, dyadic isolation was a significant predictor in all three regression equations, whereas none of the interaction terms were significant. However, in contrast to the findings regarding social network isolation, when outliers were removed from the data set, the interaction term between dyadic isolation and autism was a significant predictor of dyadic sadness, $b = -0.325$, $p < .05$, and dyadic loneliness, $b = -0.452$, $p < .05$. This suggests that adults with autism endorse different levels of sadness and loneliness in response to dyadic isolation than their typically developing peers.

To interpret the effects of autism and social network isolation, it was necessary to look at the effect of each variable dependent on the other variable in the interaction term. For college freshmen, dyadic sadness increased 0.580 and dyadic loneliness increased 0.663 for every one point increase in dyadic isolation. For adults with autism, dyadic sadness and dyadic loneliness increased at a lower rate, 0.255 and 0.211 respectively, with every one point increase in dyadic isolation.

An interesting pattern emerged when looking at the effect of autism on dyadic sadness and dyadic loneliness in the context of dyadic isolation levels. At the lowest level of dyadic isolation, 1.0, dyadic sadness and dyadic loneliness were higher for adults with autism, by 0.166 and 0.353 respectively, compared to their typically developing peers.

However, as dyadic isolation increased, autism was associated with decreased levels of dyadic sadness and dyadic loneliness. This suggests that whereas adults with autism experience higher levels of dyadic sadness and dyadic loneliness than their typically developing peers at low levels of dyadic isolation, they experience lower levels of dyadic sadness and dyadic loneliness than their peers at higher levels of dyadic isolation.

Hypothesis 6: Both adults with high functioning autism and their typically developing peers will experience increased levels of mental health difficulties with increased levels of social network isolation. Furthermore, it is expected that, for both groups, this relationship between isolation and mental health functioning will be mediated by the experience of distress. This same pattern of mediation is expected to hold true for typically developing adults with regard to dyadic isolation; however, the relationship between dyadic isolation and mental health functioning is less likely to exist in the autism population.

This hypothesis was examined separately for each group, adults with autism and college freshmen. Within each group and for each form of isolation, social network and dyadic, a series of four regressions were run to determine the relationships between isolation, distress, and mental health functioning. An example, is found below.

- 1) Gender + Social Network Isolation = Mental Health Functioning
- 2) Gender + Social Network Distress = Mental Health Functioning
- 3) Gender + Social Network Isolation = Distress
- 4) Gender + Social Network Isolation + Distress = Mental Health Functioning

The mediation model did not hold for adults with autism because neither social network isolation nor dyadic isolation was a significant predictor of mental health functioning. Thus, although adults with autism reported higher levels of mental health

difficulties than their typically developing peers, $b = .399, p < .05$, these difficulties were not related to perceived levels of isolation. In contrast, social network distress fully mediated the relationship between social network isolation and mental health functioning in college freshmen. In addition, though the mediation model did not hold with regard to dyadic isolation in the college freshmen group when the full data set was used, when outliers were removed from the data set, distress fully mediated the relationship between dyadic isolation and mental health functioning in college freshmen. The findings of these mediation models are depicted in Figures 5 and 6.

Discussion

The purpose of this study was to examine the experience of isolation and loneliness in adults with high functioning autism as compared to their typically developing peers. First, perceived rates of isolation in adults with autism were compared to those of typically developing peers at risk for the experience of isolation (college freshmen). It was expected that adults with autism would experience greater levels of isolation with regard to the absence of social networks and dyadic peer relationships. Results from the study indicate that, as predicted, adults with high functioning autism reported experiencing greater levels of isolation than typically developing peers. Interestingly, adults with autism were not just more isolated than a random sample of typically developing peers; they were more isolated than typically developing peers who are at risk for the experience of isolation and loneliness (Jackson, Fritch, Nagasaka, & Gunderson, 2002; Jackson, Soderlind, & Weiss, 2000; DiTomasso & Spinner, 1997; Medora & Woodward, 1986).

Contrary to expectation, though adults with autism were more isolated than their peers, results from the study suggest that they experienced general distress related to isolation in a manner similar to their typically developing peers. Adults with autism experienced distress with regard to isolation from both social networks and dyadic relationships and, consistent with expectations, they experienced greater levels of distress with regard to the absence of social networks than the absence of dyadic relationships. Though the experience of greater distress with regard to the absence of a social network was thought to be unique to

autism, exploratory analyses revealed that typically developing adults also endorsed higher rates of distress with regard to isolation from social networks than isolation from dyadic peer relationships. Furthermore, there were no group differences in the experience of general distress with regard to rates of isolation, for either social network or dyadic relationships. Thus, it appears that adults with autism experience distress resulting from isolation in a manner consistent with their typically developing peers, suggesting that although individuals with autism may put greater emphasis on the importance of concrete friendship characteristics (such as common activities and propinquity) than their typically developing peers (Bauminger & Kasari, 2000; Merkler & Mesibov, 2002), the absence of more abstract friendship characteristics (such as intimacy and trust) has a significant emotional impact for them.

Results from the current study also indicate that the presence of one type of relationship (social network or dyadic) did not ameliorate the distress felt at the absence of the other, for either the adults with autism or their typically developing peers. There was not a significant interaction between the different forms of isolation with regard to either social network or dyadic distress in adults with autism. For college freshmen, there was not a significant interaction between the different forms of isolation with regard to social network distress, but there was a significant interaction between the different forms of isolation with regard to dyadic distress. Interestingly, the effects of this interaction were contrary to expectations. At lower levels of dyadic isolation, increasing levels of social network isolation were associated with increasing levels of distress. However, at higher levels of dyadic isolation, increasing levels of social network isolation were associated with decreasing levels of distress. Similarly, at lower levels of social network isolation, increasing

levels of dyadic isolation were associated with increasing levels of distress and, at higher levels of social network isolation, increasing levels of dyadic isolation were associated with decreasing levels of distress. It may be that, for typically developing young adults, those who experience isolation from both a social network and dyadic peer relationships are more accustomed to being isolated and therefore experience less distress in the absence of dyadic relationships than those who experience only one form of isolation. Isolation from both social network and dyadic relationships may also indicate a preference to have fewer social connections.

