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Introduction

Velo-cardio-facial syndrome (VCFS) involves congenital malformation of the heart, cleft palate, and a characteristic facial appearance. More than 80% of those affected show a deletion on chromosome 22q11. Research indicates that developmental and behavioral impairments are typical for children with VCFS. Speech, language and feeding difficulties are common for these young children. Current research also provides evidence for various social skills deficits of children with VCFS. Common social skill deficits include attention and concentration difficulties and withdrawal. A distinctive pattern of cognitive skills and social/emotional functioning is also a defining characteristic of VCFS. The social presentation of children with VCFS is characterized by impulsive behavior, and impaired ability to read social cues and respond appropriately. A significant proportion of VCFS patients are diagnosed with bipolar or schizophrenia in adult years. Many of the cognitive and social characteristics that are seen in children with VCFS are similar to children with Nonverbal Learning Disabilities (NLD). Past studies have discovered social skill deficits in children with VCFS, yet no study has examined the deficits in detail. This study will examine the social skills and friendships of children with VCFS, specifically their ability to read social situations and how this may affect their quality and quantity of friendships.
Chapter I Review of Literature

The Social Skills and Friendships of Children with Velo-Cardio-Facial Syndrome

In 1978, Shprintzen described twelve children with a similar pattern of characteristics. He diagnosed these children with a newly recognized congenital malformation syndrome, termed Velo-Cardio-Facial Syndrome (VCFS). Shprintzen (1981) described the newly discovered features typical of patients with VCFS. They included typical facies, cleft palate, cardiac malformations, learning disabilities, hearing loss, speech and language impairment, and microsomia (small stature). Other malformations included narrow hands with hyperextensibility of the digits, and abundant scalp hair. Shprintzen (1978) recommended that diagnosis be based on the possible combinations of these features.

Today researchers have further described these characteristics. The typical facies of patients with VCFS include a prominent nose, narrow palpebral (eyelid) fissures, flattened cheekbones, and a small mouth. Current literature indicates the syndrome can be diagnosed in the absence of one or two of the major features (Shprintzen et al., 1978; Sprintzen, Goldberg, Young, & Wolford, 1981; Carneol, Marks, & Weik, 1999; Motzin, Marion, Goldberg, Shprintzen, & Saenger, 1993).

Recent experience with patients that have VCFS indicate that developmental and behavioral impairments are typical for young children. Feeding difficulties are common, as are speech and language difficulties. Other research provides evidence for variable social skill deficits of children with VCFS. Swillen et al. (1997) also found that children
typically have social deficits, including internalizing problems such as withdrawal and problems with attention and concentration.

Empirical studies exist regarding social skill and friendship development in children without VCFS, but there are few systematic studies that examine the specific social skills and friendships of children with VCFS.

Etiology of VCFS

At this time, the 22q11 gene deletion is a defining characteristic of VCFS and has an incidence of 1 in 4,000. Syndromes currently associated with this deletion include VCFS and DiGeorge syndrome (Gerdes et al., 1999). Lindsay et al. (1995) determined that 81% of VCFS patients have the 22q11 deletion. Specific criteria have not been set to determine the number of findings needed to diagnosis VCFS, so when a suspicion is raised, further assessment is indicated (Carneol, Marks, & Weik, 1999). Fluorescence in situ hybridization (FISH) techniques can be performed to determine prenatal diagnosis (Thomas & Graham, 1997).

Researchers suggest that when the typical developmental profile of the syndrome is seen, testing for the 22q11 deletion should be done (Motzhin, Marion, Goldberg, Shpritzen, & Saenger, 1993; Thomas & Graham, 1997). Certain combinations of features have been determined to be more suggestive of the deletion than others. For example, the presence of severe heart disease is associated with a high frequency (66%) of 22q11 deletions. Although, 22q11 deletion has been found to be the most common cause of the VCFS phenotype, it is not the only cause. Currently, possible etiologies of VCFS in individuals without the chromosome deletion are being investigated. Possible causes of
VCFS include a deletion in the critical area, a mutation in the gene itself, or genetic heterogeneity (Thomas & Graham, 1997).

Some children who are affected by the 22q11 deletion have been found to have mildly affected parents. When parents of these children have been tested, 25% of the parents have the same 22q11 deletion as the child. The deletion may also be inherited from a parent as an unbalanced translocation. An affected person with a known 22q11 deletion has a 50% risk of transmitting the deletion on to his or her children (Driscoll et al., 1993). VCFS is an autosomal dominant disorder, affecting chromosomes other than the sex chromosomes and male to male transmission has been documented (Williams, Shprintzen, & Goldberg, 1985). Because VCFS is an autosomal dominant disorder caused by a deletion, abnormal gene dosage may be the cause of the syndrome. There appears to be an imbalance of the VCFS gene product as compared to other gene products. This imbalance may disrupt the transfer of genetic information at a critical stage of embryo development, which results in the development of an abnormal phenotype (Ravnan, Chen, Golabi, & Lebo, 1996). VCFS’s major malformations are hypothesized to result from a disruption in neural crest cell development. The neural crest is one of the folds that form the neural tube giving rise to the spinal ganglia and structures of the autonomic nervous system. These malformations include cardiac malformations and submucous clefts of the soft palate along with velopharyngeal insufficiency (Wang et al., 1998).
Clinical Features

Physical Outcomes

The clinical spectrum associated with VCFS is broad and variable, and screening of VCFS patients usually detects one or more associated features. The most consistent features include congenital heart defects, learning difficulties, velopharyngeal dysfunction with or without cleft, and typical facies (Vantrappen et al., 1998; Thomas & Graham, 1997).

Infants with 22q11 deletions are usually normal size at birth, but may demonstrate postnatal failure to thrive. The reason for the failure to thrive is difficult to isolate as these infants commonly have frequent upper and lower respiratory infections, along with heart defects. Hypotonia is observed in 70-80% of infants with VCFS and obstructive sleep apnea occurs in 50% of infants (Thomas & Graham, 1997). General hypotonia seen in VCFS and velopharyngeal problems leads to an increased frequency of feeding problems in the first months of life, mainly due to a poor sucking reflex and nasal regurgitation. Feeding problems typically decrease within the first year of life in most patients (Carneol, Marks, & Weik, 1999; Lipson et al., 1991; Vantrappen et al., 1998).

Microcephaly, the smallness of the head associated with mental defect, occurs in 40% of patients with VCFS. As mentioned earlier, most patients also have a typical facial appearance that tends to become more distinct as they get older. The typical facies of patients with VCFS include a prominent nose, narrow palpebral (eyelid) fissures, flattened cheekbones, and a small mouth (Shprintzen et al., 1978; Sprintzen Goldberg, Young, & Wolford, 1981; Carneol, Marks, & Weik, 1999; Motzin, Marion, Goldberg, Shprintzen, & Saenger, 1993). The nasal passages and eustachian tubes are often narrow,
which predisposes children to frequent ear infections, which may then result in conductive hearing loss (Thomas & Graham, 1997).

Cleft palate is seen in up to 85% of patients with VCFS, although this percentage may be high due to the fact that a large percentage of reported individuals present to craniofacial clinics. A large majority of patients with VCFS have some degree of velopharyngeal (relating to the soft palate and pharynx) incompetence with hypernasal speech (Lipson et al., 1991; Thomas & Graham, 1997; Vantrappen et al., 1998). Features of speech correlated with velopharyngeal dysfunction include reduced breath pressure, nasal emission, and articulation errors. There is great variability in speech problems ranging from severe to slight or normal. Individuals with VCFS often demonstrate articulation and phonological disorders not associated with velopharyngeal dysfunction. These include phonological delays, disorders, dyspraxia of speech, and a high-pitched voice (Carneol, Marks, & Weik, 1999).

Cardiac anomalies were considered to be one of the important features of VCFS in early literature. Cardiac anomalies vary in their occurrence and severity and have incidence values that range from 82% to 39% (Goldberg et al., 1993). The major cardiac findings common to VCFS are ventral septal defects, Tetralogy of Fallot, and right sided aortic arch defects (Carneol, Marks, & Weik, 1999; Goldberg et al., 1993; McLean et al., 1993; Thomas & Graham, 1997). Researchers conclude that the absence of cardiac disease should not stop the clinician from making a diagnosis of VCFS (McLean et al., 1993).

Endocrine problems are also seen in VCFS patients, with hypocalcemia (deficiency of calcium in the blood) seen in 10-20% of individuals, which usually presents between
birth and three months of age with a variety of symptoms including seizures, tremors and rigidity. Hypothyroidism may also be present in VCFS individuals (Goldberg et al., 1993; Thomas & Graham, 1997).

Cognitive Outcomes

Cognitive deficits in individuals with a diagnosis of VCFS have been described as ranging from mental retardation to learning disabilities (Carneol, Marks, & Weik, 1999; Gerdes et al., 1999; Golding-Kushner, Weller, & Shprintzen, 1985; Swillen et al., 1997). Gerdes et al. (1999) reveal a range of developmental and behavioral findings. The results of this study found that only 25% of the children were functioning in the average range and the remainder demonstrated mild or significant delays. The emergence of language skills was also delayed in all of the children, especially in the area of expressive language. In preschool years, children with VCFS are typically developmentally delayed, with mild hypotonia, language and speech delays. Children with more significant delays may also be at high risk to be eventually diagnosed with mild or moderate mental retardation. Nine of the twelve children in this study exhibited behaviors during assessment that were highly active, impulsive, highly emotional, and disorganized.

Swillen et al. (1997) found that learning disabilities have been diagnosed in 82% to 100% of children with VCFS. Mental retardation appears to be present in 40% to 46% of children with VCFS. Research also confirms a wide variability in intelligence of individuals with VCFS. At this point, there is no clear explanation for the variability in intelligence. There is no data that suggests a correlation between intelligence and heart defects. This lack of data suggests that the global delays and intelligence variations are
directly associated with the 22q11 deletion and are not explained by other physical anomalies such as palatal defects or cardiac problems (Gerdes et al., 1999).

Research has found a consistent intelligence profile of children with VCFS. This profile consists of a significant difference in the average verbal IQ and average performance IQ, with a significantly lower performance IQ score (Swillen et al., 1997). Several case studies suggest similarities in the academic and psychosocial presentation of VCFS and the Nonverbal Learning Disability (NLD) syndrome. NLD syndrome is a cluster of neuropsychological, academic, and social-emotional characteristics that reflect primary deficiencies in non-verbal reasoning. The assets of NLD include early speech and vocabulary development, good rote memory skills, attention to detail, early reading skill development and excellent spelling skills (Frankenberger, 2000).

Three main categories of deficits and dysfunction in NLD include motoric deficits, visual-spatial-organizational deficits, and social deficits. Motoric deficits include a lack of coordination, balance problems and difficulties with graphomotor skills. Visual-spatial-organizational deficits of NLD include a lack of image, poor visual recall, faulty spatial perceptions, and difficulties with spatial relations. Social deficits of children with NLD include the lack of ability to comprehend nonverbal communication, difficulties adjusting to transitions and novel situations, and deficits in social judgment and social interactions (Frankenberger, 2000).

In general, children with NLD are believed to have significant deficits in social perception, social judgment, and social interaction skills, which become more evident as the child gets older. Children with NLD are also at risk for the development of
internalized forms of psychopathology. Children who exhibit the NLD syndrome are frequently noted to be hyperactive during early childhood (Rourke, 1989).

It is uncertain at this time if VCFS children may also be diagnosed with NLD, but certain similarities between the neuropsychological assets and deficits of children with VCFS and NLD are notable. Speech and language are found to be delayed in both syndromes, yet those with NLD typically develop a high volume of speech output, while children with VCFS typically do not develop high speech output. A tendency towards concrete thinking has been seen in both syndromes. However it may be that those with VCFS have additional language problems not seen in the NLD syndrome. Both groups demonstrate strengths in the area of intact auditory attention span and ease in learning rote verbal material. Similar patterns of academic performance have also been noted in both syndromes. In both groups, single word reading is better developed than reading comprehension. Both groups of children tend to show problems in mechanical arithmetic and with mathematical reasoning. In general, both groups of children show deficits in problem solving, concept formation, and appreciation of incongruities (Fuerst, Dool, & Rourke, 1995).

Both groups of children demonstrate significant impairments in social interactions, yet the reasons for these impairments are currently unknown. In NLD syndrome, evidence suggests that the neuropsychological deficits contribute to poor social skills. The social withdrawal in young children with VCFS might result partly from the impaired ability to communicate effectively with others. It may also be that the concrete thinking, reasoning problems, and difficulties with novel situations contribute to poor social interaction skills (Fuerst, Dool, & Rourke, 1995).
Language delays are also typical of children with VCFS. Gerdes et al., (1999) found language delays in 84% of the VCFS children studied. Seventy five percent of the VCFS population had not yet developed any verbal communication at two years of age. This study also reveals a pattern of significant speech disorders in VCFS children, which is not caused by oral/motor involvement or palatal defects alone. The language of children with VCFS has been described as concrete and abstract reasoning as limited. Deficits in voice quality and articulation have also been noted. There is a strong need for early evaluation and therapy to help develop communication strategies suited to the child's needs (Golding-Kushing, Weller, & Shprintzen, 1985).

Golding-Kushing, Weller, & Shprintzen (1985) found that the thought processes of children with VCFS tend to remain immaturity concrete, as they grow older, with abstract reasoning skills below average. Specifically, children with VCFS have a difficult time understanding concepts and processes used for application to novel stimuli. They found that reading comprehension and mathematical abilities were significantly below language abilities (Fuerst, Dool, & Rourke, 1995).

Motor development is commonly delayed, as the majority of children with VCFS reach typical developmental milestones at later ages than children without VCFS (Swillen et al., 1997). As a consequence of hypotonia, typically seen during infancy in children with VCFS, the mean age for walking is 17 months, with only 27% of children walking before the age of 15 months. Minor difficulties with coordination may persist into adolescence (Fuerst, Dool, & Rourke, 1995).
Social and Emotional Outcomes

Psychosis is a well-recognized feature of 22q11 deletion. Ten to 22% of individuals with 22q11 deletion develop major psychiatric disorders, most commonly paranoid schizophrenia and bipolar affective disorder (Gothelf et al., 1999; Papalos et al., 1996; Thomas & Graham, 1997). These psychological disorders typically begin to manifest during adolescence or early adulthood. The association of psychosis with 22q11 deletion is unknown at this time. Additionally, patients with VCFS may also have severe vegetative symptoms such as loss of appetite, low energy, low self esteem, poor concentration, and difficulty making decisions (Goldberg et al., 1993).

Extremes in behavior are typical for many children with VCFS; for example, some individuals are disinhibited and impulsive, while others are more serious and shy. Swillen et al. (1997) found a typical behavioral profile of children with VCFS. Specifically, children were found to have significant scores in areas of attention problems, social problems, thought problems, and withdrawal. From this study, researchers concluded that children and adolescents with VCFS may exhibit social problems and problems with attention and concentration. In general, poor social interactions, bland affect, loss of interest in life, and generalized anxiety have also been observed in VCFS children. Older children with VCFS are also at risk for developing psychiatric disorders such as schizophrenia and depression. Common symptoms reported by adolescent and adults with VCFS are those associated with anxiety and depressive disorders, such as disturbed mood, severe vegetative symptoms, disturbed appetite, fatigue, and low self-esteem (Swillen et al., 1997; Thomas & Graham, 1997).
The physiological basis for these cognitive and behavioral disorders is unknown. Brain anomalies have been documented in only a few cases and the pattern of anomalies is not consistent (Mitnick, Bello, & Shprintzen, 1994; Thomas & Graham, 1997).

As severe psychological disorders tend to manifest in adolescence, it is important to understand the behavior of children with VCFS. There does not appear to be one distinct behavioral expression of VCFS in the preschool years, rather two extreme patterns have been observed. On the one hand, some children with VCFS have been observed to exhibit extreme shyness and inhibition, while other children show attention problems and social problems (Golding-Kushner, Weller, & Shprintzen, 1985; Gerdes et al., 1999; Swillen, 1997). The social withdrawal in children and adolescents with VCFS might be partially due to their impaired ability to communicate with others. Research also suggests that neuropsychological deficits may contribute to their poor interaction skills. It is important that children with 22q11 deletion and VCFS be monitored for early signs of psychopathology, since early intervention has been shown to lead to improved functioning (Bassett et al., 1998).