An examination of the effect of isolation on individual negative affect ratings (sad, angry, anxious, lonely) indicated that there were no differences in the rates at which adults with autism reported sadness and anger compared to loneliness. Previous studies suggest that children with high functioning autism may not fully understand that the experience of loneliness involves isolation from others as well as negative affect (Bauminger & Kasari, 2000; Merkler & Mesibov, 2002). In this study, however, adults with high functioning autism appeared to report the experience of loneliness accurately, endorsing loneliness as a form of distress when isolated as frequently as sadness and anger. It is possible that the structured form of the Isolation and Affect Measure aided adults with autism in their accurate reporting of loneliness by linking affect ratings to individual questions about the experience of isolation. Irrespective of their understanding of the concept of loneliness, it is clear that high functioning adults with autism experience distress (in various forms of negative affect) as a result of isolation and are therefore, by definition, lonely.

When comparing individual negative affect ratings with regard to social network isolation, there were no differences between adults with autism and their typically developing

peers. In contrast, when examining the effect of dyadic isolation on individual affect ratings for most of the adults, there were differences between the groups regarding the endorsement of sadness and loneliness. At low levels of dyadic isolation, adults with autism endorsed higher rates of sadness and loneliness. However, as rates of dyadic isolation increased, adults with autism endorsed lower levels of sadness and loneliness than their typically developing peers. Overall, dyadic isolation was associated with sadness and loneliness in both adults with autism and their typically developing peers. Yet, rates of increase in levels of sadness and loneliness as a result of increased dyadic isolation were lower in adults with autism compared to their peers. Adults with autism often have a long history of failed relationships, which may lead them to feel insecure about any existing relationships and about the possibility of forming lasting dyadic relationships in the future. Perhaps, as a result of this, adults with autism experience some elevated levels of sadness and loneliness with respect to existing dyadic relationships, resulting in higher ratings of sadness and loneliness associated with low levels of dyadic isolation. It is also possible that they experience a higher rate of sadness and loneliness at low levels of dyadic isolation because the individual relationships that they are able to make and maintain do not fully meet their friendship needs. This higher level of sadness and loneliness in the absence of dyadic isolation may leave less room for increased levels of sadness and loneliness when the experience of isolation increases.

Another possible explanation for lower endorsement of sadness and loneliness in adults with autism regarding increased rates of isolation is that the adults who are more isolated may prefer not to maintain close, dyadic relationships. If they prefer not to have dyadic relationships, then they would not experience sadness or loneliness in the absence of

such relationships. This explanation seems unlikely, however, considering that rates of anger and overall distress are comparable between groups in the context of dyadic isolation.

DiTomasso and Spinner (1997) identified the loneliness experienced in the absence of peer relationships as the best predictor of increased levels of mental health difficulty, specifically anxiety and depression. Consistent with their findings, for most college freshmen in this study, the relationship between isolation and mental health functioning was fully mediated by the experience of distress. Interestingly, though adults with autism reported increased mental health difficulties compared to their typically developing peers, their experience of isolation (either social network or dyadic) was not associated with mental health functioning. Perhaps, given the difficulties they face in making and maintaining social relationships, even those adults with high functioning autism who have social relationships experience high levels of distress. They likely have a history of failed social relationships and may experience anxiety or depression over the state of their current relationships and whether they are going to last. They may also experience a sense of hopelessness, that they will never have successful relationships, based on previously experienced difficulties maintaining social relationships. It is also possible that their existing social network and dyadic relationships are not adequately meeting their needs.

This study offers several important contributions. The subjective experience of isolation and loneliness in individuals with autism is an important area of research and one that has historically received little attention. There is only a small body of literature, though slowly expanding, that addresses the experience of social relationships and loneliness in individuals with autism. Of this literature few, if any, studies explore the experience of social relationships and loneliness in *adults* with autism. In addition, studies investigating

the experience of loneliness in children with autism have not yet distinguished between the different kinds of loneliness (social network and dyadic) outlined in literature targeting the typically developing population (Bukowski & Hoza, 1989; DiTomasso & Spinner, 1997; Furman & Robbins, 1985; Hoza, Bukowski, & Beery, 2000; Rubenstein & Shaver, 1982; Weiss, 1973; Weiss, 1984). Furthermore, previous studies have documented reports of loneliness in children with autism (Bauminger and Kasari, 2000; Merkler and Mesibov, 2002), but raised questions about whether increased reports of loneliness in this population actually reflected loneliness or perhaps just isolation. This study is one of the first to explore autistic adults' experience of isolation, both social network and dyadic, and their feelings of distress resulting from isolation (loneliness). Results appear to indicate that not only are adults with autism more isolated than their peers, even those peers already at high risk for isolation, they also experience distress as a result of that isolation. In fact, their ratings of distress resulting from isolation are comparable to the distress reported by typically developing peers. Thus, in looking at the individual constructs that comprise loneliness (isolation and negative affect, or distress), it appears that adults with autism are reporting increased levels of loneliness (isolation and distress combined) when compared to typically developing peers.

Some limitations of this study should be noted. First, though small sample sizes are not uncommon in autism research (Bauminger, Shulman, & Agam 2003; Bauminger, Shulman, & Agam 2004; Downs & Smith, 2004; Rieffe, Terwogt, & Stockmann, 2000; Travis, Sigman, & Ruskin, 2001), having a limited number of participants (37 autism, 82 neurotypical, 119 total) allows only for detection of moderate to large group differences. If there were more subtle differences between these groups in their experience of isolation and

loneliness, those could not be detected with the sample used in this study. Second, it was not possible to control for potential effects of age and cognitive ability, given that differences in these characteristics varied systematically by group. This introduces the possibility that some of the findings may be influenced by differences in age and cognitive ability, though the absence of within group effects for these variables suggests that this is unlikely. Third, the sample consisted primarily of Caucasian adults, and it is unclear to what extent the findings can be generalized to more diverse populations. In addition, findings from this study can only be extended to high functioning adults with autism, and not those who may demonstrate greater levels of cognitive impairment. Fourth, findings from this study are based only on self-report measures. This introduces the risk that participants may respond in a socially desirable manner or, in the case of adults with autism, may misperceive actual levels of isolation. Although using self-report provides important information regarding perceptions of isolation and distress, when helping to arrange meeting times for their adult children with autism, many parents in this study raised concerns that their children did not necessarily perceive themselves as isolated, even though those around them would describe them as such.

The results from this study suggest directions for future research. First, because this study addressed perceptions of isolation and subsequent distress only in adults with high functioning autism, it will be important for future studies to examine the implication of these findings for autistic adults who are also cognitively impaired. Second, research exploring perceptions of isolation in adults with autism compared to perceptions of their isolation by typically developing adults who are close to them, such as a parent, peer, or spouse, might offer additional insight into their appraisal of existing social and interpersonal relationships.

Finally, of the participants in this study diagnosed with autism (37), 19 (51%) reported a social network comprised of typically developing peers, 8 (22%) reported a social network comprised of adults with autism, 16 (43%) reported having a typically developing close friend, and 8 (22%) reported having a close friend with autism. Studies exploring the nature of these relationships might offer additional insight into the characteristics of adults with autism associated with maintaining social network and/or dyadic relationships as well as into the defining features of these relationships (e.g. frequency of contact, duration, stability). In addition, research investigating levels of satisfaction and feelings regarding existing social network and dyadic relationships in adults with autism might help clarify whether their relationships meet their needs or contribute to levels of distress due to difficulties navigating social situations.

In summary, results of the present study suggest that adults with high functioning autism are more isolated than their typically developing peers and experience distress as a result of this isolation. In fact, their experience of overall levels of distress when isolated does not differ from that of their peers with regard to either social network or dyadic isolation. In combination, these findings suggest that adults with autism are experiencing loneliness and not just isolation. Adults with high functioning autism also report greater mental health difficulties than their at-risk peers, though isolation is not a predictor of mental health difficulty in this population. This may suggest that adults with high functioning autism who have social relationships still experience mental health difficulties, perhaps anxiety and/or depression, because existing relationships do not meet their needs or because they experience anxiety regarding the stability of existing relationships.

Taken together, these findings have important clinical implications. If adults with high functioning autism are more isolated than typically developing peers who are at risk for isolation and they are distressed as a result of this isolation, they may benefit most from efforts to provide them with opportunities to develop *meaningful* social network and dyadic relationships. Such opportunities may include encouragement to join local community groups (e.g. church groups, activity groups) or membership in counseling support groups or social skill/activity groups. Participation in such groups directly facilitates membership in a social network and may provide opportunity to develop more intimate dyadic relationships with individual group members. Much work needs to be done on how to cultivate these relationships and on what the implications of doing that might be.

Appendix

Items from the Isolation and Affect measure

Social Network Isolation

1. I fit in with a group of people.
2. I have a group of people my age to hang out with.
3. I know a group of people who let me join them in activities.
4. I feel like I am part of a group.
5. I have a group of people to do things with.
6. I know a group of people who like me.
7. I have a group of people who include me in activities.
8. I know a group of people who respect my opinion.
9. I have a group of people to do fun things with.
10. I know a group of people who invite me to go out with them.
11. I have a group of people I enjoy spending time with.
12. I have a group of people who include me in conversation.
13. I know a group of people who share interests that are similar to mine.
14. I know a group of people who notice when I am not there.
15. I have a group of people who value my input when planning activities.

Dyadic Isolation

1. I have someone who is always there for me when I need it.
2. I have someone my age who is a really close friend.
3. I have a friend who really cares about how I feel inside.
4. I have a friend whom I can talk to about important things.
5. I have someone special my age to share things with.
6. I have a friend I can depend on to always care about me.
7. I have a best friend.
8. I know someone my age who thinks I am really special.
9. I have a close friend whom I can really trust.
10. I know someone my age with whom I can share secrets and personal information.
11. I have a friend who is interested in how I'm feeling.
12. I have a friend to share good news with.
13. I have someone my age who listens to and respects my opinion.

Note. After each individual item, participants are asked to rate how (Happy, Sad, Angry, Anxious, Lonely) they feel when thinking of their response. They rate each emotion on a likert scale ranging from 1 (not at all) to 5 (absolutely). It is these ratings (with Happiness reverse scored) that compose the distress subscales for the Isolation and Affect measure.

Items from the Companionship and Intimacy Subscales of the NRI
(Furman & Buhrmester, 1985)

Participants were asked to answer questions about the friend they selected and then given the following instructions: Now we would like you to answer the following questions about the person you have selected above. The response format for each question was a 5-point likert scale ranging from 1 (little or none) to 5 (the most).

1. How much free time do you spend with this person?
2. How much do you talk about everything with this person?
3. How much do you hang out and have fun with this person?
4. How much do you share your secrets and private feelings with this person?
5. How often do you go places and do enjoyable things with this person?
6. How much do you talk to this person about things that you don't want others to know?

Positive and Negative Affect Schedule
(Watson, Clark, & Tellegen, 1988)

Below are a number of words that describe different feelings and emotions. Read each item and then mark the appropriate answer in the space next to that word. Indicate to what extent you have felt this way in general, that is, on the average. Use the following scale to record your answers.

1 Very slightly Or not at all	2 A little	3 Moderately	4 Quite a bit	5 Extremely
-------------------------------------	---------------	-----------------	------------------	----------------

- | | |
|---|---|
| <p>_____ interested</p> <p>_____ distressed</p> <p>_____ excited</p> <p>_____ upset</p> <p>_____ strong</p> <p>_____ guilty</p> <p>_____ scared</p> <p>_____ hostile</p> <p>_____ enthusiastic</p> <p>_____ proud</p> | <p>_____ irritable</p> <p>_____ alert</p> <p>_____ ashamed</p> <p>_____ inspired</p> <p>_____ nervous</p> <p>_____ determined</p> <p>_____ attentive</p> <p>_____ jittery</p> <p>_____ active</p> <p>_____ afraid</p> |
|---|---|

Items from the Social Emotional Loneliness Scale for Adults
(DiTomaso & Spinner, 1993)

Participants are instructed to rate each item from 1 (disagree strongly) to 7 (agree strongly).