**Treatment**

An early and accurate diagnosis of VCFS is important to make prevention and early intervention possible for all areas affected by the diagnosis, including health, development, social and emotional well being, and academic success. Surgical correction of velopharyngeal inadequacy is recommended to improve overall speech. Many factors should be investigated to ensure proper intervention strategies and surgical care. It is also important to examine the degree of cardiac impairment, and upper airway obstruction (Carneol, Marks, & Weik, 1999).
When VCFS is diagnosed, further evaluation of a language or learning disability is also recommended. Speech therapy is recommend as early as possible. The goal of speech therapy is to improve the child's communication and to hopefully enhance the child's self confidence and decrease frustration (Vantrappen et al., 1998). Also, early formal hearing assessment should be included along with the speech therapy (Thomas & Graham, 1997).

Children with learning difficulties detected in the early elementary grades need continued educational support. At this point, preliminary research suggests support for the use of interactive computer instruction for VCFS students (Kok & Solomon, 1995).

In general, a thorough case history, interviews, clinical evaluations and ongoing monitoring of health, communication, cognitive, and social-emotional status of those with VCFS is important (Carneol, Marks, & Weik, 1999).

Social Competence

As described above, children with VCFS typically have deficits in the area of social interactions, comprehension of novel situations, and problem solving skills. Because of these social deficits, it is important to specifically investigate what kinds of deficits these children are experiencing and how this affects their social competence and friendships. Social competence has been defined in many ways based on the perspectives of different social theorists. In general, social competence has been defined as the ability to adapt effectively to life situations, interact with the environment, and generate skilled behavior. The definitions vary widely on the emphasis of social cognitive skills and capacity, behavioral performance, and judgments by others (Dodge, 1986).
Recently, investigators have made a distinction between the terms social competence and social skills. Social competence typically refers to the overall effectiveness of social behaviors as judged by others. The term social skills refers to behaviors that predict social outcomes such as peer acceptance, others’ judgments of behavior, and other social behaviors known to correlate with peer acceptance (Hughes, 1989).

**Measurement of Social Competence**

The main goal of the assessment process in social skill development is to identify the specific behaviors that are deficient. This approach is referred to as the known-group approach, which is based on the assumption that differences observed between competent and less competent children account for their success on measures of peer acceptance. However, it is likely that the children differ on many other dimensions as well. The lengthy list of cognitive and behavioral differences between popular and unpopular children support the view that social competence is multidetermined. While this known group approach identifies parts of social competence, it does not suggest methods for integrating them into a unified model (Hughes & Hall, 1987).

Much of the research of children’s socialization has been limited by inadequate measurement. Many of the tests and assessment techniques used to measure social competence have problems with reliability or have questionable validity. An information processing analysis of social competence has been recommended to specify components that link assessment to intervention, which may improve the ability to see how the child improves (Hughes & Hall, 1987).
In order to develop a more systematic conceptual model of social competence, many researchers have used the information-processing model to assess social competence in children. This view of social competence advocates a careful understanding of social task requirements, such as the preconditions and preskills that have to be met before a specific intervention can be planned (Hughes & Hall, 1987).

In order to answer the question of what is social competence, Dodge & Feldman (1986) formulated a theoretical model of social functioning, which incorporates five major units of social interaction. These units include social cues or stimuli, social information processing of cues by a child, social behaviors by a child that occur as a function of child’s processing cues, judgments by peers about the child’s behavior and peers behavior toward the child. The measurement of these five processes is hypothesized to help assess a child’s risk for later problems and to help create a definition of social competence.

Dodge et al. (1986) explain that social interactions begin with a set of social cues, which are the social situation for the child and create a social task. The child’s performance during the social task is what is judged to be effective or ineffective and competent or incompetent. Thus, the social task is important in understanding social competence and social behavior. The child’s behavior in a certain social situation is hypothesized to occur as a function of the way that the child processes social cues. Competent behavior is said to result from skillful processing and deviant processing is hypothesized to lead to deviant behavior. Social information processing models have been developed to further describe the mental processes involved in the task of receiving social cues and responding competently.
Dodge & Price (1994) used Dodge's five step model of social competence with 259 first, second, and third grade, typically developing children. Research found evidence for the idea that processing biases and deficits are correlated with incompetent peer related performance in group entry and that these deficits provide value in predicting performance. Also, as a child is confronted with more demands for behavioral performance by peers and teachers, that child responds over time with increasing skill in social information processing that helps to increase behavioral competence. These findings indicate a consistent pattern of associations between social information processing variables and behavioral competence in a sample of children representing the normal range of behavior.

Dodge et al. (1984) found that the ability to discriminate intention cues could be used to examine developmental social status differences among children. Researchers developed a reliable measure of children's skills in discriminating intention cues. This measure was used to test the hypothesis that intention cue detection is related to social competence in children. The measure was given to 176 children in kindergarten, second and fourth grade and results indicate that scores on the measure increase as a function of increasing age. Results also indicate that children in popular and average groups scored higher than deviant children. These findings suggest that children who are deficient in the ability to detect the intentions of peers are likely to display behavioral responses that are viewed by peers as inappropriate to the situation.

Dodge & Feldman (1994) continued to find that the assessment of children's social cognition's have resulted in significant differences between children of high and low sociometric status. Children considered unpopular are less skillful at interpreting...
cues, are biased in their attributions of others, and attribute social failures to internal causes. Research also shows that unpopular children generate more deviant responses to interpersonal dilemmas, are deficient in evaluation responses and have less competent enactment of responses.

Several other researchers have developed models of assessing social skills and competence in typically developing children. Hughes & Hall (1987) have developed a model of the assessment of social competence in children. Hughes & Hall (1987) have found that research on social cognitive processes in socially competent and incompetent children provides support for the existence of group differences in areas of attributions for peers' social behaviors, selective attention to social cues, cue detection skills, interpersonal cognitive problem-solving skills, outcome expectancies for social behaviors, empathy, and perspective-taking abilities.

Hughes & Hall (1987) explain that socially competent outcomes require that components of social cognition are linked with cognitive and behavioral skills in order to reduce the “problem space” associated with a social problem. Understanding how children systematically reduce problem space associated with a problem provides qualitative information about the level of a child’s social skill competence. Socially competent behavior emphasizes the child’s ability to read social situations, generate appropriate strategies and apply them in a strategic plan.

Social problem solving can be viewed as the appropriate application of performance related variables such as skills and abilities. As long as the individual’s perception of a social situation is accurate and they use an appropriate repertoire to the social problem, then problem resolution is judged to be competent. Outcomes of social
competence then, require that the components of social cognition be linked with cognitive and behavioral skills (Hughes & Hall, 1987).

Specifically Hughes & Hall's (1987) analysis of social competence emphasizes the child's responsibility for reading social situations, generating appropriate strategies and applying them in a strategic plan. The first component in the decision making process addresses the question, "Does the child have problems related to reading a social situation?" (p. 251). Social situations are ambiguous and accurate interpretations of the situation require the child to attend to and interpret different social cues. This can be thought of as social awareness or social sensitivity. It is the ability to accurately label a social object or event's meaning at a given moment in time. Reading a social event is understood to be the ability to accurately identify the personal state of others and to accurately identify social situations. Hughes & Hall also explain that reading situations is similar to reading comprehension or social insight, which is the ability to understand the nuances associated with social situations. The child's knowledge of social mores and ability to represent these social mores cognitively are also required at this step. Problems reading social cues could result from faulty role taking ability, poor social comprehension, poor social inference skills, or poor representational skills. Reading a situation requires both a surface understanding of the event and a deeper understanding of the situation (Hughes, 1989). It is this first component of Hughes & Hall's model that will only be assessed in children with VCFS because the ability to read a social situation appears to be a typical deficit in these children.

The second component of the model is, "Does the child have problems generating appropriate problem-solving strategies?" (p. 251). The generation stage is referred to as
social communication or social problem solving. In other words, how does the child respond to the situation? The third component involves the translation of knowledge into action. This component involves the fluency with which skilled behaviors are performed with some strategic plan and to the ability to effectively monitor one's own performance. The ability to self-monitor for errors in actions or reactions allows the child to provide continuous feedback to the reading and generating components. New information can be used to update the strategic plans and modify behaviors, which result in more desirable results from social interactions (Hughes & Hall, 1987).

This model of assessment is built around a series of questions pertinent to each of the decision-making points. Reliable, valid and feasible assessment measures are available for use at the Read stage of assessment to answer the following questions: “Does the child accurately label others’ intentions?” “Does the child accurately label others’ emotions?” “Does the child sense social problems?” “What goals does the child construct in social situations?” “Does the child see the problem from multiple and differing social perspectives?” and “Does the child seek information that would be useful in clarifying the problem?” (p. 254) Hughes & Hall’s (1987) model is a useful assessment procedure to test the Dodge & Feldman (1986) hypothesis that children who are deficient or deviant in the way they process social information may have a difficult time behaving competently with peers which may lead to negative views by peer groups.
Social Competence and Peer Interactions

Social competence is an important variable as school aged children begin to develop friendships. A body of evidence suggests that a positive association exists between student's social competence and academic performance, which includes achievement, school adjustment, and motivation for schoolwork. Research shows that children's social competence in relating to their peers is positively associated with their achievement in school, while children who were rejected by peers were found to have lower levels of school achievement. Children who are assumed to have lower levels of social competence appear to be at greater risk for doing poorly in school than other children. In general, a significant association appears to exist between children's social competence and their school success. Specifically, being accepted by one's peers, and being able to make and keep friends are correlates of school success, while being actively rejected by peers is a strong correlate of school-related difficulties (Patrick, 1997).

Children who are less socially competent than their peers have also demonstrated deficiencies in declarative social knowledge. Specifically, less competent children do not appear to understand the importance of reciprocity in friendships and therefore reciprocate less often and are more likely to be unpopular with peers. Low socially competent children have also been observed to have limited conditional knowledge about friendship strategies. Children's knowledge of appropriate and inappropriate strategies for making friends is associated with their peers' perceptions of prosocial and antisocial behavior and level of peer acceptance. For some poorly accepted children, having a limited repertoire of appropriate behavioral and problem-solving strategies seems to be a contributor to their social acceptance difficulties (Patrick, 1997).
Many children with learning disabilities are rated by teachers, parents, and peers as being less socially competent than their non-disabled peers. Specifically, empirical evidence suggests that children with a language impairment and a learning disability have greatest risk for dysfunctional social behavioral adjustment and are specifically at risk for poor social competence. Children with language learning disabilities (LLD) exhibit difficulties expressing understanding of ambiguous sentences, producing speech that expresses the intention of others, making inferences, and understanding the meaning of figurative language. These primary language processing deficits that characterize LLD have an indirect effect on social functioning and impede broader communication skills. While the failure to comprehend thoughts, feelings, and intentions of others may interfere with the establishment and maintenance of friendships (Vallance & Wintre, 1997). Rubin & Asendorpf (1993) feel that peer interactive experiences are essential for normal social-cognitive development and social behavioral development. Their research has found that children with poorer communication skills may not effectively converse with others which increases the likelihood of negative feedback, negative self perceptions and anxiety and restrict their opportunities to develop social skills.

Peer relationships are also an area of potential deficits in children with Cranio-Facial Anomalies (CFA). Many children report that they are dissatisfied with the quality of their peer relationships, especially when they are dissatisfied with their physical appearance or when their physical defect is more noticeable. Researchers found that children with CFA that had less social competence described themselves as more socially anxious and more dissatisfied with their peer relationships. Specifically, less socially
competent children with CFA reported less companionship with peers, which may lead to
greater social isolation for the group (Pope & Ward, 1997).

From this research, it may be that children with CFA that have problematic peer
relationships are characterized by a unique pattern of uncomfortable peer encounters,
social anxiety, and withdrawn behavior. This combination of social withdrawal, social
anxiety, and self-consciousness that are associated with low social competence may lead
to a risk of peer rejection because these children tend to be socially awkward and make
peers uncomfortable. In general, children with craniofacial syndromes may be at risk for
poor psychological adjustment, low social competence, and peer rejection (Pope & Ward,
1997).

Interpersonal Competence and Friendships

Social competence in close relationships with parents and friends is considered
interpersonal competence, which is the ability to establish and maintain close personal
relationships. As children develop, they learn new areas of social competence that may
not have been needed in previous relationships. In the early elementary school years,
children develop comparative criteria for classifying peers. Into adolescence, friendships
move outside of the classroom and require greater individual initiative in starting
conversations and providing emotional support (Bukowski, Boivin, & Hoza, 1994).

Intimate friendships are characterized by several dimensions, such as the degree
of mutuality or the extent to which behaviors and feelings of one partner in an intimate
friendship are returned (Sharabany, 1994). Research has focused on identifying children
at risk for childhood and later adjustment problems. Among these children are those that
lack peer acceptance and those that are rejected by their peers. Children who lack close
friends may also be at risk for adjustment difficulties. A child may be accepted by peers, yet still have no close friends. Social acceptance refers to the degree to which an individual is liked or valued by a group, where friendship is a specific relationship between two people (Price & Ladd, 1986).

Children without friends are deprived of experiences that promote social development and adjustment. Friendships can provide a context in which the child can acquire a variety of competencies and they serve as resources for emotional support. In general, previous and ongoing friendships may be used as important models for the formation of future friendships. There is growing research to suggest that friendships may serve important social functions during childhood and that children who do not have friends may be denied important experiences and suffer in their social development (Price & Ladd, 1986).

The interpersonal intimacy of children with NLD has been shown to be impaired. Typically, these problems developing close interpersonal attachments are not noticed until late childhood when dating begins. NLD children may have difficulty maintaining meaningful friendships because of their problems expressing language, which leads to increased rejection by peers. In general, difficulties with socialization, problems maintaining close interpersonal relationships and the decreased likelihood of developing intimate relationships contribute to low self worth and may increase the risk for depression and suicide attempts (Roman, 2000).

Research evidence reveals that children just as adults, associate loneliness with unpleasant emotions and perceptions of social relationship deficits. It appears that social difficulties related to withdrawal and inhibition of social responsiveness may lead to
feelings of loneliness. By middle elementary school, children view social inhibition and withdrawal as maladaptive. The negative social reputation associated with withdrawal may then lead children to develop negative self-perceptions and increase their withdrawal. In general, social withdrawal, poor peer acceptance, few or no friendships, and an internal attributional style may lead to loneliness in children (Renshaw & Brown, 1993).

**Measurement of Friendships**

Based on past research, it is important to assess the quality of children's friendships, as well as their popularity or status in a peer group because both may be important determinants of social development and adjustment. Currently, many investigators are examining children's friendships and a range of methodological approaches have been developed to study the quality of children's friendships (Furman, 1996).

Questionnaires and interviews are available for gaining children's perspectives on their relationships. In order to use either questionnaires or interviews, it is important to determine which relationships should be rated or which relationships should be considered friendships. In general, two approaches have been used. One is that investigators have asked participants to pick the relationships that they will rate. Other researchers select the relationships to be rated on the basis of sociometric data. In order for a relationship to be considered a friendship, both children must nominate each other as one of their three best friends. Mutual nomination has appealing features in that friendships are commonly defined as mutual relationships. Second, most children will name others as friends when asked, but many nominations are not reciprocated. A
number of psychometric problems do arise in this methodology. For example, nominations provide relatively insensitive indices of friendship because they are dichotomous ratings. Also, the fixed number of three friends can lead to misidentification of friendships. Reservations are also often expressed about questionnaires, interviews and other self-report measures, yet they are central to the study of interpersonal relationships (Furman, 1996).

At this point, only a moderate amount of agreement exists concerning which features should be examined in the assessment of friendships. Companionship is one feature that is included in all measures, but others are specific to particular instruments. Further empirical studies should help determine which features are related children’s friendships and those features that are secondary in importance. Children’s perceptions of their friendships are important determinants of the kind of relationship that exists. These perceptions are likely to shape the course of the relationship by affecting their own behavior and their interpretations of their partner’s behavior (Furman, 1996).

Several developmental issues are also important to consider when measuring friendship perceptions. The researcher must make sure that the items are appropriate indices for the ages of the subjects. Interpretations of differences among children of different ages may be further complicated by developmental changes in friendships. Children and adolescents of any age very in how intimate their friendships are. These issues also apply to research on cultural and sex differences. One consistent finding is the assertion that girls’ relationships are more intimate or that intimacy is manifested differently by girls and boys. Because of these possible differences, it is important that
measures have comparable means for different ages and for males and females (Furman, 1996).

Assessment problems do exist and are complicated by the fact that children do not have one and only one friendship and some children do not have friendships. The characteristics of best friendships may be important predictors, but it may be that the characteristics of other friendships are just as important. In general, examining the qualitative features of friendships is only one part of understanding the role of friendships in development (Furman, 1996).