List of items:

1. I am an important part of someone else's life.
2. I feel alone when I'm with my family.
3. No one in my family really cares about me.
4. I have a romantic partner with whom I share my most intimate thoughts and feelings.
5. There is no one in my family I can depend upon for support and encouragement, but I wish there were.
6. I really care about my family.
7. There is someone who wants to share their life with me.
8. I have a romantic or marital partner who gives me the support and encouragement I need.
9. I really belong to my family.
10. I have an unmet need for a close romantic relationship.
11. I wish I could tell someone who I am in love with that I love them.
12. I find myself wishing for someone with whom to share my life.
13. I wish my family was more concerned about my welfare.
14. I'm in love with someone who is in love with me.
15. I wish I had a more satisfying romantic relationship.
16. I have someone who fulfills my needs for intimacy.
17. I feel a part of my family.
18. I have someone who fulfills my emotional needs.
19. My family really cares about me.
20. There is no one in my family I feel close to, but I wish there were.
21. I have a romantic partner to whose happiness I contribute.
22. My family is important to me.
23. I feel close to my family.
24. What's important to me doesn't seem important to the people I know.
25. I don't have a friend(s) who shares my views, but I wish I did.
26. I feel part of a group of friends.
27. My friends understand my motives and reasoning.
28. I feel "in tune" with others.
29. I have a lot in common with others.
30. I have friends that I can turn to for information.
31. I like the people I hang out with.
32. I can depend on my friends for help.
33. I have friends to whom I can talk about the pressures in my life.
34. I don't have a friend(s) who understands me, but I wish I did.
35. I do not feel satisfied with the friends that I have.
36. I have a friend(s) with whom I can share my views.
37. I'm not part of a group of friends and I wish I were.

Table 1

Correlations between Isolation Subscales of the Isolation and Affect Measure and Subscales of the NRI and BSI

	NRI Companionship	NRI Intimacy	BSI Depression	BSI Anxiety
Social Network Isolation	-.566*	-.358*	-.005	-.051
Dyadic Isolation	-.521*	-.622*	-.017	-.058

* p<.05

Note. Higher scores on isolation measures indicate greater levels of isolation.

Table 2

Correlations between Distress Subscales of the Isolation and Affect Measure and Subscales of the SELSA and PANAS

	SELSA Family	SELSA Romantic	SELSA Friendship	PANAS Positive	PANAS Negative
Social Network Distress	.364*	.352*	.759*	-.277*	.342*
Dyadic Distress	.363*	.334*	.788*	-.179	.307*

** p<.05

Note. Higher scores on affect subscales indicate higher levels of negative affect.

Table 3

Descriptive Statistics for Dependent Variables by Diagnostic Group and for Entire Sample

	Autism (N=37)	Neurotypical (N=82)	Total (N=119)
Group Isolation			
Mean	2.76	1.69	2.02
Median	2.80	1.47	1.73
Standard Deviation	1.29	.69	1.04
Skewness	.48	1.28	1.34
Kurtosis	-.81	1.20	1.29
Dyadic Isolation			
Mean	2.61	1.57	1.89
Median	2.15	1.27	1.46
Standard Deviation	1.39	.77	1.11
Skewness	.68	2.22	1.62
Kurtosis	-.80	5.52	1.86
Group Distress			
Mean	9.91	7.15	8.01
Median	8.80	6.50	7.20
Standard Deviation	3.90	2.20	3.10
Skewness	1.09	1.58	1.69
Kurtosis	.529	2.92	3.08
Dyadic Distress			
Mean	10.69	9.42	9.81
Median	9.77	9.08	9.15
Standard Deviation	3.17	1.49	2.22
Skewness	1.96	.945	2.45
Kurtosis	4.94	3.29	10.21
BSI Global			
Mean	1.17	.73	.87
Median	1.09	.62	.67
Standard Deviation	.81	.48	.64
Skewness	.89	1.01	1.35
Kurtosis	-.052	.31	1.71

Table 4

Regression of Social Network Membership and Gender on Isolation Measures (N=119)

	Social Network Isolation	Dyadic Isolation
Autism	.904* (.202)	.805* (.220)
Female	-.342 (.187)	-.474 (.204)
Intercept	1.923	1.89
R ²	.252*	.225*

* p<.05

Note. Standard errors of unstandardized regression coefficients are in parentheses

Table 5

Regression of Gender and Isolation Measures on Distress

	Autism Group (N=37)		Neurotypical Group (N=82)	
	Social Network Distress	Dyadic Distress	Social Network Distress†	Dyadic Distress†
Female	.161 (1.072)	1.567 (1.223)	-.228 (.307)	.220 (.352)
Social Network Isolation	2.531* (.420)	.079 (.479)	1.976* (.310)	.097 (.356)
Dyadic Isolation	-.021 (.030)	.965* (.036)	.557 (.300)	.690* (.344)
Intercept	3.603	7.658	3.065	8.105
R ²	.613*	.238*	.664*	.118*

* p<.05

Note. Standard errors of unstandardized regression coefficients are in parentheses

† Regression without outliers presented here

Table 6

Regression of Group Membership, Gender, Isolation Measures, and Interaction terms on Distress Measures (N=119)

	Social Network Distress	Dyadic Distress
Autism	.536 (.930)	-.556 (.949)
Gender	-.187 (.378)	.548 (.440)
Social Network Isolation	2.593* (.295)	--
Dyadic Isolation	--	.342 (.307)
Autism*Social Network Isolation	-.233 (.373)	--
Autism*Dyadic Isolation	--	.668 (.390)
Intercept	2.893	8.508
R ²	.701*	.207*

* p<.05

Note. Standard errors of unstandardized regression coefficients are in parentheses

Table 7

Regression of Gender, Social Network Isolation, Dyadic Isolation, and Social Network Isolation*Dyadic Isolation on Distress Measures by Group Membership

	Autism Group (N=37)		Neurotypical Group (N=82)	
	Social Network Distress	Dyadic Distress	Social Network Distress	Dyadic Distress
Female	.123 (1.155)	1.555 (1.317)	-.218 (.312)	.214 (.371)
Social Network Isolation	2.456* (.877)	.054 (.999)	2.051* (.455)	1.454* (.542)
Dyadic Isolation	-.361 (.986)	.936 (1.125)	.972 (.645)	2.215* (.768)
Social Network Isolation*Dyadic Isolation	.028 (.288)	.009 (.329)	-.080 (.211)	-.773* (.252)
Intercept	3.814	7.728	2.551	5.706
R ²	.613*	.238	.715*	.126*

* p<.05

Note. Standard errors of unstandardized regression coefficients are in parentheses

Table 8

Regression of Gender and Isolation on Individual Emotion Ratings for Social Network (1) and Dyadic (2) Ratings in Adults with Autism

	Sad		Angry		Lonely	
	1	2	1	2	1	2
Female	-.062 (.293)	.422 (.317)	-.051 (.249)	.256 (.343)	-.041 (.332)	.374 (.374)
Social Network Isolation	.459* (.090)	--	.322* (.077)	--	.475* (.102)	--
Dyadic Isolation	--	.555* (.091)	--	.347* (.098)	--	.511* (.107)
Intercept	.554	.208	.587	.468	.635	.416
R ²	.433*	.537*	.342*	.278*	.390*	.413*

* p<.05

Note. Standard errors of unstandardized regression coefficients are in parentheses

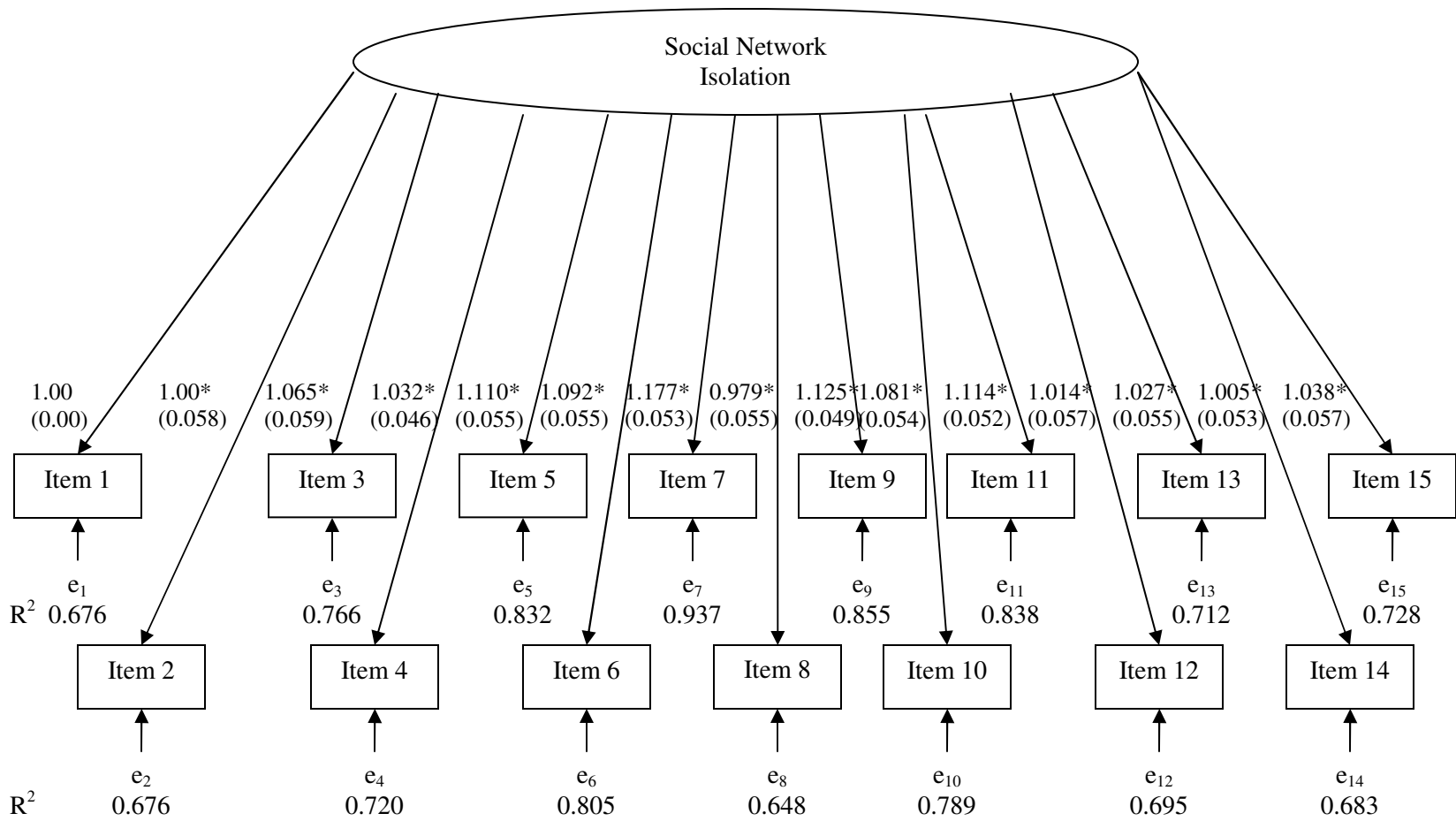
Table 9

Regression of Autism, Gender, Isolation, and Autism*Isolation on Individual Emotion Ratings for Social Network (1) and Dyadic (2) Ratings