Limitations of Previous Studies

Many of the studies reviewed in the area of VCFS, share many of the same strengths and weaknesses. The studies have revealed important characteristics of VCFS that have increased the diagnostic accuracy and improved treatment interventions for individuals with VCFS. On the other hand, these studies typically do not use comparison groups or control groups which leaves many questions unanswered and does not permit researchers to have complete confidence in their results. Many of the studies are case examples, which are helpful clinically, but do not answer many of the research questions and do not allow for a comparison between VCFS children and children without VCFS.

Many of the studies cover a wide range of developmental outcomes and have found social and emotional deficits along with other outcomes, yet these studies have not yet focused on the specifics of social skills and the friendships of children with VCFS. Several of the studies mention that they have found that children with VCFS do show social skills deficits, yet there are no specifics mentioned as to the types of deficits, instead many simply report that developmental and behavioral impairments are typical
(Wang et al., 1998). Another weakness of at least one study reviewed is that VCFS was suspected in the participants used, but the diagnosis was not corroborated with the 22q11 deletion (Driscoll et al., 1993). The lack of diagnostic certainty could lead to results, which may not be based on children with VCFS.

In general, almost all of the studies reviewed, mentioned the need for further research on the development of children with VCFS, as this is a relatively newly diagnosed syndrome. Specifically, Swillen et al. (1997) suggest further studies are needed to assess the predictive value of the social and emotional functioning outcomes concerning psychiatric status as adults. Studies with control groups are needed to confirm results and to better understand deficits specific to VCFS, which will lead to better certainty of prognosis and improved intervention programs for VCFS children.
Chapter II
Rationale and Hypotheses

Research has recently increased in the area of VCFS, yet there is no systematic study that specifically addresses the social skill deficits of children with VCFS and how this affects their friendships. Past research shows evidence of a lack of social skills in children with VCFS, but do not provide specifics, which may help with intervention and treatment to improve these deficits. The current study will compare children with VCFS, ages 8-12 years with children in the same age group without VCFS to specifically examine their ability to read social situations and the quality of their friendships. The children will be measured on variables using Hughes & Hall (1987) information processing model of social competence. Specifically, Hughes & Hall explain that in order to have social competence, a child must be able to read the social situation, which includes knowledge of social mores and the ability to represent social mores competently. Several assessment measures will be used to answer the questions of the reading social cue component of the information-processing model. Children will be measured on their ability to accurately label others’ intentions, the ability to accurately label others’ emotions, the ability to detect social problems, the ability to see the problem from multiple and differing social perspectives, and if the child is able to seek information that would be useful in clarifying the problem.

The hypotheses for this study include:

1.) Children with VCFS will not label others’ intentions as accurately as the control group.
2.) Children with VCFS will not label others' emotions as accurately as the control group.

3.) Children with VCFS will not detect social problems as well as the control group.

4.) Children with VCFS will not seek information that would be useful to clarify problems as well as the control group.

5.) Children with VCFS will have fewer friendships and fewer positive social interactions compared to the control group.
Chapter III

Method

Participants

There will be two groups of participants age’s 6-12 years of age. One group will consist of children with VCFS (N=25) and the other group (N=25) will consist of children without VCFS, matched for age. The control group will consist of the siblings of the VCFS individuals and will be the normative sample. The VCFS group will consist of patients from Cincinnati Children’s Hospital Medical Center and will be recruited from the Genetics department. All individuals in the VCFS group have been confirmed genetically with a 22q11 deletion on the basis of a previous FISH analysis. Parents will be informed of the nature of the research and written informed consent (see Appendix F) will be obtained from the children’s parents as well as verbal assent form the children involved. Any children that are unable to read or write will be excluded from this study because the nature of the measures involved.

Design

A between group design will be used to compare the two groups on several dependent variables. The independent variable will be the diagnostic status (VCFS versus children without VCFS). The dependent variables are measures of: social competence, labeling others’ intentions, labeling others’ emotions, the ability to detect social problems, recognizing information that is helpful to clarify a problem, and the number and quality of friendships of these two groups of children. These dependent variables will be measured using several reliable and valid instruments.
In order to analyze this data, a MANOVA analysis will be run in order to analyze all of the dependent variables at the same time. The means of all six dependent variables will be compared between the VCFS group and the control group to determine which variables are statistically significant. A .05 alpha level will be used to determine which dependent variables are significant. The significant variables will be entered into a logistic regression equation using a predictor variable. The predictor variable will be group (VCFS or normal child). The possible criterion variables will be the significant dependent variables (i.e. social competence, the ability to label intentions, the ability to label emotions, the ability to detect social problems, the ability to recognize information to clarify a problem, and the number and quality of friendships).

Because little or no past research has been done on the social skills of children with VCFS, the standard convention of an effect size estimate of .80 will be used to determine the amount of power (Howell, 1997). With a large estimated effect size of .80 and an estimated sample size of 25 participant per group, the power will be .80. This means that there is an 80% chance of detecting a significant difference between the two groups and only a 20% chance of a Type II error. The calculation for power analysis found that the number of participants per group needed for a power of .80 is 25 participants per group.

Measures

To assess the general social competence in both groups of children, the Self Perception Profile for Children (Harter, 1985) will be administered (see Appendix A). This self-report instrument assesses children’s sense of competence across different domains. Three domains of competence have been identified using this scale: cognitive,
scholastic competence, social acceptance, athletic competence, physical appearance, and behavioral conduct. A fourth subscale, general self-worth is also included. The child is asked to decide which kind of child he or she is most like, the ones described on the right or the left. Once the child has made this decision, the child decides whether the description on that side is sort of true or really true for her or him. Each item is scored from a 1 to a 4, where a score of 1 indicates low perceived competence and a score of 4 reflects high perceived competence. Scores are then summed and averaged for each subscale, resulting in six separate subscale means. Across all samples, the subscale reliabilities range from .75 to .83, .75 to .84, .77 to .86 and .73 to .82 for the four subscales. Test-retest reliability data were .78, .80, .87, and .70. Subscale means for four samples have been shown to be very stable across subscale as well as grade and this pattern has been replicable (Harter, 1982).

To assess the children’s ability to label others’ intentions, the Intention-Cue Discrimination Task (Dodge, Murphy, & Buchsbaum, 1984) will be administered (See Appendix B). In this measure, children are presented with 14 sets of three vignettes on video, each depicting a social interaction between two children in which one child provokes another. In two of the three vignettes in each set, the actor displays the same intention, in the third vignette, the actor displays a different intention and the child must identify the different vignette. Experimenters coded children’s responses to the intention-cue discrimination task as correct versus incorrect. Coders agreed exactly on the category of a child’s response in 98.2% of the cases. The internal consistency of the 24-item measure is also adequate at .73.
Perspective taking is the ability to recognize, articulate, and coordinate different perspectives and internal states of others and interpersonal problem solving is the resolution of problems with others. The ability to understand the perspective of others will be assessed using the Affective Perspective Taking Task (Marsh, Serafica, & Barenboim, 1981) (See Appendix C). This measure assesses the following abilities: problem definition, alternative thinking, consequential thinking, and solution adequacy. The measure consists of two dilemmas that require the children to analyze and resolve interpersonal problems. Following the presentation of the dilemmas, children are asked a series of four questions that reflect each of the general problem solving abilities: a) What are all the things you would be thinking about if you had to solve this problem?; b) How many ways can you solve this problem?; c) What might happen if... (each solution given in response to the preceding question is read; and d) What do you think would be the best way to solve this problem? Why? Responses to these questions are scored to assess these general abilities: problem definition, alternative thinking, consequential thinking, and solution adequacy. Solutions that do not deal adequately with these perspectives receive a score of zero and responses receive higher scores (1 to 4) to reflect more adequate solutions. Research has found test-retest reliability of .72, with internal consistency reliability of .74. Interrater reliability has been established by having two independent judges’ score the protocols of a random sample and correlations between ratings of the judges were .99.

To assess the children’s ability to detect social problems and to recognize information that is helpful to clarify the problem, the Purdue Elementary Problem Solving Inventory (Feldhusen, Houtz, & Ringenbach, 1972) will be administered (see...
Appendix D). Specifically, the authors found behaviors that are involved in the phases of the problem-solving process, which include: sensing a problem, identifying the problem, asking questions, guessing causes, clarification of goals, judging if more information is needed, analyzing details of the problem and identifying critical elements, redefinition or transformation, seeing implications, verification, solving a single solution problem, and solving a multiple solution problem.

The task consists of cartoons that represent children in realistic problem situations. The children are shown pictures and are asked questions about the pictures. Factor analysis confirms that of the 12 types of hypothesized problem solving abilities designed for the Purdue Problem Solving Inventory, six of these abilities were represented by items in the test. These were items that represented selection of the best possible solution, noticing relevant details, sensing that a problem existed, defining the problem, foreseeing consequences, and redefining common objects in unusual roles. Correlations have also been calculated with other measures and the problem solving score has been correlated .51 with a measure of logical thinking, .21 with a measure of conceptual ability, and .52 with reading comprehension (Feldhusen, Houtz, & Ringenbach, 1972). These results provide evidence for the validity of the instrument because several factors appear to correspond to abilities originally hypothesized as being measured by the inventory (Speedie, Houtz, Ringenbach, & Feldhusen, 1973).

Lastly, the friendship quality and quantity will be measured using the Friendship Questionnaire (Furman & Adler, 1982) (See Appendix E). This questionnaire assesses 16 features of friendship that fall under four factors: warmth/closeness, conflict, exclusivity, and relative status/power. Most of these features have been selected from
literature on children's friendships, especially on children's conceptions of friendships.

For the warmth/closeness, conflict, and exclusivity scales, children rate how characteristic a description in of a one friendship, using a 5-point Likert scale. Each of the sixteen scales includes three items with a total of 48 items. The Cronbach alphas of the scales are satisfactory with a mean of .77. This measure has been used with third through seventh-grade children (Furman, 1996).

Procedure

Once the study is approved by the Children's Hospital Medical Center IRB, along with Xavier University's IRB, then the VCFS group of children will be obtained through the Human Genetics Division of Cincinnati's Children's Hospital. A letter will be sent or given to parents of children with VCFS explaining the study, the purpose, procedures, and the benefits they will receive from participation. Once the letter is sent to parents, the researchers will contact parents to participate in the study. After parents agree to participate, they will be given a consent form to sign explaining the purpose, procedures, who to contact for further information on the study, and benefits their child would receive from their participation in this study. Any foreseen risks will also be explained, such as the identification of children with social skill deficits, which may be distressing to the parents. The control group will be obtained by using siblings of the participants involved, matched for demographic variables such as age, educational level and school system. After both groups give consent, the measures will be administered to the VCFS group and the control group. The measures will be counterbalanced to reduce fatigue effect on the last test administered. A debriefing letter will also be sent to the parents by the examiners to explain the purpose of the study and who to contact with further
questions. After the measures are administered and upon completion of the study, the researcher will contact the parents or caregivers and offer the opportunity for them to receive feedback about the social competence and intellectual ability of their child. All information will be kept confidential to protect the parents and children.
Chapter IV

Results

A MANOVA, multivariate design will be the first analysis conducted. This analysis is used to test the difference between more than one dependent variable at one time. Since this study utilizes six dependent variables, the MANOVA will be used to test the difference in means between the two groups on the six different measures of social skills and friendship. All dependent variable means will be run at the same time and this analysis will give an overall level of significance. If it turns out that this overall F value is not significant than there is no statistically significant difference overall and the analysis will stop. If the overall F value is statistically significant at a .05 alpha level than it is important to probe the overall significance to find which dependent variables show a statistically significant difference between the VCFS group and the control group. A MANOVA analysis will control for alpha error and prevent alpha error from increasing.

When the overall level is significant, then a logistic regression analysis is used to determine what would be the best combination of variables to use as predictor variables. A logistic regression analysis is used to do a multiple regression equation with dichotomous criteria. This analysis allows two major functions, the ability to weight highest the predictor variables that discriminate the most between the two groups and to develop independent equations for each group. Logistic regression analysis is recommended over discriminant analysis because a discriminant analysis can sometimes give p values of greater than 1 or less than 0, where logistic regression does not. This analysis also does not give restrictive assumptions that must be fulfilled, such as linearity or homoscendascity.
Chapter V

Discussion

Based on past research, it is hypothesized that children with VCFS will have mean scores on the social skills and friendship measures that are statistically significantly lower than the control group. In past studies, it has been found that VCFS children do exhibit social interaction difficulties, yet no specific studies have been done. Based on the current study, the expected results will be that the VCFS group of children will have difficulty reading a social situation and specifically they will have lower mean scores on each dependent variable that measures this ability. This result will logically follow research that states that children with VCFS have difficulties appreciating subtle social cues. It would also follow that these children will have fewer quality friendships as compared to the control group of children. Children who have difficulties interacting with others, will probably have fewer intimate friendships.

The results of this study will have important implications for intervention programs for children with VCFS. If the hypotheses are confirmed, it will be important for parents of children with VCFS to involve their children in appropriate early intervention programs, especially in the areas of social skills. Future research is still needed in order to assess other social skills and to track these skills over time to see if improvement is noted with intervention programs.

The findings will need to be interpreted with caution given various limitations of this study. First, the sample size is small, but still large enough for this new area of research. One does need to be cautious in generalizing from this one investigation. Secondly, a cross-sectional design was utilized rather than a longitudinal design. Future
research needs to assess the same child longitudinally in order to more definitively document these findings. Third, there are other factors independent of whether the child had VCFS or not that may affect development of social skills. Factors such as socioeconomic status of the family and quality of the family environment and modeling of social skills by parents may affect the social skill development. Despite these limitations, the results from this study will provide preliminary evidence pertaining to the possible social skill deficits that occur in children with VCFS.
References


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Appendices
Appendix A: The Perceived Competence Scale for Children
**What I Am Like**

<table>
<thead>
<tr>
<th>Really True for me</th>
<th>Sort of True for me</th>
<th>Sample Sentence</th>
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<tbody>
<tr>
<td>Some kids would rather play outdoors in their spare time</td>
<td>BUT</td>
<td>Other kids would rather watch T.V.</td>
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<tr>
<td>Some kids feel that they are very good at their school work</td>
<td>BUT</td>
<td>Other kids worry about whether they can do the school work assigned to them.</td>
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<tr>
<td>Some kids find it hard to make friends</td>
<td>BUT</td>
<td>Other kids find it’s pretty easy to make friends.</td>
</tr>
<tr>
<td>Some kids do very well at all kinds of sports</td>
<td>BUT</td>
<td>Other kids don’t feel that they are very good when it comes to sports.</td>
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<tr>
<td>Some kids are happy with the way they look</td>
<td>BUT</td>
<td>Other kids are not happy with the way they look.</td>
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<tr>
<td>Some kids often do not like the way they behave</td>
<td>BUT</td>
<td>Other kids usually like the way they behave.</td>
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<tr>
<td>Some kids are often unhappy with themselves</td>
<td>BUT</td>
<td>Other kids are pretty pleased with themselves.</td>
</tr>
<tr>
<td>Some kids feel like they are just as smart as other kids their age</td>
<td>BUT</td>
<td>Other kids aren’t so sure and wonder if they are as smart.</td>
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<tr>
<td>Some kids have a lot of friends</td>
<td>BUT</td>
<td>Other kids don’t have very many friends.</td>
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<th>Really True for me</th>
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<tr>
<td>9. Some kids wish they could be alot better at sports</td>
<td>BUT Other kids feel they are good enough at sports.</td>
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<td>10. Some kids are happy with their height and weight</td>
<td>BUT Other kids feel they are different.</td>
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<td>11. Some kids usually do the right thing</td>
<td>BUT Other kids often don't do the right thing.</td>
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<td>12. Some kids don't like the way they are leading their life</td>
<td>BUT Other kids do like the way they are leading their life.</td>
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<td>13. Some kids are pretty slow in finishing their school work</td>
<td>BUT Other kids can do their school work quickly.</td>
<td></td>
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<td>14. Some kids would like to have alot more friends</td>
<td>BUT Other kids have as many friends as they want.</td>
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<td>15. Some kids think they could do well at just about any new sports activity they haven't tried before</td>
<td>BUT Other kids are afraid they might not do well at sports they haven't ever tried.</td>
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<td>16. Some kids wish their body was different</td>
<td>BUT Other kids like their body the way it is.</td>
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<td>17. Some kids usually act the way they know they are supposed to</td>
<td>BUT Other kids often don't act the way they are supposed to.</td>
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<td>18. Some kids are happy with themselves as a person</td>
<td>BUT Other kids are often not happy with themselves.</td>
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<td>19. Some kids often forget what they learn</td>
<td>BUT Other kids can remember things easily.</td>
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<td>20. Some kids are always doing things with a lot of kids</td>
<td>BUT Other kids usually do things by themselves.</td>
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<td>Question</td>
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<table>
<thead>
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<th>Really True for me</th>
<th>Sort of True for me</th>
<th>Really True for me</th>
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<tbody>
<tr>
<td>33. Some kids <em>don't</em> do well at new outdoor games</td>
<td>Other kids are <em>good</em> at new games right away.</td>
<td></td>
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<tr>
<td>34. Some kids think that they are good looking</td>
<td>Other kids think that they are not very good looking.</td>
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</tr>
<tr>
<td>35. Some kids behave themselves very well</td>
<td>Other kids often find it hard to behave themselves.</td>
<td></td>
</tr>
<tr>
<td>36. Some kids are not very happy with the way they do a lot of things</td>
<td>Other kids think the way they do things is <em>fine</em>.</td>
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Susan Harter, Ph.D., University of Denver, 1985