	Sad		Angry		Lonely	
	1	2	1	2	1	2
Autism	.175 (.274)	-.200 (.262)	-.154 (.218)	-.207 (.246)	.298 (.299)	.031 (.297)
Female	.016 (.111)	.162 (.121)	-.025 (.089)	.143 (.114)	.055 (.122)	.169 (.138)
Social Network Isolation	.573* (.087)	--	.218* (.069)	--	.624* (.095)	--
Dyadic Isolation	--	.422* (.085)	--	.210* (.080)	--	.490* (.096)
Autism*Social Network Isolation	-.117 (.110)	--	.103 (.088)	--	-.152 (.120)	--
Autism*Dyadic Isolation	--	.113 (.108)	--	.137 (.101)	--	.021 (.122)
Intercept	.371	.458	.738	.696	.327	.424
R ²	.508*	.504*	.386*	.288*	.497*	.439*

* p<.05

Note. Standard errors of unstandardized regression coefficients are in parentheses

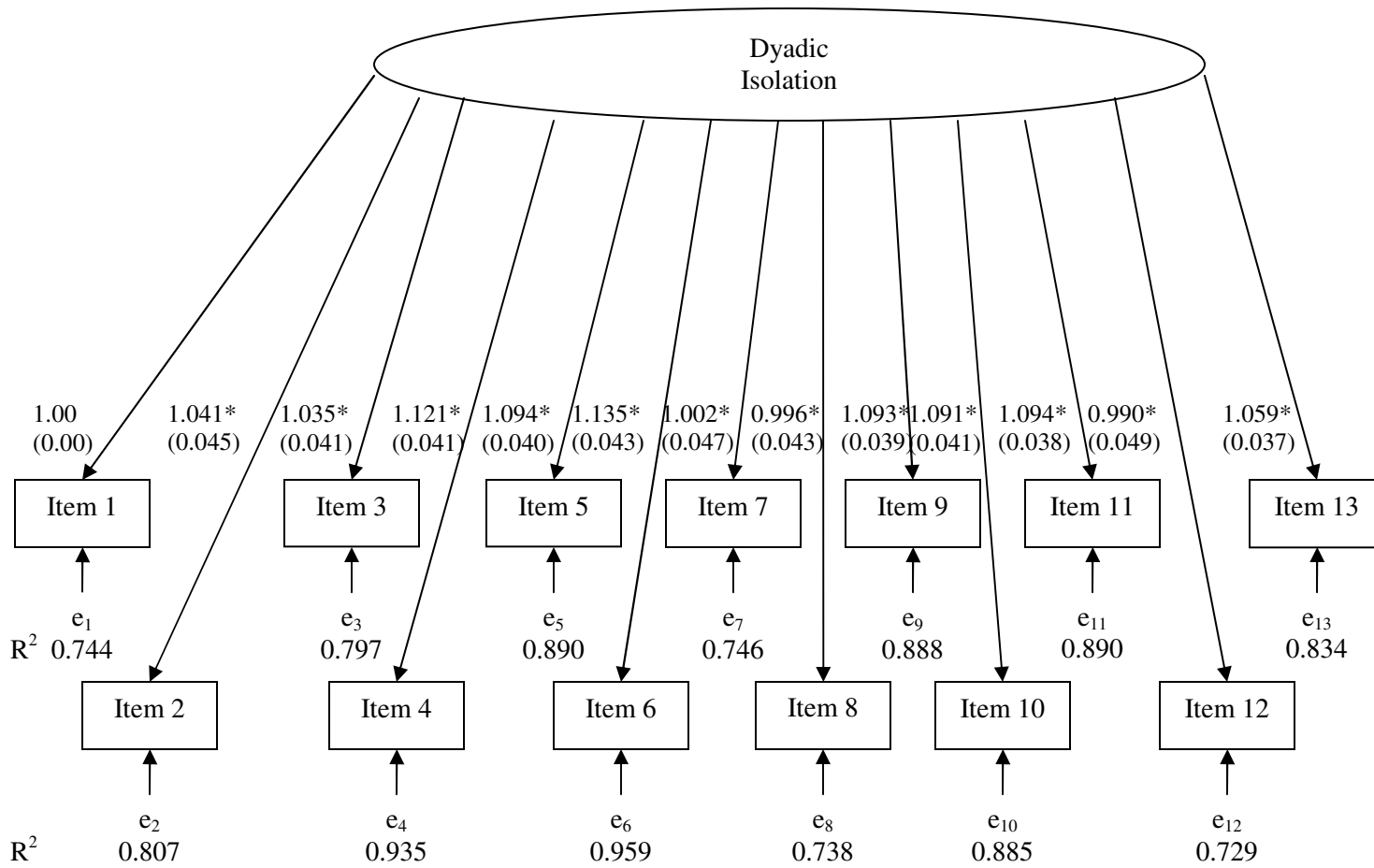


Model Level $X^2 = 67.879$ (26df), $p = 0.0000$; CFI = 0.974; RMSEA = 0.124

* $p < 05$

Note: Standard errors of factor loadings are in parentheses

Figure 1. Confirmatory Factor Analysis for Social Network Isolation.