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Appendix B: The Intention Cue Discrimination Task
Date______  Initials______  ID______  Page____

Story_____

1. Tell me what happened in this story?

________________________________________________________________________

2. Was the other kid ( Were the other kids): 1 - Being mean
   2 - Not being mean
   (3 - It's hard to tell
   4 - Don't know)

3. What would you do if this happened to you?

________________________________________________________________________

4. Do you think that's a good thing or a bad thing to say or do?

Response A    BAD    bad    good    GOOD
              1      2      3      4

Response B    BAD    bad    good    GOOD
              1      2      3      4

Response C    BAD    bad    good    GOOD
              1      2      3      4

Story_____

1. What happened?

________________________________________________________________________

2. Was the other kid ( Were the other kids): 1 - Being mean
   2 - Not being mean
   (3 - It's hard to tell
   4 - Don't know)

3. What would you do if this happened to you?

________________________________________________________________________

4. Do you think that's a good thing or a bad thing to say or do?

Response A    BAD    bad    good    GOOD
              1      2      3      4

Response B    BAD    bad    good    GOOD
              1      2      3      4

Response C    BAD    bad    good    GOOD
              1      2      3      4
Appendix C: The Affective Perspective Taking Task
3. Debbie/Paul has three friends who are playing with her/him at her/his house. Her/his Dad comes home and surprises her/him with tickets to the circus for Saturday afternoon. There are five tickets: two for her/his mom and dad, one for Debbie/Paul, and two for her/his friends. There is a problem here because Debbie/Paul cannot take all three friends, and no more tickets can be bought. Debbie/Paul must decide who will go to the circus. Susan/John is Debbie's/Paul's best friend and sometimes gets hurt feelings if she's/he's not included. Jenny/Brian is not as close a friend, but her/his family doesn't have much money, and she/he doesn't get to do many fun things. Wendy/Steve just moved here a few weeks ago. She/he really wants to make new friends, and last week she/he and her/his family took Debbie/Paul to a movie.

1. What are all the things you would be thinking about if you had to solve this problem? (What are the things that are important to solve this problem? Pretend you are Debbie/Paul. Probe: anything else, etc.)

2. How many ways can you solve this problem? (Any other ways?)

3. What might happen if (read each solution from 2.)? (Anything else?)

4. What do you think would be the best way to solve the problem? Why? (Make sure they choose one solution as best.)
A. Andy/Sally is the boss while his/her Mother is out. He/she is babysitting for his/her younger brother/sister while their mother is out. Before their mother left, she reminded Andy/Sally not to let his/her younger brother/sister Dave/Barbara use the frisbee he/she just brought into the house. While their mother is out Dave's/Barbara's friend Pete/Joan comes over for a visit. While Pete/Joan is there he/she finds the frisbee and throws it across the room. The frisbee strikes a plant that is sitting on the window ledge and knocks it off, breaking a lamp. Just then, the mother comes home. Now, there is a problem: who should clean up the mess and pay for the lamp?

1. What are all the things you would be thinking about if you had to solve this problem? (What are the things that are important to solve this problem? Pretend you are Andy/Sally. Probe: anything else, etc.)

2. How many ways can you solve this problem? (Any other ways?)

3. What might happen if (read each solution from 2.)? (Anything else?)

4. What do you think would be the best way to solve the problem? Why? (Make sure they choose one solution as best.)
Appendix D: Purdue Elementary Problem Solving Inventory
How many books are on the shelves?

Who put the bookcase where it is?

Where will he set the books when he gets to the shelf?

Ask the boy who is sitting in the corner to help.

Put the books in the box.

Place the books on top of the bookshelf.

Set the books on the table.

Push the table over by the shelf.

Kick the box out of the way.
A: All the big boys go on one team.

B: All the boys with glasses go on one team.

C: They should choose sides evenly.

A: Out in the hallway.

B: In boxes under the bed.

C: In somebody else's room.

A: Empty out the drawers.

B: Carry it up just like it is.

C: Carry the drawers up first.
A

GET A HIGHER CHAIR.

B

PLACE A PIECE OF FOLDED PAPER UNDER ONE LEG.

C

PRESS DOWN HARDER WITH HER PENCIL.

A

PUT A PIECE OF CARDBOARD OVER THE WINDOW PANE.

B

PUT THE CHAIR IN FRONT OF THE WINDOW.

C

BUILD A FIRE IN THE FIREPLACE.

A

CUT THE STRING.

B

MAKE THE KITE HEAVIER.

C

PUT A TAIL ON THE KITE.
A: The light might not work.
B: He might hit his head on the ceiling.
C: He might fall off the chair and get hurt.

A: She will get a pink color.
B: She will spill all of it.
C: The paint will dry up.

A: The cabinet might fall over.
B: The shelf might break under the load.
C: The boxes might not fit.

A: They will take turns playing with it.
B: One of the girls will win.
C: The doll may rip.
A
CHECK HER WORK.

B
WRITE A LETTER TO A FRIEND.

C
COPY HER ANSWERS ON ANOTHER PIECE OF PAPER.

A
EMPTY THE TUB OF WATER.

B
GO AND GET A TOWEL.

C
MAKE SURE THE TUBE DOESN'T HAVE A HOLE IN IT.

A
WATCH OUT FOR ICE ON THE STAIRS.

B
SLIDE DOWN THE RAIL.

C
MAKE A SNOWMAN ON THE STEPS.

A
STOP AND DRINK SOME OF THE COKE.

B
CHECK TO SEE IF THEY GOT THE RIGHT CHANGE.

C
PLAY WITH THE TOY ON THE WAY HOME.

Page 13
A  
THE BASEBALL MIGHT 
HIT THE MAN.

B  
THE BASEBALL MIGHT 
BREAK A WINDOW.

C  
THE LITTLE BOY MIGHT 
CATCH THE BALL.

A  
THE BOY'S DOG IS 
LOST.

B  
THE BOY BROKE THE 
DOG'S ROPE.

C  
THE BOY THINKS HIS 
DOG HAS RUN AWAY.

A  
THE BOY SEES SOMETHING THAT SURPRISES HIM.

B  
THE BOY IS AFRAID IT WILL RAIN.

C  
THE BOY IS AFRAID HIS TENT WILL FALL DOWN.

A  
THE BOY IS CRYING BECAUSE HIS BOAT IS TOO SMALL.

B  
HE IS CRYING BECAUSE HIS BOAT HAS FLOATED TOO FAR AWAY.

C  
HE IS CRYING BECAUSE HE HAS TO GO HOME NOW.
A
THE GIRL WANTS TO
KNOW HOW TO PLAY THE
GAME.

B
THE GIRL WANTS TO
KNOW IF SHE HAS WON.

C
THE GIRL WONDERS WHERE
HER OTHER PLAYING
PIECE IS.
A
WHY IS THE DOOR SO BIG?

B
WHY IS IT SHOWING?

C
WHY IS THE SMALL BOY TRYING SO HARD TO OPEN THE DOOR?

A
WHAT CAN YOU SEE FROM THE WINDOW?

B
IS THE WOMAN SCOLDING THE BOYS?

C
WHY IS THERE A PICTURE ON THE WALL?

A
WERE THE 3 BOYS MEAN TO THE SMALL BOY?

B
ARE THE BOOKS INTERESTING?

C
CAN THEY GET A DRINK?
A
WHY IS THE TREE SO SMALL?

B
WHY ARE THE KIDS PULLING ON THE TREE?

C
WHY IS THE GIRL WEARING A STRIPED DRESS?

A
WHY IS THE HOUSE SO LARGE?

B
WHY IS THE GIRL RUNNING TOWARD THE BOYS?

C
IS THE SMALL BOY HER BROTHER?

A
WHY ARE THE BOYS NEAR THE SIDEWALK?

B
DID THE GIRL COME OUT OF THE HOUSE?

C
WHY IS THE DOG BARKING AT THE BOYS?
A

THE BLACK CAR SLID ON ICE.

B

THE WHITE CAR WAS GOING TOO FAST.

C

THE SUN WAS TOO BRIGHT.

A

THE SUN BLINDED THE DRIVER OF THE BLACK CAR.

B

THE STOP SIGN WAS TOO SMALL TO SEE.

C

THE BLACK CAR WAS DRIVING TOO FAST TO STOP.

A

SHOULD I TAKE OAK OR MAIN STREET?

B

WHAT IS THE ADDRESS OF THE A & P STORE?

C

HOW FAR IS IT TO THE A & P STORE?

A

WILL WE STILL GET RECESS AFTER THE REPORT?

B

DID Geronimo Kill General Custer?

C

HOW LONG SHOULD THE REPORT BE?
Appendix E: The Friendship Questionnaire
**Friend Relationship Questionnaire - Child**

First Name/Subject Number __________________________

Boy _____  Girl _____  Age _____  Grade _____

**INSTRUCTIONS:** A lot of people have different kinds of friends. We want to find out how things are between you and one of your friends.

Name of friend ______________ Is this person a boy ___ or a girl ___? Please check one.

Circle the one number that best describes your relationship with your friend.

<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. How long have you known your friend?</td>
<td>1. Less than 6 months</td>
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<td></td>
<td>2. 6 months</td>
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<td></td>
<td>3. 1 - 2 years</td>
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<td>4. 2 - 3 years</td>
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<td></td>
<td>5. 3 - 5 years</td>
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<td></td>
<td>6. More than 5 years</td>
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<tr>
<td>2. How long has this person been your friend?</td>
<td>1. Less than 6 months</td>
</tr>
<tr>
<td></td>
<td>2. 6 months - 1 year</td>
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<td></td>
<td>3. 1 - 2 years</td>
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<td></td>
<td>4. 2 - 3 years</td>
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<tr>
<td></td>
<td>5. 3 - 5 years</td>
</tr>
<tr>
<td></td>
<td>6. More than 5 years</td>
</tr>
<tr>
<td>3. Some friends really care about each other, while others don't care</td>
<td>1. Hardly at all</td>
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<td>very much. How much do you and this friend care about each other?</td>
<td>2. Not too much</td>
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<td>3. Somewhat</td>
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<td>4. Very much</td>
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<td></td>
<td>5. Extremely much</td>
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<td>4. How much do you and your friend disagree and quarrel with each other?</td>
<td>1. Hardly at all</td>
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<td></td>
<td>2. Not too much</td>
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<td></td>
<td>3. Somewhat</td>
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<td>4. Very much</td>
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<td></td>
<td>5. Extremely much</td>
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<td>5. How much do you and your friend cooperate with each other?</td>
<td>1. Hardly at all</td>
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<td>2. Not too much</td>
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<td>3. Somewhat</td>
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<td>4. Very much</td>
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<td>5. Extremely much</td>
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<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
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</table>
| 6. Who is better at school work, you or your friend?                     | 1. He/she is a lot better  
2. He/she is a little better  
3. We are about the same  
4. I am a little better  
5. I am a lot better |
| 7. Who cares more about each other, you or your friend?                 | 1. This friend cares a lot more  
2. This friend cares a little more  
3. We care about the same  
4. I care a little more  
5. I care a lot more |
| 8. Some friends insult each other a lot, while others insult each other a little. How much do you and your friend insult and call each other names? | 1. Hardly at all  
2. Not too much  
3. Somewhat  
4. Very much  
5. Extremely much |
| 9. How much do you and your friend like the same things?                | 1. Hardly at all  
2. Not too much  
3. Somewhat  
4. Very much  
5. Extremely much |
| 10. How much do you and your friend tell each other everything?          | 1. Hardly at all  
2. Not too much  
3. Somewhat  
4. Very much  
5. Extremely much |
| 11. How much do you tell your friend what to do?                         | 1. Hardly at all  
2. Not too much  
3. Somewhat  
4. Very much  
5. Extremely much |
2. Not too much  
3. Somewhat  
4. Very much  
5. Extremely much |
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<tr>
<th>Question</th>
<th>Options</th>
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<tr>
<td>13. How much do you and your friend try to out-do or beat each other at</td>
<td>1. Hardly at all</td>
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<td>things?</td>
<td>2. Not too much</td>
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<td></td>
<td>3. Somewhat</td>
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<td></td>
<td>4. Very much</td>
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<td>5. Extremely much</td>
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<td>14. How much do you and your friend admire each other?</td>
<td>1. Hardly at all</td>
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<td></td>
<td>2. Not too much</td>
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<td></td>
<td>3. Somewhat</td>
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<td>4. Very much</td>
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<td>5. Extremely much</td>
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<td>15. Who is better at sports, you or your friend?</td>
<td>1. He/she is a lot better</td>
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<td></td>
<td>2. He/she is a little better</td>
</tr>
<tr>
<td></td>
<td>3. We are about the same</td>
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<td></td>
<td>4. I am a little better</td>
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<td></td>
<td>5. I am a lot better</td>
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<td>16. Who insults and calls each other names more, you or your friend?</td>
<td>1. My friend does a lot more</td>
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<td></td>
<td>2. My friend does a little more</td>
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<td></td>
<td>3. We do about the same amount</td>
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<td></td>
<td>4. I do a little more</td>
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<td></td>
<td>5. I do a lot more</td>
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<td>17. How much do you get mad at your friend when she/he spends time with</td>
<td>1. Hardly at all</td>
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<td>other people?</td>
<td>2. Not too much</td>
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<td></td>
<td>3. Somewhat</td>
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<td></td>
<td>4. Very much</td>
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<td></td>
<td>5. Extremely much</td>
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<tr>
<td>18. How much does your friend get mad at you when you spend time with</td>
<td>1. Hardly at all</td>
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<tr>
<td>other people?</td>
<td>2. Not too much</td>
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<td>3. Somewhat</td>
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<td>4. Very much</td>
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<td></td>
<td>5. Extremely much</td>
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<td>19. How much do you and your friend go places and do things together?</td>
<td>1. Hardly at all</td>
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<td></td>
<td>2. Not too much</td>
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<td>3. Somewhat</td>
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<td>4. Very much</td>
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<td>5. Extremely much</td>
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</tbody>
</table>
| 20. Who is more popular, you or your friend?                            | 1. He/she is a lot more  
2. He/she is a little more  
3. We are about the same  
4. I am a little more  
5. I am a lot more                                                   |
| 21. How much do you and your friend love or really like each other?     | 1. Hardly at all  
2. Not too much  
3. Somewhat  
4. Very much  
5. Extremely much                                                      |
| 22. Some kids get mad at and get in fights with their friend a lot, while other kids do this a little. How much do you and your friend get mad at and get in fights with each other? | 1. Hardly at all  
2. Not too much  
3. Somewhat  
4. Very much  
5. Extremely much                                                      |
| 23. How much do you and your friend do nice things for each other?      | 1. Hardly at all  
2. Not too much  
3. Somewhat  
4. Very much  
5. Extremely much                                                      |
| 24. Who is smarter, you or your friend?                                | 1. He/she is a lot smarter  
2. He/she is a little smarter  
3. We are about the same  
4. I am a little smarter  
5. I am a lot smarter                                                   |
| 25. Some kids think they do more nice things for their friend, while other kids think that their friend does more nice things for them. Who does more nice things for each other, you or your friend? | 1. My friend does a lot more  
2. My friend does a little more  
3. We do about the same  
4. I do a little more  
5. I do a lot more                                                        |
| 26. How much do you and your friend bug and pick on each other in mean ways? | 1. Hardly at all  
2. Not too much  
3. Somewhat  
4. Very much  
5. Extremely much                                                      |
<table>
<thead>
<tr>
<th>Question</th>
<th>Option 1</th>
<th>Option 2</th>
<th>Option 3</th>
<th>Option 4</th>
<th>Option 5</th>
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<td>private feelings with each other?</td>
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<tr>
<td>30. Some friends look up to and feel proud of each other, while others</td>
<td>1. Hardly at all</td>
<td>2. Not too much</td>
<td>3. Somewhat</td>
<td>4. Very much</td>
<td>5. Extremely much</td>
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<tr>
<td>do not look up to and feel proud of their friends. How much do you and</td>
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<tr>
<td>your friend look up to and feel proud of each other?</td>
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<tr>
<td>31. Who is better at games you play outside, you or your friend?</td>
<td>1. He/she is a lot better</td>
<td>2. He/she is a little better</td>
<td>3. We are about the same</td>
<td>4. I am a little better</td>
<td>5. I am a lot better</td>
</tr>
<tr>
<td>32. Who tries to out-do or beat each other more, you or your friend?</td>
<td>1. My friend does a lot more</td>
<td>2. My friend does a little more</td>
<td>3. We do about the same</td>
<td>4. I do a little more</td>
<td>5. I do a lot more</td>
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<thead>
<tr>
<th>Question</th>
<th>Options</th>
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<tbody>
<tr>
<td>34. How much does your friend want you only to do things with him/her?</td>
<td>1. Hardly at all</td>
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<td>2. Not too much</td>
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<td>3. Somewhat</td>
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<td>4. Very much</td>
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<td></td>
<td>5. Extremely much</td>
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<tr>
<td>35. How much do you play around and have fun with your friend?</td>
<td>1. Hardly at all</td>
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<td>2. Not too much</td>
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<td>3. Somewhat</td>
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<td>4. Very much</td>
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<td></td>
<td>5. Extremely much</td>
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<tr>
<td>36. Who has more friends, you or your friend?</td>
<td>1. He/she has a lot more</td>
</tr>
<tr>
<td></td>
<td>2. He/she has a few more</td>
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<td></td>
<td>3. We have about the same</td>
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<tr>
<td></td>
<td>4. I have a few more</td>
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<td></td>
<td>5. I have a lot more</td>
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<tr>
<td>37. Some kids argue with their friend a great deal, while other kids</td>
<td>1. Hardly at all</td>
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<td>argue with their friend a little. How much do you and your friend</td>
<td>2. Not too much</td>
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<tr>
<td>argue with each other?</td>
<td>3. Somewhat</td>
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<td></td>
<td>4. Very much</td>
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<td></td>
<td>5. Extremely much</td>
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<tr>
<td>38. How much do you and your friend share things with each other?</td>
<td>1. Hardly at all</td>
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<td></td>
<td>2. Not too much</td>
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<td></td>
<td>3. Somewhat</td>
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<td>4. Very much</td>
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<td></td>
<td>5. Extremely much</td>
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<tr>
<td>39. Who learns things more easily, you or your friend?</td>
<td>1. He/she learns a lot more easily</td>
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<tr>
<td></td>
<td>2. He/she learns a little more easily</td>
</tr>
<tr>
<td></td>
<td>3. We learn with about the same ease</td>
</tr>
<tr>
<td></td>
<td>4. I learn a little more easily</td>
</tr>
<tr>
<td></td>
<td>5. I learn a lot more easily</td>
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<tr>
<td>Question</td>
<td>Options</td>
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</tbody>
</table>
| 40. Who wants to do more things together, you or this friend? | 1. This friend wants to a lot more  
2. This friend wants to a little more  
3. We want to about the same  
4. I want to a little more  
5. I want to a lot more |
| 41. How much do you and your friend think highly of each other? | 1. Hardly at all  
2. Not too much  
3. Somewhat  
4. Very much  
5. Extremely much |
| 42. Some friends are very mean to each other, while others are not very mean. How much are you and your friend very mean to each other? | 1. Hardly at all  
2. Not too much  
3. Somewhat  
4. Very much  
5. Extremely much |
| 43. Some kids are a lot like their friend, while others are pretty different. How much are you and your friend alike? | 1. Hardly at all  
2. Not too much  
3. Somewhat  
4. Very much  
5. Extremely much |
| 44. How much do you tell your friend things that you don't want other people to know? | 1. Hardly at all  
2. Not too much  
3. Somewhat  
4. Very much  
5. Extremely much |
| 45. How much do you and your friend think each other is good at many things? | 1. Hardly at all  
2. Not too much  
3. Somewhat  
4. Very much  
5. Extremely much |
| 46. Who is better in gym, you or your friend? | 1. He/she is much better  
2. He/she is a little better  
3. We are about the same  
4. I am a little better  
5. I am much better |
### Questionnaire:

1. **47. Some kids think that they disagree and quarrel more than their friend, while other kids think that their friend disagrees and quarrels more. Who disagrees and quarrels with each other more, you or your friend?**
   - 1. My friend does a lot more
   - 2. My friend does a little more
   - 3. We do about the same amount
   - 4. I do a little more
   - 5. I do a lot more

2. **48. How much do you get upset when your friend goes places with other people?**
   - 1. Hardly at all
   - 2. Not too much
   - 3. Somewhat
   - 4. Very much
   - 5. Extremely much

3. **49. How much does your friend get upset when you go places with other people?**
   - 1. Hardly at all
   - 2. Not too much
   - 3. Somewhat
   - 4. Very much
   - 5. Extremely much

4. **50. How much free time do you and your friend spend together?**
   - 1. Hardly any
   - 2. Not too much
   - 3. Some time
   - 4. Quite a bit of time
   - 5. A lot of time

5. **51. Who do kids like more, you or your friend?**
   - 1. Kids like my friend a lot more
   - 2. Kids like my friend a little more
   - 3. Kids like us about the same
   - 4. Kids like me a little more
   - 5. Kids like me a lot more
Appendix F: Parent/Guardian Informed Consent Form
Children's Hospital Medical Center Consent to Participate in a Research Study
The Social Skills and Cognitive Functioning of Children with Velo-Cardio-Facial Syndrome

Before agreeing that my child or I will participate in this study, it is important that I read and understand the following explanation. It describes, in words that can be understood by a lay person, the purpose, procedures, benefits, risks and discomforts of the study and the precautions that will be taken. It also describes the alternatives available and the rights to withdraw from the study at any time. It is important to understand that no guarantee or assurance can be made as to the results of the study. It is also understood that refusal to participate will not influence the availability of standard medical treatment.

OBJECTIVES OF THE STUDY:

I, ___________________________ of ___________________________, have been asked for my children ____________________________, ____________________________ and ____________________________, ____________________________ to participate in a research study.

The purpose of the present study is to assess how children with VCFS are functioning cognitively, academically, emotionally, and socially relative to their unaffected siblings.

PROCEDURES:

Trained doctoral students in clinical psychology from Xavier University will assess both children with VCFS and their sibling. Each child will be assessed individually. To assess intelligence and academic performance, the Weschler Intelligence Scale for Children - Third Edition (WISC-III) and Weschler Individual Achievement Test (WIAT) will be administered. Five measures will be administered to assess social skills: Self Perception Profile for Children, Intention-Cue Discrimination Task, Affective Perspective Taking Task, Purdue Elementary Problem Solving Inventory, and The Friendship Questionnaire.

BENEFITS:

The benefit for children with VCFS will be information to help guide academic decisions. Following your child's participation, you will receive a report of the assessment findings for your child, which will include: a summary and interpretation of the intelligence, achievement, and social skill measures scores. If you are a parent of a child who is seen by the Craniofacial Center you will be asked to share the results from the study with the...
team to assist in the child’s care. In addition, a brief report of test results will be provided about the unaffected sibling.

**RISKS, DISCOMFORTS AND PRECAUTIONS:**

The main discomfort for the participants is that procedures are lengthy and may be boring. Participants will be monitored throughout the procedures. Periodic breaks will be taken as needed by the child. If a child becomes too disruptive or agitated, assessment procedures will be rescheduled. Any adverse effects from the assessment procedures will be reported to Children’s Hospital Medical Center Institutional Review Board.

**ALTERNATIVES:**

If you decide not to participate in this research study, all medical care through the Genetics Division at Children’s Hospital Medical Center will still remain available for your child. There are no consequences if you decide not to have your child participate in this study.

**CONFIDENTIALITY:**

To protect confidentiality, materials will be identified by a number rather than the patient’s name. In addition, materials will be kept in a locked cabinet. As the parent or legal guardian, you will have control over who will receive the study results. Children’s Hospital Medical Center Institutional Review Board may also have access to the patient’s record.

**AVAILABILITY OF INFORMATION:**

The research study investigators will be available to answer any questions that the participants or parent/guardian may raise relevant to the study, including the research, the research participants’ rights and whom to contact in the event of a research-related injury.

Please direct any questions related to the study to the two primary investigators: Janet R. Schultz, Ph.D. at Xavier University (513) 745-3248 or Howard Saal M.D. at Children’s Hospital Medical Center (513) 636-4760.

For information regarding the research participant’s rights, please contact the Chairman of the Children’s Hospital Medical Center Institutional Review Board: Irwin Light, M.D. (513) 636-8039.

**THE RIGHT TO WITHDRAW:**

You are free to withdraw from this investigation at any time. Withdrawal from the study will not jeopardize access to health care and standard therapy will remain available in the event of withdrawal.
Any significant new findings developed during the course of the research, which may relate to a participant’s willingness to continue to participate will be provided to participants.

**WITNESSING AND SIGNATURES:**

Based on the information provided above and having had the opportunity to discuss any concerns with investigator or her designee I voluntarily consent for myself/my child to participate in this research study.

Subject’s signature indicating consent or assent

________________________________________

Mother/Legal Guardian

________________________________________

Father

________________________________________

Investigator or specific individual who has been designed to obtain consent

________________________________________

Witness as to voluntary signature

________________________________________

Date

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Appendix G: Child Assent Form
CHILD/MINOR ASSENT FORM

I, ___________________________________________ understand that my parents (mom and dad) have given permission (said it’s okay) for me to take part in a project about children with Velo-Cardio-Facial Syndrome under the direction of Janet R. Schultz, Ph.D. and Howard Saal, M.D.

I am taking part because I want to. I have been told that I can stop at any time I want to and nothing will happen to me if I want to stop.

_________________________________________
Signature
Developmental History Questionnaire

Please respond to the following questions as they apply to your child with velo-cardio-facial syndrome (VCFS).

Name of Child with VCFS ______________________ Date of Birth __________________

1. At what age was your child diagnosed with VCFS? ____________________________

2. Regarding school performance:
   (a) Has your child repeated any grades? ______________________________________
   (b) If yes, what grade(s)? _____________________________________________
   (c) Is your child enrolled in special education classes? ______________________
   (d) If yes, what kind? _________________________________________________

3. Previous psychological testing:
   (a) Has your child received previous psychological or intelligence testing? _____
   (b) If so, when? ______________________________________________________
   (c) What tests were given? _____________________________________________

Please respond to the following questions as they apply to your child who does not have velo-cardio-facial syndrome (VCFS).

Name of Child _______________________ Date of Birth _________________________

4. At what age was your child diagnosed with VCFS? ____________________________

5. Regarding school performance:
   (a) Has your child repeated any grades? _________________________________
   (b) If yes, what grade(s)? _____________________________________________
   (c) Is your child enrolled in special education classes? ______________________
   (d) If yes, what kind? _________________________________________________

6. Previous psychological testing:
   (a) Has your child received previous psychological or intelligence testing? _____
   (b) If so, when? ______________________________________________________
   (c) What tests were given? _____________________________________________

Please respond to the following questions as they relate to other members of the family.

7. What is the mother's highest level of education? ___________________________

8. What is the father's highest level of education? ___________________________

9. Has anyone else in the family been diagnosed with VCFS? __________________

10. If so, who? _________________________________________________________

11. Has anyone had learning disabilities? _________________________________

12. If so, who? _________________________________________________________

13. Is there any history of mental retardation in the family? __________________

14. Are there members of the family who are considered gifted? _______________
Appendix I: Xavier University IRB form
APPLICATION FOR FULL COMMITTEE REVIEW - COVER PAGE

XAVIER UNIVERSITY
INSTITUTIONAL REVIEW BOARD
Application for Approval of Research Involving
the Use of Human Subjects

APPLICATION FOR FULL COMMITTEE REVIEW

PRINCIPAL INVESTIGATOR
Shannon Jonson, M.A.

University
Title: Psy D Student
Dept. Psychology
Is P.I. Sponsor/Advisor Only: No

Phone Number: 533-9252

Department
Title: Psy D Student
Dept. Psychology

SUBMISSION DATE: 6/16/01

PROJECT TITLE
Therapeutic Skills - Cognitive Functioning of Children with Velocardio-Facial Syndrome

NAMES/DEGREES OF ALL OTHER INVESTIGATORS:

Jana K. Schmitt, Ph.D., ABD
Howard Sadik, M.D.

PROCEDURES
(List all procedures to be done for purposes of the study, including surveys, charts, reviews, etc.)

TRAINING GRADUATE STUDENTS IN CLINICAL PRACTICE: Triennially, IV will assess psychological status of children with Cattell-Watson Individual Achievement Test. Children will be administered the 

WILL HIV testing be performed for research purposes?
□ Yes □ No

WILL ANY RADIOACTIVE TESTING BE PERFORMED FOR RESEARCH PURPOSES?
□ Yes □ No

DRUGS & DEVICES:

List all approved drugs and/or devices being studied:

List all new drugs and/or devices and all approved ones being investigated for a new use. Each drug or Significant-Risk device must have an exemption number from the FDA.

NAME IN DENT/ID #: 42151

FUNDING:

□ Federal Govt. □ Other Govt. (i.e., State, City, WHO)

□ Pharmaceutical/Device Co. □ Other Private

□ Campus & University-wide Programs □ Departmental

Agency/Sponsor Name: [Specify if not known]

FUNDING: Will this study be funded?
□ Yes □ No □ Pending

□ Study Sponsor

□ Third Party Carriers (Insurance, etc.)

□ Subject

□ Other (Specify Investigator)

If yes, discuss in detail within the protocol.

REPRODUCED WITH PERMISSION OF THE COPYRIGHT OWNER. FURTHER REPRODUCTION PROHIBITED WITHOUT PERMISSION.
Title of Study: The Social Skills and Cognitive Functioning of Children with Velo-Cardio-Facial Syndrome (VCFS)

- This study has already received full approval by the Cincinnati Children's Hospital Medical Center IRB on April 20, 2001.

1. STUDY AIM/PURPOSE: VCFS is a relatively newly identified syndrome. Clinical reports suggest that children with VCFS have impairments in many areas of functioning. The purpose of the present study is to assess how children with VCFS are functioning cognitively, academically, emotionally, and socially relative to their unaffected siblings. The investigators' hypotheses are that children with VCFS will function differently than their unaffected siblings in all areas assessed.

2. BACKGROUND:
   Social and Emotional Outcomes
   Children with VCFS have been described as deficient in their social skills, lacking both quality and quantity of interactions (Golding-Kushner et al., 1985). Pope and Ward (1997), in a study of preadolescent children with craniofacial anomalies, found that those with less social competence reported being more socially anxious and more dissatisfied with their peer relationships. In that study, parents described these children as experiencing internalizing problems and withdrawing socially. This study concluded that poor social competence was related to dissatisfaction with appearance. Lipson et al. (1991) suggested that social withdrawal of children with VCFS may be at least partially due to the frustration experienced as a result of speech difficulties. Difficulties in social interaction may also be affected by how others perceive children with VCFS. In addition to VCFS altering the appearance of some patients with the syndrome, these children also may be perceived as lethargic due to exhibiting little facial expression and often a low volume, monotone voice (Golding-Kushner et al., 1985). A further complication with communication is that children with VCFS show decreased expressive vocabulary and are deficient in their general fund of knowledge (Golding-Kushner et al., 1985).

   Late onset psychosis is also a well-recognized feature of 22q11 deletion. Ten to 22% of individuals with 22q11 deletion develop major psychiatric disorders, most commonly paranoid schizophrenia and bipolar affective disorder (Goethelf et al., 1999; Papalos et al., 1996; Thomas & Graham, 1997). These psychological disorders typically begin to manifest during adolescence or early adulthood. The association of psychosis with 22q11 deletion is unknown at this time. Additionally, patients with VCFS may also have severe vegetative symptoms such as loss of appetite, low energy, low self esteem, poor concentration, and difficulty making decisions (Goldberg et al., 1993).
Extremes in behavior are typical for many children with VCFS; for example, some individuals are disinhibited and impulsive, while others are more serious and shy. Swillen et al. (1997) found a typical behavioral profile of children with VCFS. Specifically, children were found to have significant scores in areas of attention problems, social problems, thought problems, and withdrawal. From this study, researchers concluded that children and adolescents with VCFS may exhibit social problems and problems with attention and concentration. In general, poor social interactions, bland affect, loss of interest in life, and generalized anxiety have also been observed in VCFS children. Older children with VCFS are also at risk for developing psychiatric disorders such as schizophrenia and depression. Common symptoms reported by adolescent and adults with VCFS are those associated with anxiety and depressive disorders, such as disturbed mood, severe vegetative symptoms, disturbed appetite, fatigue, and low self-esteem (Swillen et al., 1997; Thomas & Graham, 1997).

The physiological basis for these cognitive and behavioral disorders is unknown. Brain anomalies have been documented in only a few cases and the pattern of anomalies is not consistent (Mitnick, Bello, & Shprintzen, 1994; Thomas & Graham, 1997).

As severe psychological disorders tend to manifest in adolescence, it is important to understand the behavior of children with VCFS. There does not appear to be one distinct behavioral expression of VCFS in the preschool years, rather two extreme patterns have been observed. On the one hand, some children with VCFS have been observed to exhibit extreme shyness and inhibition, while other children show attention problems and social problems (Golding-Kushner, Weller, & Shrintzen, 1985; Gerdes et al., 1999; Swillen, 1997). The social withdrawal in children and adolescents with VCFS might be partially due to their impaired ability to communicate with others. Research also suggests that neuropsychological deficits may contribute to their poor interaction skills. It is important that children with 22q11 deletion and VCFS be monitored for early signs of psychopathology, since early intervention has been shown to lead to improved functioning (Bassett et al., 1998).

Cognitive Functioning
Since the identification of VCFS, learning disabilities have been one of the hallmark characteristics (Shprintzen, 1978). Learning disabilities have been estimated to occur in up to 99% of patients (Goldberg et al., 1993), making it one of the most common features of the disorder. Studies provide evidence for the existence of learning disabilities, yet there is variability in the literature as to the degree of cognitive impairment. Swillen et al. (1997) studied 37 children and adolescents and found 55% of the sample had normal (IQ>86) or borderline (IQ 71-85) functioning. Of the remaining 45% of the sample who had intellectual functioning in the mentally retarded range (IQ<70), 82% had mild mental retardation (IQ 55-69), 12% had moderate mental retardation (IQ<50), and one child had severe mental retardation. The most recent article examining intelligence in children with a 22q11 deletion, found that 3 out of the 4 children studied (all under the age of 5), had IQ’s in the borderline to mentally retarded.

Research has suggested that the degree of cognitive impairment may vary depending on whether it is a familial deletion or de novo, with the incidence of mental retardation being higher for familial deletions. Swillen et al. (1997) found that 70.5% of the children and adolescents in the study with mental retardation had a familial deletion, and that 83% of the cases with a familial deletion had mental retardation, compared to the 28% of mental retardation found in the de novo group. Another factor that may contribute to the discrepancy in the literature is that many studies have included patients who have been diagnosed with VCFS clinically, but not through FISH to verify the presence of a 22q11 deletion. Although in rare cases VCFS occurs without the presence of the deletion, consistent methods of identifying and diagnosing are needed to accurately assess the cognitive functioning of children with VCFS. The most frequently referenced article in this domain, which is also the most comprehensive, is by Golding-Kushner et al. (1985). This is a retrospective, cross-sectional study including 26 children with VCFS who were diagnosed at a craniofacial center. Intelligence tests were administered to 17 of the children, with the tests varying depending on the age of the child. The preschool age group was assessed with the Stanford-Binet and the Leiter International Performance Test, with mean IQ scores of 87 and 84 respectively. The older children were administered the Wechsler Intelligence Scale for Children-Revised (WISC-R). The 8-year-olds performed better on the Performance measures, with a mean IQ of 79, than the 13-year-olds who obtained a mean IQ of 70. However, on the Verbal measures, scores were slightly lower in the 8-year-old group (VIQ of 76) than in the 13-year-old group (VIQ of 79). These findings indicate that cognitive functioning and language abilities were comparatively normal prior to age six, with difficulty arising over time. Previous findings by Shprintzen et al. (1981) supported that older children show decreased performance on intelligence measures. Shprintzen et al. (1981) found that while all of the children who were old enough to be tested had a learning disorder. However, several children who had been assessed prior to age 5, obtained IQ scores within the normal range (between 80-90). Contrary to those findings, a recent study of preschool children who had a 22q11 deletion, found delays even before age 6, with 75% showing mild or significant delays (Gerdes, Solot, Wang, Moss, LaRossa, Randall, Goldmuntz, Clark, Driscoll, Jawad, Emanuel, McDonald-McGrinn, & Zackai, 1999).

In addition to differences in intellectual functioning across ages, research has also suggested a possible difference between the verbal and performance abilities of children with VCFS. Golding-Kushner et al. (1985) found verbal abilities to be more strongly developed than performance abilities for the oldest group of children. Similar to the results found by Golding-Kusher et al. (1985), Swillen et al. (1997) found a difference between the verbal and performance abilities. This study examined a group of children ranging from 8-months to 20-years, finding a statistically significant difference between the total average verbal
IQ (78, SD = 14.7) and average performance IQ (70, SD = 11.3). However, this difference was not true of each group when separated out by age.

**Academic Performance**

School performance and educational level is another important area of concern for children with VCFS. Research suggests that children with VCFS are generally two or more years behind their peers in school performance despite attempts at remediation (Kok & Solman, 1995). Swillen et al. (1997) found that 43% of the children attended regular classes, with each child receiving speech therapy and in need of some remedial teaching, especially for mathematics. In addition, several of these children had to repeat at least one grade. Another study found that 62% of young children were in regular nursery school or kindergarten programs (Golding-Kushner et al., 1985). However, only half of the children in primary school were able to attend regular classes, and several had to repeat grades or were referred to special education classes. Those children who were not enrolled in regular classes were in special classes for the learning disabled. Swillen et al. (1997) found that of those children who did not attend regular classes, 82% were enrolled in schools for the mildly to moderately mentally retarded.

2. **SIGNIFICANCE:** Following previous studies, VCFS significantly impacts main activities in children of the age group being studied. This study will help to determine how the diagnosis impacts central activities such as social and cognitive skills of childhood development. This study may help to formulate intervention strategies for children with VCFS and their families.

3. **METHODS:**

   A. **General Study Design:** A between group design will be used to compare the two groups on several dependent variables. The independent variable will be the diagnostic status (VCFS versus children without VCFS). The children will be assigned to the two different groups based on the diagnosis of 22q11 deletion and VCFS. Those children ages 7-12 at Children’s Hospital Medical Center that have been diagnoses through the Human Genetics department with 22q11 deletion will be in the VCFS group. The dependent variables are measures of social competence, labeling others’ intentions, labeling others’ emotions, inability to detect social problems, recognizing information that is helpful to clarify a problem, the quality of friendships, and the IQ and achievement scores of these two groups of children.

   B. **Methods of Data Analysis:** In order to analyze this data a MANOVA analysis will be run in order to analyze all of the dependent variables at the same time. The means of all dependent variables will be compared between the VCFS group and the control group to determine which variables are statistically significant. A .05 alpha level will be used to determine significance. The significant variables will then be entered into a logistic regression equation using a predictor variable.
The predictor variable will be group (VCFS or child without VCFS). The possible criterion variables will be the significant dependent variables.

C. Subject Selection

1. Who and Why: There will be two groups of participants ages 7-12 years of age. One group will consist of children with VCFS and the other group will consist of children without VCFS. The control group will consist of the siblings of the VCFS individuals and will be the normative sample. These siblings will be in the same age group (8-12 years) as the children with VCFS. The sibling control group will be matched for socioeconomic class because they are part of the same family as the VCFS group. The VCFS group will consist of patients from the Division of Human Genetics at Children's Hospital Medical Center. All individuals in the VCFS group will be confirmed genetically with a 22q11 deletion and VCFS on the basis of a fluorescence in situ hybridization (FISH) analysis.

2. Total Number/Number per Group: A total of 50 participants will be studied, 25 subjects in each the experimental and control conditions.

3. Inclusion/Exclusion criteria: Male and female participants of any ethnic group, between the ages of seven and twelve, will be included in this study. Inclusion in the experimental group requires the presence of the 22q11 deletion as confirmed by fluorescence in situ hybridization (FISH), in addition, having a sibling in the same age range (7-12) without the deletion. Participants with other chronic medical conditions will not be included.

D. Subject Recruitment

1. Source: Participants will be patients of Howard Saal, M.D., Head of Human Genetics at Children's Hospital Medical Center based on the presence of VCFS and if they and their unaffected siblings are in the specified age range.

2. Initial Contact Method: All possible participants will be sent a letter from the investigators which explains the study, purpose, procedures and the benefits they will receive from participation. Once the letter is sent to parents, the researchers will contact parents to participate in the study.

E. Consent Process and Documentation: After parents agree to participate, they will be given a consent form to sign explaining the purpose, procedures, who to contact for further information on the study, and the benefits their child will receive from their participation. Any foreseen risks will also be explained. Verbal assent will be taken from children age eleven and older that are involved in the study.

F. Procedures

1. Study Procedures: After both groups give consent, the measures will be administered on an individual basis to the VCFS group and the control group. After the measures are administered and upon completion of the study, the researchers will provide the parents with a summary of their child's
functioning based on the evaluation. All information will be kept confidential to protect the parents and children.

2. Time: The assessment process is expected to take around four hours per child.

3. Study Sites: The assessment process will take place in the psychology department at Xavier University in Elet Hall.

G. Risks and Discomforts: The main discomfort for the participants is that the procedures and lengthy and may be boring. Participants will be monitored throughout the procedures and periodic breaks will be taken as needed by the child. If a child becomes too disruptive or agitated, assessment procedures will be rescheduled.

H. Treatment and Compensation for Injury: This study is with minimal risk and direct benefit to participants and no injuries are expected. However, any adverse effects from the assessment procedures will be reported to Children’s Hospital Medical Center and Xavier University IRB’s.

I. Alternatives: If the parent and child decide not to participate in the study, all medical care through the Human Genetics Division at Children’s Hospital Medical Center will still remain available for the child. There are no consequences if the parent decides not to have their child participate in this study.

J. Costs to the Subject: There are no costs for the subject.

K. Reimbursement of Subjects: There is no reimbursement for the subjects.

L. Confidentiality of Records: To protect confidentiality, materials will be identified by a number rather than the patient’s name. In addition, materials will be kept in a locked cabinet.

5. QUALIFICATIONS OF INVESTIGATORS: Janet R. Schultz, Ph.D. is a professor of psychology at Xavier University in the Psychology Department and is serving as advisor of the study. Howard Saal, M.D. is the Head of the Division of Human Genetics at Children’s Hospital Medical Center and is also a Professor of Human Genetics. Shannon H. Johnson, M.A. is a fourth year doctoral level graduate student in psychology at Xavier University and is trained to administer all measures. Victoria L. Meier, M.S. is a third year doctoral level graduate student in psychology at Xavier University and is also trained to administer all measures.

6. REFERENCE TO SPECIAL REQUIREMENTS AND ATTACHMENTS: None

7. BIBLIOGRAPHY:


INFORMED CONSENT DOCUMENT

Project Title: The Social Skills and Cognitive Functioning of Children with Velo-Cardio-Facial Syndrome

Investigators: Janet R. Schultz, Ph.D. Psychology Department, Xavier University 745-3248 and Howard Saal, M.D. Children's Hospital Medical Center, Head of Human Genetics 636-8430

You are being asked to participate in a project conducted through Xavier University (and if applicable – any other cooperating institution). The University requires that you give your signed agreement to participate in this project.

The investigator will explain to you in detail the purpose of the project, the procedures to be used, and the potential benefits and possible risks of participation. You may ask him/her any questions you have to help you understand the project. A basic explanation of the project is written below. Please read this explanation and discuss with the researcher any questions you may have.

If you then decide to participate in the project, please sign the last page of this form in the presence of the other person who explained the project to you. You should be given a copy of this form to keep.

1. Nature and Purpose of the Project:
The purpose of the present study is to assess how children with VCFS are functioning cognitively, academically, emotionally, and socially relative to their unaffected siblings.

2. Explanation of Procedures:
Trained doctoral students in clinical psychology from Xavier University will assess both children with VCFS and their sibling. Each child will be assessed individually. To assess intelligence and academic performance, the Weschler Intelligence Scale for Children – Third Edition (WISC-III) and Weschler Individual Achievement Test (WIAT) will be administered. Five measures will be administered to assess social skills: Self Perception Profile for Children, Intention-Cue Discrimination Task, Affective Perspective Taking Task, Purdue Elementary Problem Solving Inventory, and The Friendship Questionnaire.

3. Discomfort and Risks:
The main discomfort for the participants is that procedures are lengthy and may be boring. Participants will be monitored throughout the procedures. Periodic breaks will be taken as needed by the child. If a child becomes too disruptive or agitated, assessment procedures will be rescheduled. Any adverse effects from the assessment procedures will be reported to Children’s Hospital Medical Center Institutional Review Board.

4. Benefits:
The benefit for children with VCFS will be information to help guide academic decisions. Following your child’s participation, you will receive a report of the assessment findings.
for your child, which will include: a summary and interpretation of the intelligence, achievement, and social skill measures scores. In addition, if you are a parent of a child who is seen by the Craniofacial Center you will be asked to share the results from the study with the team to assist in the child’s care.

5. Confidentiality:
To protect confidentiality, materials will be identified by a number rather than the patient’s name. In addition, materials will be kept in a locked cabinet. As the parent or legal guardian, you will have control over who will receive the study results. Children’s Hospital Medical Center Institutional Review Board may also have access to the patient’s record.

6. Refusal/Withdrawal:
If you decide not to participate in this research study, all medical care through the Genetics Division at Children’s Hospital Medical Center will still remain available for your child. There are no consequences if you decide not to have your child participate in this study.

Refusal to participate in this study will have no effect on any future services you may entitled to from the University. Anyone who agrees to participate in this study is free to withdraw from the study at any time with no penalty.

I understand also that it is not possible to identify all potential risks in an experimental procedure, and I believe that reasonable safeguards have been taken to minimize both the known and potential but unknown risks.

____________________________________  _____________
Signature  Date

____________________________________  _____________
Witness  Date

THE DATE APPROVAL STAMP ON THIS CONSENT FORM INDICATES THAT THIS PROJECT HAS BEEN REVIEWED AND APPROVED BY THE XAVIER UNIVERSITY INSTITUTIONAL REVIEW BOARD FOR THE PROTECTION OF HUMAN SUBJECTS IN RESEARCH.
CHILD / MINOR ASSENT FORM

I, _________________________________ understand that my parents (mom and dad) have given permission (said it's okay) for me to take part in a project about children with Velo-Cardio-Facial Syndrome under the direction of Janet R. Schultz, Ph.D. and Howard Saal, M.D.

I am taking part because I want to. I have been told that I can stop at any time I want to and nothing will happen to me if I want to stop.

____________________________________
Signature
Appendix J: Children’s Hospital Medical Center IRB form
I PURPOSE OF STUDY:

VCFS is a relatively newly identified syndrome. Clinical reports suggest that children with VCFS have impairments in many areas of functioning. The purpose of the present study is to assess how children with VCFS are functioning cognitively, academically, emotionally, and socially relative to their unaffected siblings.

II. SIGNIFICANCE OF STUDY IN RELATION TO HUMAN HEALTH:

Following previous studies, VCFS significantly impacts main activities in children of the age group being studied. This study will help to determine how the diagnosis impacts central activities such as social and cognitive skills of childhood development. This study may help to formulate intervention strategies for children with VCFS and their families.

III. PREVIOUS WORK DONE IN THIS AREA:

1. None

2. Social and Emotional Outcomes

Children with VCFS have been described as deficient in their social skills, lacking both quality and quantity of interactions (Golding-Kushner et al., 1985). Pope and Ward (1997), in a study of preadolescent children with craniofacial anomalies, found that those with less social competence reported being more socially anxious and more dissatisfied with their peer relationships. In that study, parents described these children as experiencing internalizing problems and withdrawing socially. This study concluded that poor social competence was related to dissatisfaction with appearance. Lipson et al. (1991) suggested that social withdrawal of children with VCFS may be at least partially due to the frustration experienced as a result of speech difficulties. Difficulties in social interaction may also be affected by how others perceive children with VCFS. In addition to VCFS altering the appearance of some patients with the syndrome, these children also may be perceived as lethargic due to exhibiting little facial expression and often a low volume, monotone voice (Golding-Kushner et al., 1985). A further complication with communication is that children with VCFS show decreased expressive vocabulary and are deficient in their general fund of knowledge (Golding-Kushner et al., 1985).
Late onset psychosis is also a well-recognized feature of 22q11 deletion. Ten to 22% of individuals with 22q11 deletion develop major psychiatric disorders, most commonly paranoid schizophrenia and bipolar affective disorder (Gothelf et al., 1999; Papolos et al., 1996; Thomas & Graham, 1997). These psychological disorders typically begin to manifest during adolescence or early adulthood. The association of psychosis with 22q11 deletion is unknown at this time. Additionally, patients with VCFS may also have severe vegetative symptoms such as loss of appetite, low energy, low self-esteem, poor concentration, and difficulty making decisions (Goldberg et al., 1993).