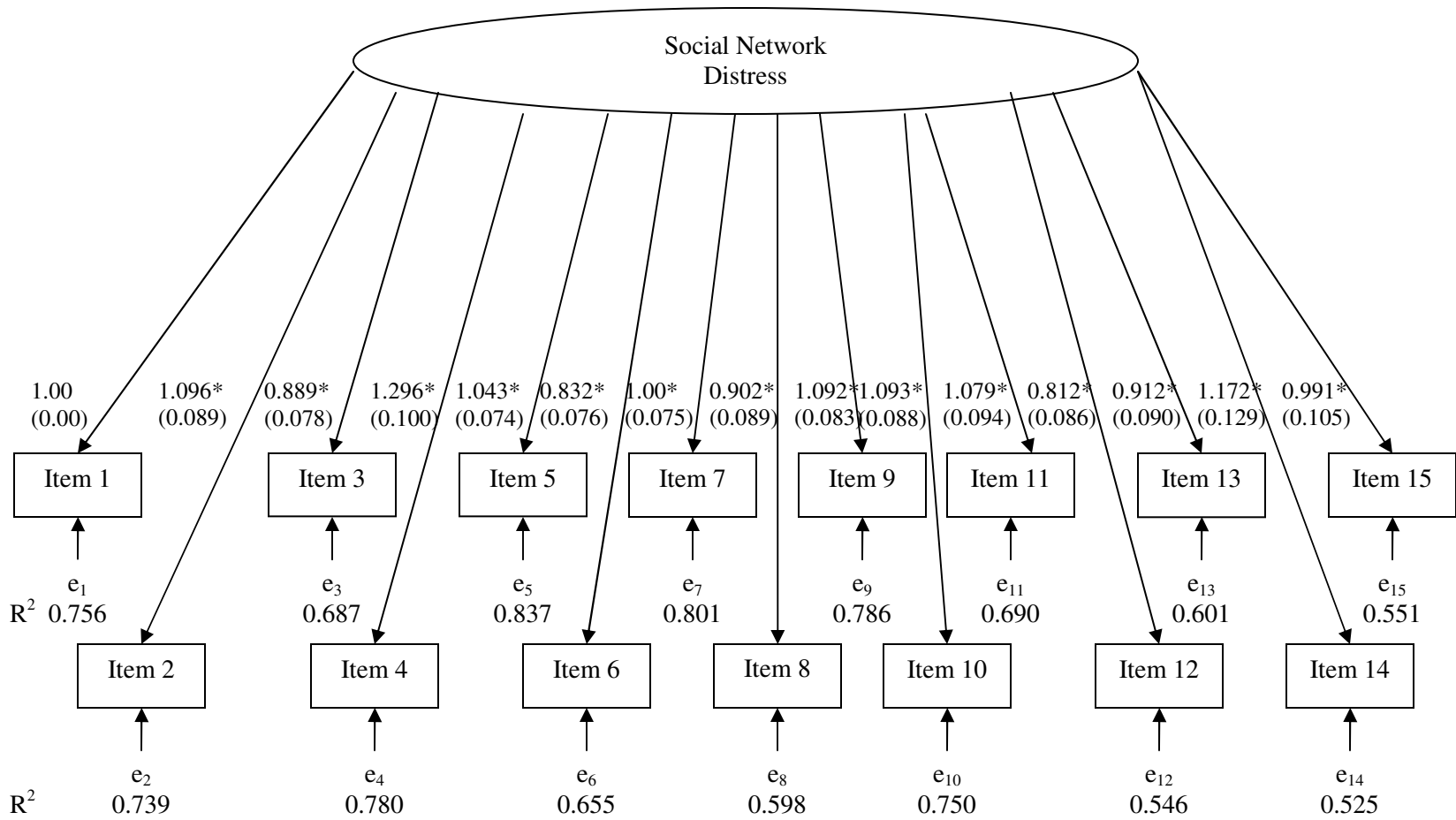


Model Level $X^2 = 34.426$ (19df), $p = 0.0164$; CFI = 0.993; RMSEA = 0.088

* $p < 05$

Note: Standard errors of factor loadings are in parentheses

Figure 2. Confirmatory Factor Analysis for Dyadic Isolation.