Extremes in behavior are typical for many children with VCFS; for example, some individuals are disinhibited and impulsive, while others are more serious and shy. Swillen et al. (1997) found a typical behavioral profile of children with VCFS. Specifically, children were found to have significant scores in areas of attention problems, social problems, thought problems, and withdrawal. From this study, researchers concluded that children and adolescents with VCFS may exhibit social problems and problems with attention and concentration. In general, poor social interactions, bland affect, loss of interest in life, and generalized anxiety have also been observed in VCFS children. Older children with VCFS are also at risk for developing psychiatric disorders such as schizophrenia and depression. Common symptoms reported by adolescent and adults with VCFS are those associated with anxiety and depressive disorders, such as disturbed mood, severe vegetative symptoms, disturbed appetite, fatigue, and low self-esteem (Swillen et al., 1997; Thomas & Graham, 1997).

The physiological basis for these cognitive and behavioral disorders is unknown. Brain anomalies have been documented in only a few cases and the pattern of anomalies is not consistent (Mitnick, Bello, & Shprintzen, 1994; Thomas & Graham, 1997).

As severe psychological disorders tend to manifest in adolescence, it is important to understand the behavior of children with VCFS. There does not appear to be one distinct behavioral expression of VCFS in the preschool years, rather two extreme patterns have been observed. On the one hand, some children with VCFS have been observed to exhibit extreme shyness and inhibition, while other children show attention problems and social problems (Golding-Kushner, Weller, & Shrintzen, 1985; Gerdes et al., 1999; Swillen, 1997). The social withdrawal in children and adolescents with VCFS might be partially due to their impaired ability to communicate with others. Research also suggests that neuropsychological deficits may contribute to their poor interaction skills. It is important that children with 22q11 deletion and VCFS be monitored for early signs of psychopathology, since early intervention has been shown to lead to improved functioning (Bassett et al., 1998).

**Cognitive Functioning**

Since the identification of VCFS, learning disabilities have been one of the hallmark characteristics (Shprintzen, 1978). Learning disabilities have been estimated to occur in up to 99% of patients (Goldberg et al., 1993), making it one of the most common features of the disorder. Studies provide evidence for the
existence of learning disabilities, yet there is variability in the literature as to the
degree of cognitive impairment. Swillen et al. (1997) studied 37 children and
adolescents and found 55% of the sample had normal (IQ>86) or borderline (IQ
71-85) functioning. Of the remaining 45% of the sample who had intellectual
functioning in the mentally retarded range (IQ<70), 82% had mild mental
retardation (IQ 55-69), 12% had moderate mental retardation (IQ<50), and one
child had severe mental retardation. The most recent article examining
intelligence in children with a 22q11 deletion, found that 3 out of the 4 children
studied (all under the age of 5), had IQ’s in the borderline to mentally retarded
range (Eliez, Palacio-Espasa, Spira, Lacroix, Pont, Luthi, Robert-Tissot,

Research has suggested that the degree of cognitive impairment may vary
depending on whether it is a familial deletion or de novo, with the incidence of
mental retardation being higher for familial deletions. Swillen et al. (1997) found
that 70.5% of the children and adolescents in the study with mental retardation
had a familial deletion, and that 83% of the cases with a familial deletion had
mental retardation, compared to the 28% of mental retardation found in the de
novo group. Another factor that may contribute to the discrepancy in the
literature is that many studies have included patients who have been diagnosed
with VCFS clinically, but not through FISH to verify the presence of a 22q11
deletion. Although in rare cases VCFS occurs without the presence of the
deletion, consistent methods of identifying and diagnosing are needed to
accurately assess the cognitive functioning of children with VCFS. The most
frequently referenced article in this domain, which is also the most
comprehensive, is by Golding-Kushner et al. (1985). This is a retrospective,
cross-sectional study including 26 children with VCFS who were diagnosed at a
craniofacial center. Intelligence tests were administered to 17 of the children,
with the tests varying depending on the age of the child. The preschool age group
was assessed with the Stanford-Binet and the Leiter International Performance
Test, with mean IQ scores of 87 and 84 respectively. The older children were
administered the Wechsler Intelligence Scale for Children-Revised (WISC-R).
The 8-year-olds performed better on the Performance measures, with a mean IQ
of 79, than the 13-year-olds who obtained a mean IQ of 70. However, on the
Verbal measures, scores were slightly lower in the 8-year-old group (VIQ of 76)
than in the 13-year-old group (VIQ of 79). These findings indicate that cognitive
functioning and language abilities were comparatively normal prior to age six,
with difficulty arising over time. Previous findings by Shprintzen et al. (1981)
supported that older children show decreased performance on intelligence
measures. Shprintzen et al. (1981) found that while all of the children who were
old enough to be tested had a learning disorder. However, several children who
had been assessed prior to age 5, obtained IQ scores within the normal range
(between 80-90). Contrary to those findings, a recent study of preschool children
who had a 22q11 deletion, found delays even before age 6, with 75% showing
mild or significant delays (Gerdes, Solot, Wang, Moss, LaRossa, Randall,
Goldmuntz, Clark, Driscoll, Jawad, Emanuel, McDonald-McGrinn, & Zackai,
1999).
In addition to differences in intellectual functioning across ages, research has also suggested a possible difference between the verbal and performance abilities of children with VCFS. Golding-Kushner et al. (1985) found verbal abilities to be more strongly developed than performance abilities for the oldest group of children. Similar to the results found by Golding-Kushner et al. (1985), Swillen et al. (1997) found a difference between the verbal and performance abilities. This study examined a group of children ranging from 8-months to 20-years, finding a statistically significant difference between the total average verbal IQ (78, SD = 14.7) and average performance IQ (70, SD = 11.3). However, this difference was not true of each group when separated out by age.

Academic Performance

School performance and educational level is another important area of concern for children with VCFS. Research suggests that children with VCFS are generally two or more years behind their peers in school performance despite attempts at remediation (Kok & Solman, 1995). Swillen et al. (1997) found that 43% of the children attended regular classes, with each child receiving speech therapy and in need of some remedial teaching, especially for mathematics. In addition, several of these children had to repeat at least one grade. Another study found that 62% of young children were in regular nursery school or kindergarten programs (Golding-Kushner et al., 1985). However, only half of the children in primary school were able to attend regular classes, and several had to repeat grades or were referred to special education classes. Those children who were not enrolled in regular classes were in special classes for the learning disabled. Swillen et al. (1997) found that of those children who did not attend regular classes, 82% were enrolled in schools for the mildly to moderately mentally retarded.

References


IV. RESEARCH PLAN:

1. A total of 50 subjects will be studied, 25 subjects in each the experimental and control conditions. Subjects will be selected through the Division of Human Genetics.

2. Male and female subjects of any ethnic group, between the ages of 6 and 12, will be included in this study. Inclusion in the experimental group requires the presence of the 22q11 deletion as confirmed by fluorescence in situ hybridization (FISH), in addition having a sibling in the same age range without the deletion. Subjects with other chronic medical conditions will not be included.

3. Randomization is not pertinent to this study, as subject will be assigned to groups based on presence or absence of genetic deletion.

4. Children will be assessed at Children's Hospital Medical Center. Trained doctoral students in clinical psychology at Xavier University will assess both the experimental and control group subjects simultaneously but separately. To assess intelligence and academic performance, the Weschler Intelligence Scale for Children – Third Edition (WISC-III) and Weschler Individual Achievement Test (WIAT) will be administered. To assess microlevel social skills, six measures will be administered in a counter-balanced order to minimize fatigue effects: Self Perception Profile for Children, Intention-Cue Discrimination Task, Affective Perspective Taking Task, Purdue Elementary Problem Solving Inventory, and The Friendship Questionnaire.
5. Achenbach’s Child Behavioral Checklist (CBCL) is a well-standardized assessment procedure. Reliability and validity norms are satisfactory (Sattler, 1992). The developmental questionnaire that will be used is attached.

6. None

7. None

8. Based on a power analysis, it was determined that 25 subjects per group will needed to obtain a power level of .80. To analyze the data the following statistical procedures will be used: analysis of variance (ANOVA) and multiple analysis of variance (MANOVA) will be used to analyze the scores on both cognitive and social skill measures, while R to Z transformation will be used to further analyze cognitive skills and logistic regression will be used to further analyze social skills.

9. The Division of Genetics is the only department from Children’s Hospital Medical Center that will be utilized in this study.

10. None

V. POTENTIAL BENEFITS:

The benefit for children with VCFS will be information to help guide academic decisions. Following their child’s participation, parents will receive a report of the assessment findings for their child, which will include: a summary and interpretation of the intelligence, achievement, and social skill measures scores. In addition, parents of children who are seen by the Craniofacial Center will be asked to share the results from the study with the team to assist in the child’s care. The control group will receive no feedback or benefit. Although no report will be written regarding the unaffected siblings, parents will be notified if there are indications of significant problems in one of these areas.

VI. POTENTIAL RISKS, DISCOMFORTS, INCONVENIENCES, AND PRECAUTIONS:

1. The main discomfort for the participants is that procedures are lengthy and may be boring.
2. Participants will be monitored throughout the procedures. Periodic breaks will be taken as needed by the child. If a child becomes too disruptive or agitated, assessment procedures will be rescheduled.
3. Any adverse effects from the assessment procedures will be reported to Children’s Hospital Medical Center Institutional Review Board.
4. Minimal risk but with direct benefit to participants.
VII. CONFIDENTIALITY:

To protect confidentiality, materials will be identified by a number rather than the patient’s name. In addition, materials will be kept in a locked cabinet. Parents will have control over who will receive the study results.

VIII. PERIOD OF TIME ESTIMATED TO COMPLETE PROJECT AS DESCRIBED:

Data collection will be conducted from December 2000-July 2001

IX. FUNDING

None

X. PAYMENT FOR STUDIES:

There will be no charge or reimbursement for families’ participation in the study.
Chapter VI Dissertation

Abstract

The difference in social skills, friendships, and social competence were compared between children with Velo-Cardio-Facial Syndrome (VCFS) and children without VCFS. Eleven children with VCFS and eleven sibling control children without VCFS ages 7-11 years old completed the Self-Perception Profile for Children, the Intention Cue Discrimination Task, the Affective Perspective Taking Task, the Purdue Elementary Problem Solving Inventory (PEPSI), and the Friendship Questionnaire to measure social skills, friendships, and perceived social competence. The results indicated that children with VCFS had significantly lower scores on multiple measures of social skills. Specifically, children with VCFS displayed more encoding errors, more aggressive responses to problem situations, difficulties understanding others' affect, difficulties with problem solving and less intimate friendships. However, children with VCFS did not score significantly lower on a measure of perceived social competence. These findings suggest that children with VCFS may be more likely to have social skill deficits in the areas of understanding others' intentions and affect, problem solving and they may experience less intimacy and companionship in their friendships. Despite these deficits, it appears that children with VCFS still have similar perceptions of their abilities compared to other children.
The Social Skills and Friendships of Children with Velo-Cardio-Facial Syndrome

Velo-Cardio-Facial Syndrome (VCFS) is a relatively recently recognized congenital malformation syndrome. Patients exhibit features such as typical facial appearance, cleft palate, cardiac malformations, learning disabilities, hearing loss, speech and language impairment, microsomia, social skill deficits, and behavioral impairments (Shprintzen 1981; Shprintzen, 1978; Swillen et. al, 1997). Many children with VCFS are ill as infants with complicated heart malformations, failure-to-thrive, chronic upper and lower respiratory illness, and feeding difficulties (Shprintzen, 2000). The 22q11 chromosome deletion is a defining characteristic of VCFS, with 81% of patients diagnosed with the deletion (Gerdes et al., 1999; Lindsay et al., 1995). An affected person with a known 22q11 deletion has a 50% risk of transmitting the deletion on to his or her children (Driscoll et al., 1993).

Several studies reveal cognitive deficits in individuals with a diagnosis of VCFS. These deficits range from mental retardation (40% to 46% of children with VCFS) to learning disabilities (82% to 100% of children with VCFS) (Carneol, Marks, & Weik, 1999; Gerdes et al., 1999; Golding-Kushner, Weller, & Shprintzen, 1985; Swillen et al., 1997). There has also been reported a wide variability in intelligence of individuals with VCFS. It appears that the global delays and intelligence variations are directly associated with the 22q11 deletion and are not explained by other physical anomalies such as palatal defects or cardiac problems (Gerdes et al., 1999).

Previous studies have found a consistent intelligence profile of children with VCFS. This profile consists of a significant difference in the average verbal IQ and
average performance IQ, with a significantly lower performance IQ score (Henry et al., 2002; Swillen et al., 1997; Swillen et al. 1999). Several case studies suggest similarities in the academic and psychosocial presentation of VCFS and the Nonverbal Learning Disability (NLD) syndrome. NLD syndrome is a cluster of neuropsychological, academic, and social-emotional characteristics that reflect primary deficiencies in nonverbal reasoning (Swillen, 1999; Rourke, 1989). It is important that future research examine these similarities.

Golding-Kushner, Weller, & Shprintzen (1985) found that the thought processes of children with VCFS tend to remain immaturity concrete, as they grow older, with abstract reasoning skills below average. Specifically, children with VCFS have a difficult time understanding concepts and processes used for application to novel stimuli, which may affect their problem solving abilities (Fuerst, Dool, & Rourke, 1995).

Gerdes et al. (1999) found language delays in 84% of the VCFS children studied. Seventy-five percent of the VCFS population had not yet developed any verbal communication at two years of age. Gerdes et al. (1999) found that receptive language skills tend to be better than expressive language. This study concluded that speech intelligibility is the likely cause of many language delays in children with VCFS.

Psychosis is also a well-recognized feature of 22q11 deletion. Ten to 22% of individuals with 22q11 deletion develop major psychiatric disorders, most commonly paranoid schizophrenia and bipolar affective disorder (Gothelf et al., 1999; Papolos et al., 1996; Thomas & Graham, 1997; Murphy, 2001). These psychological disorders typically begin to manifest during adolescence or early adulthood. It has been reported that deletion of chromosome 22q11 represents one of the highest known risk factors for the
development of schizophrenia (Murphy, 2001). Additionally, patients with VCFS may also have severe vegetative symptoms such as loss of appetite, low energy, low self esteem, poor concentration, and difficulty making decisions (Goldberg et al., 1993). All research thus far has shown that psychiatric illness in VCFS is a primary feature of the syndrome and is not secondary to other problems such as social background or histories of illness (Sphritzen, 2000).

A limited number of studies have examined specific emotional and behavioral deficits in children with VCFS. In general, it has been found that extremes in behavior are typical for many children with VCFS; for example, some individuals are disinhibited and impulsive, while others are more serious and shy. Swillen et al. (1997) identified a typical behavioral profile of children with VCFS. Specifically, children were found to have significant scores in areas of attention problems, social problems, thought problems, and withdrawal. From this study, researchers concluded that children and adolescents with VCFS may exhibit social problems and problems with attention and concentration. In general, poor social interactions, bland affect, loss of interest in life, and generalized anxiety have also been observed in VCFS children. The physiological basis for these cognitive and behavioral disorders is unknown. Brain anomalies have been documented in only a few cases and the pattern of anomalies is not consistent (Sphrintzen, 2000; Mitnick, Bello, & Shprintzen, 1994; Thomas & Graham, 1997).

Children with VCFS typically have deficits in the area of social interactions, comprehension of novel situations, and problem solving skills (Thomas & Graham, 1997). Because of these past findings, it was important to further investigate the specific kinds of deficits these children are exhibiting and how this affects their social
competence and friendships. In general, social competence has been defined as the ability to adapt effectively to life situations, interact with the environment, and generate skilled behavior (Dodge, 1986). It was predicted that children with VCFS would have lower levels of social competence compared to children without VCFS.

Hughes & Hall (1987) developed a model of the assessment of social competence in children. This model has been useful in comparing social cognitive processes in socially competent and incompetent children and examining group differences in areas of attributions for peers' social behaviors, selective attention to social cues, cue detection skills, interpersonal cognitive problem-solving skills, outcome expectancies for social behaviors, empathy, and perspective-taking abilities.