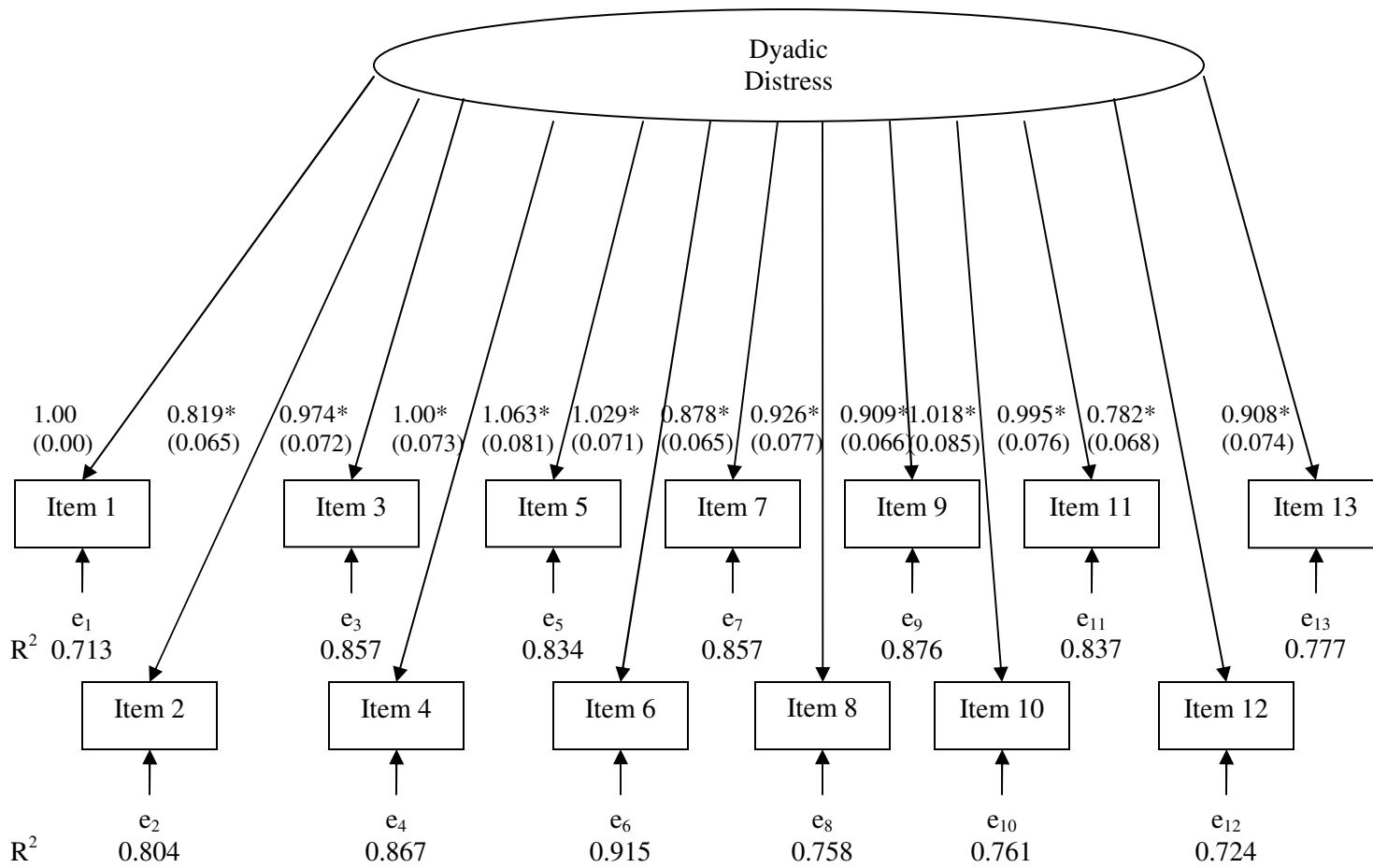


Model Level $X^2 = 349.303$ (90df), $p = 0.0000$; CFI = 0.853; RMSEA = 0.166

* $p < 0.05$

Note: Standard errors of factor loadings are in parentheses

Figure 3. Confirmatory Factor Analysis for Social Network Distress.

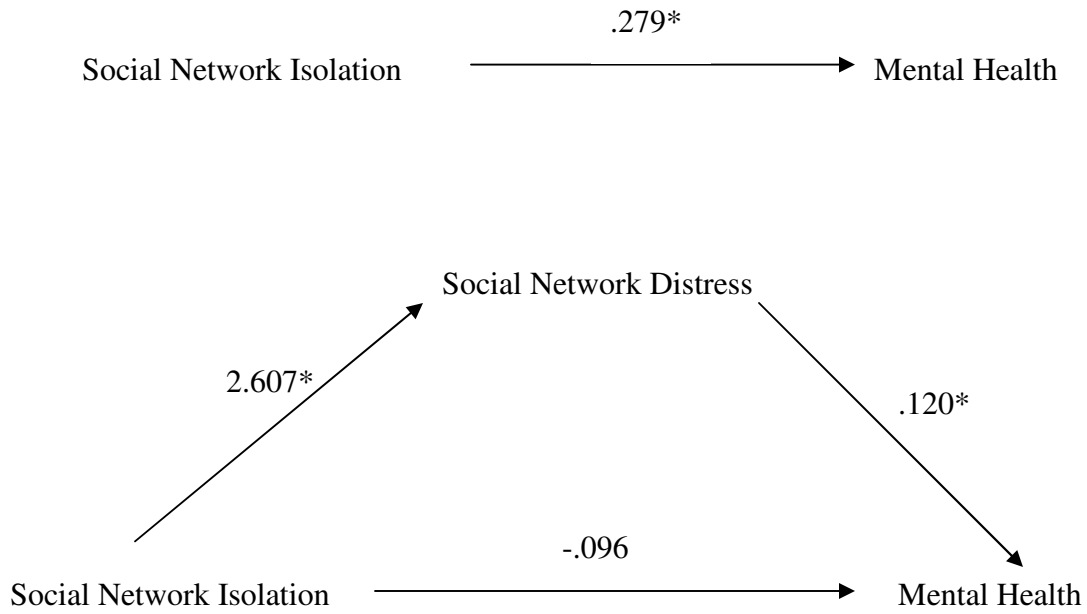


Model Level $X^2 = 173.210$ (65df), $p = 0.0000$; CFI = 0.947; RMSEA = 0.126

* $p < 05$

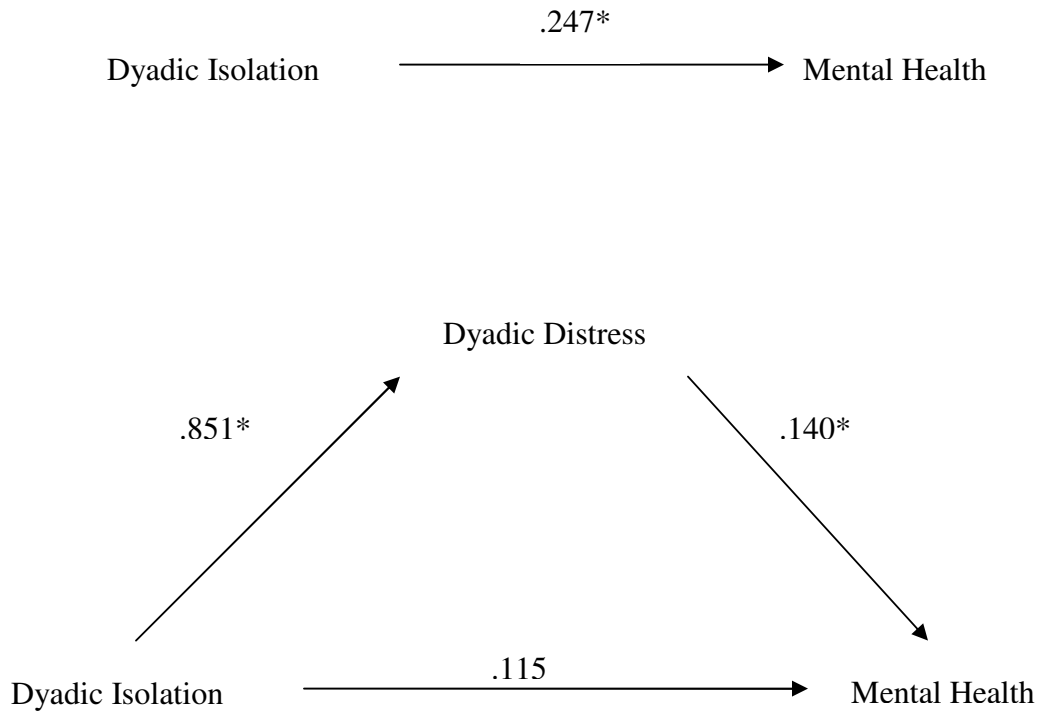
Note: Standard errors of factor loadings are in parentheses

Figure 4. Confirmatory Factor Analysis for Dyadic Distress.



* $p < .05$

Figure 5. Mediation of the Relationship between Social Network Isolation and Mental Health by Social Network Distress.



* $p < .05$

Figure 6. Mediation of the Relationship between Dyadic Isolation and Mental Health by Dyadic Distress.

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