Specifically Hughes & Hall's (1987) analysis of social competence emphasizes the child's responsibility for: 1) reading social situations, 2) generating appropriate strategies, and 3) applying them in a strategic plan. The first component in the decision-making process addresses the question, "Does the child have problems related to reading a social situation?" (p. 251). It is this first component of Hughes & Hall's three component model that was assessed because the skills it takes in order to read a social situation appear to be deficits of children with VCFS (Thomas & Graham, 1997).

The first component of this three component model was assessed in this study. The first part was chosen because past research has found that children with VCFS demonstrate deficits in the areas of social interactions, comprehension of novel situations, and problem solving skills (Thomas & Graham, 1997), which are the areas that the reading social situations component focuses upon. Specifically, the reading social situations component examines a child's ability to label others' intentions and emotions,
sense social problems, understand a problem from different perspectives, and to seek information that would be useful in clarifying a problem (Hughes and Hall, 1997).

Social competence is an important variable as school aged children begin to develop friendships. Children who are less socially competent do not appear to understand the importance of reciprocity in friendships and therefore reciprocate less often and are more likely to be unpopular with peers. For some poorly accepted children, having a limited repertoire of appropriate behavioral and problem-solving strategies seems to be a contributor to their social acceptance difficulties (Patrick, 1997).

Social competence in close relationships with parents and friends is considered interpersonal competence, which is the ability to establish and maintain close personal relationships (Bukowski, Boivin, & Hoza, 1994). Research has focused on identifying children at risk for childhood and later adjustment problems. Among these children are those that lack peer acceptance and those that are rejected by their peers. Children who lack close friends may also be at risk for adjustment difficulties (Price & Ladd, 1986).

Peer relationships are also an area of potential deficits in children with Cranio-Facial Anomalies (CFA). Many children report that they are dissatisfied with the quality of their peer relationships. Pope & Ward (1997) found that children with CFA that had less social competence described themselves as more socially anxious and more dissatisfied with their peer relationships. Specifically, less socially competent children with CFA reported less companionship with peers, which may lead to greater social isolation for the group. In general, children with craniofacial syndromes may be at risk for poor psychological adjustment, low social competence, and peer rejection (Pope & Ward, 1997).
Research thus far as investigated social skills in children with CFA and NLD; however, it is important to specifically evaluate the social skills of children with VCFS in order to better understand the deficits that may then contribute to fewer reciprocal friendships and lower social competence. Past research shows evidence of a lack of social skills in children with VCFS, but these studies do not study specific deficits and they do not use a control group. A goal of this study is to improve the understanding of specific social skill deficits in order to help with intervention and treatment.

The current study compared children with VCFS, ages 7-12 years with children in the same age group without VCFS to specifically examine their ability to read social situations and the quality of their friendships. Children were measured on their ability to accurately label others’ intentions, the ability to accurately label others’ emotions, the ability to detect social problems, the ability to see the problem from multiple and differing social perspectives, and if the child is able to seek information that would be useful in clarifying the problem. Their perceived social competence and friendship quality were also measured.

It was hypothesized that when compared to a control group children with VCFS:

1.) would not label others’ intentions as accurately as the control group.
2.) would not label others’ emotions as accurately as the control group.
3.) would not detect social problems as well as the control group.
4.) would not seek information that would be useful to clarify problems as well as the control group.
5.) would have fewer friendships and lower perceived social competence compared to the control group.
Method

Participants

Participants were Caucasian children ranging in age from 7-12 years of age (M=9.13, SD=1.49). One group consisted of children with VCFS (N= 11, 55% female, 45% male) (Mage=8.72, SD=1.49) and the other group (N= 11, 73% female, 27% male) (Mage=9.55, SD=1.44) consisted of children without VCFS. There were 22 total participants (36% male and 64% female). The original pool of participants whom we contacted included thirty families. Seven of these families did not have an unaffected sibling that met the age criteria. Six of the families were not interested in participating for various reasons, four families did not return messages or letters, one family cancelled their appointment several times and one family did not attend their scheduled appointment. The control group consisted of the unaffected siblings of the VCFS individuals and was the normative sample. The VCFS group consisted of patients from two Midwestern Children’s Hospitals and was recruited from the Human Genetics departments. The inclusion criteria were that all individuals in the VCFS group had a FISH analysis confirming the 22q11 deletion. According to parental report, the unaffected siblings were examined by a physician to confirm that they did not show characteristics of VCFS.

Measures

To assess the general perceived social competence in both groups of children, the Self-Perception Profile for Children (Harter, 1985) was administered (see Appendix A). This self-report instrument is composed of six subscales: scholastic competence, social acceptance, athletic competence, physical appearance, behavioral conduct, and global
self-worth, resulting in six separate subscale means. Across all samples, the subscale reliabilities range from .75 to .86. Test-retest reliability data were ranged from .70 to .87 (Harter, 1982).

To assess the children’s ability to label others’ intentions, the Intention-Cue Discrimination Task (Dodge, Murphy, & Buchsbaum, 1984) was administered (See Appendix B). In this measure, children are presented with 24 vignettes on video, each depicting a social interaction between children in which one child provokes another. Following the main vignette, the video shows three ways a child could respond to the provocation. The evaluator then asks several questions: 1. “Tell me what happened in this story?” 2. “Was the other kid being mean or not being mean?” 3. “What would you do if this happened to you?” and then the evaluator asks if each response is good or bad. In the norming procedure, experimenters coded children’s responses to the intention-cue discrimination task as correct versus incorrect. Coders agreed exactly on the category of a child’s response in 98.2% of the cases. The internal consistency of the 24-item measure is also adequate at .73.

The ability to understand the perspective of others was assessed using the Affective Perspective Taking Task (Marsh, Serafica, & Barenboim, 1981) (See Appendix C). The measure consists of two dilemmas that require the children to analyze and resolve interpersonal problems. Following the presentation of the dilemmas, children are asked a series of four questions that reflect each of the general problem solving abilities: a) What are all the things you would be thinking about if you had to solve this problem? b) How many ways can you solve this problem?; c) What might happen if...(each solution given in response to the preceding question is read); and d) What do you think
would be the best way to solve this problem? Why? Responses to these questions are scored to assess these general abilities: problem definition, alternative thinking, consequential thinking, and solution adequacy. Research has found test-retest reliability of .72, with internal consistency reliability of .74 and interrater reliability of .99.

To assess the children’s ability to detect social problems and to recognize information that is helpful to clarify the problem, the Purdue Elementary Problem Solving Inventory (PEPSI) (Feldhusen, Houtz, & Ringenbach, 1972) was administered (see Appendix D). The task consists of cartoon strips that represent children in problem situations that are followed by several different types of questions about the pictures (Feldhusen, Houtz, & Ringenbach, 1972).

Lastly, the friendship quality and quantity were measured using the Friendship Questionnaire (Furman & Adler, 1982) (See Appendix E). This questionnaire assesses 16 features of friendship that fall under four factors: warmth/closeness, conflict, exclusivity, and relative status/power. The Cronbach alphas of the scales are satisfactory with a mean of .77 (Furman, 1996).

**Procedure**

This study was approved by a university and a hospital Institutional Review Board. Written informed consent was obtained from all of the children’s parents and assent was received from all children that participated. After both groups gave consent/assent, the measures were administered to the VCFS group and the control group. The measures were counterbalanced to reduce fatigue effect on the last test administered. After the measures were administered and upon completion of the study, the researcher...
provided a summary of the children's performance to the parents. All information was kept confidential to protect the parents and children.

Results

A one-way multivariate analysis of variance (MANOVA) was conducted to analyze mean differences in overall social skills. The dependent variables included the scores on the Intention-Cue Discrimination Task, the Affective Perspective Taking Task, and the PEPSI. This analysis identified overall significant differences between the two groups (Wilks' Lambda = .203) $F(1, 21) = 9.84, p=.001$.

Analyses of Variance (ANOVAs) were conducted for single effects. The first hypothesis: Children with VCFS would not label others' intentions as accurately as the control group, was measured by the Intention Cue Discrimination Task. This hypothesis was supported because the ANOVA was significant for encoding errors ($M_{vcf} = 31.01; M_{nonvcf} = 24.55$), $F(1, 21) = 10.12, p=.005$. In addition, it was also supported by the aggressive response subtest ($M_{vcf} = .261; M_{nonvcf} = .037$), $F(1,21) = 5.33, p=.032$. Overall, children with VCFS were not able to explain the story accurately and they gave more aggressive responses.

The second hypothesis: Children with VCFS would not label others' emotions as accurately as the control group was measured by the Affective Perspective Taking Task. This hypothesis was supported because the ANOVA was significant for the overall score on this measure ($M_{vcfs} = 9.36; M_{nonvcfs} = 16.55$), $F(1,21) = 10.76, p=.004$.

The third hypothesis: Children with VCFS would not detect social problems as well as the control group was measured by the PEPSI. This hypothesis was supported
because the ANOVA was significant for the overall PEPSI score (Mvcfs = 24.44; Mnonvcfs = 37.82), F (1,21) = 31.66, p=.001.

The fourth hypothesis: Children with VCFS would not seek information that would be useful to clarify problems as well as the control group was also measured by the PEPSI. This hypothesis was supported because the ANOVA was significant for the overall PEPSI score (Mvcfs = 24.44; Mnonvcfs = 37.82), F (1,21) = 31.66, p=.001.

The fifth hypothesis: Children with VCFS would have fewer friendships and lower perceived social competence compared to the control group was measured by the Friendship Questionnaire and the Self-Perception Profile for Children. This hypothesis was partially supported because the ANOVAs were significant for the intimacy subtest (Mvcfs = 1.91; Mnonvcfs = 2.67), F (1,21) = 5.53, p=.029 and companionship subtest (Mvcfs = 1.61; Mnonvcfs = 2.77), F (1,21) = 7.50, p=.019 on the Friendship Questionnaire. However, the second part of the hypothesis was not supported because the ANOVAs for all subtests on the Self-Perception Profile for Children were not statistically significant.

A regression analysis was conducted to determine which of the significant social skill deficits are more associated with children with VCFS. The PEPSI problem solving measure (B = .562), p=.001; the intimacy subscale of the Friendship Questionnaire (B = .355), p=.001; and the encoding error subscale of the Intention Cue Discrimination Task (B = -.289), p=.035 were most associated with children with VCFS. Overall, problem solving deficits, lack of intimacy in friendships, and difficulties understanding others' intentions appear to be most associated with children with VCFS.
Discussion

Previous studies have found that children with VCFS have difficulties with social skills; however no studies have examined what specific social skill deficits these children may exhibit. This study assessed the ability of children with VCFS to read a social situation in comparison to a control group of siblings without VCFS. As predicted, significant results were found when the social skill measures where compared. In addition, when each dependent variable was analyzed separately, the majority of the hypotheses were supported. For example, as hypothesized, children with VCFS did not label others' intentions as accurately as the control group. Specifically, children with VCFS had more difficulty discriminating and identifying the intention of other's actions. Past research has stated that children with VCFS have difficulties in social situations; however this specific finding has not been studied. Children with VCFS also produced significantly more aggressive responses to typical social situations compared to the children without VCFS. Because children with VCFS have more difficulties understanding others' intentions, they may perceive others actions to be negative or hostile, which leads to more aggressive ways of responding. This concept is consistent with Dodge (1984) who found that children who are deficient in intention-cue detection skills are more likely to make errors in identifying intentions as hostile, which may lead to aggressive responses.

The results of this current study also support the hypothesis that children with VCFS did not label others' emotions as accurately as the control group. Children with VCFS were less able to understand other children's affect and perspectives. They may be less able to recognize and articulate differing perspectives and the internal states of
others, which may then lead to difficulties understanding the emotional states of others. The combination of difficulties understanding others intentions and affect may effect their ability to relate to others and to maintain friendships.

As the hypothesis predicted, children with VCFS scored significantly lower on a problem solving measure compared to the control group. Children with VCFS were not able to detect everyday social problems as well as the control group and they did not seek information that would be useful to clarify problems as well as the control group. Specifically, they had a difficult time determining if a problem existed or not and identifying the statement that specifies the exact problem. In addition, children with VCFS were not able to ask relevant questions to help clarify the problem presented and they were less able to accurately guess the causes of the problem as compared to children without VCFS. Lastly, these children also had a difficult time selecting the best solution to the presented problem. These findings are consistent with past research that found children with VCFS typically have deficits in the area of social interactions, comprehension of novel situations, and problem solving skills (Thomas & Graham, 1997). It appears that many of these skills are related, so that if a child is not able to understand other children in social interactions, then they probably will not be able to understand everyday social problems as well as children without VCFS.

Last, this study partially supported the hypothesis that children with VCFS would have fewer friendships and lower perceived social competence compared to the control group. Children with VCFS did not report fewer friendships as compared to the control group; however they did report significantly less intimacy and companionship in their friendships compared to children without VCFS. Although children with VCFS may
have friends, the quality of their relationships may not be as strong or connected as children without VCFS. This may be related to the difficulties that children with VCFS have understanding others' intentions and affect. These children may not feel the need to develop as intimate and connected relationships as other children do. It is important to note that children with VCFS may not define a friendship the same way as children without VCFS. Specifically, they may not feel the need for the same amount of intimacy and companionship in a relationship. This is similar to findings that children with CFA do not have the same quality of friendships as children without CFA (Pope & Ward, 1997). This difference in the definition of a friend may have contributed to the lower scores in these areas.

In addition, there was no significant difference between scores of perceived social competence between the two groups. This may be because the children with VCFS do not accurately evaluate their own skills, which relates to their social skill deficits. These children appear to perceive themselves as being similar to other children despite the significant differences in important aspects of social skills. This finding does not support the hypothesis that children with VCFS would have less social competence than the control group due to social skill deficits. In general, social competence has been defined as the ability to adapt effectively to life situations, interact with the environment, and generate skilled behavior (Dodge, 1986). It appears that children with VCFS feel that they do adapt and interact with others, despite their deficits in specific social skills. This finding may be related to factors in the environments of children with VCFS. The children evaluated tended to have highly motivated and concerned parents who may have helped their children to develop a good sense of self-worth and confidence in their
abilities. It will be important to consider this finding and evaluate it further in future research with the possibility of taking into effect the parental characteristics, which may affect a child's social competence.

Overall, problem solving deficits, lack of intimacy in friendships, and difficulties understanding others intentions appear to be strongly related to children with VCFS. The research thus far has been sparse in this area and many of the past studies did not use a control group to compare variables. This study has helped to further define the finding that children with VCFS have difficulties with social skills compared to children without VCFS. Although this study had a small sample size, it was larger than any other study in this area. In addition, it used a control group and it is the only objective evaluation of children with VCFS thus far, which is unlike previous research. It is believed that this study will help professionals working with children with VCFS to be able to provide parents with more information on possible social skill problems. These findings will help parents and clinicians to better understand children with VCFS and to develop intervention programs to target these areas.

The findings need to be considered in light of limitations of this study. First, the sample size was smaller than what the original power analysis. This small sample size may be due to the limited age range defined by the measures used and the need for the sibling control group. Many families with children with VCFS did not fit the narrow age range or they did not have unaffected siblings. Additionally, there were families that fit the criteria, but did not choose to participate and those that also did not attend the scheduled evaluation.
In addition, it is important to consider that the intellectual functioning of children with VCFS may have contributed to their low scores on measures of problem solving and social skills. According to an unpublished dissertation (2002), the children with VCFS in this study had significantly lower IQ scores than the control group. Based on this information, social skill deficits and poor problem solving abilities cannot be directly attributed to VCFS.

Another limitation is that a cross-sectional design was utilized rather than a longitudinal design, so children cannot be tracked to determine if these same social skill deficits exist, as they become older. Despite these limitations, the results from this study provide evidence that pertains to the social skill deficits that occur in school-aged children with VCFS.

These findings highlight the need for further investigation in many areas. Future research is needed to expand upon this initial study by using a larger sample size. In order to conduct a larger scale study, a different control group may need to be considered to help expand the sample size in the study. Based on the results of this study, it would be interesting to conduct additional studies on the social competence and self-esteem in children with VCFS, in order to better understand these results. Further investigation of potential mediating variables is needed to identify the mechanisms influencing the relationship between the social skill deficits and VCFS. It is important to consider how a child’s intellectual functioning relates to their difficulties with problem solving and if these deficits are still statistically significant when considering the IQ of the children with VCFS. Other mediators such as participation in special education services or additional treatment services may also play a role in a child’s ability to problem solve and in their
level of social competence. Lastly, a longitudinal follow-up study of children over a long period of time would provide important information for parents and clinicians on the outcomes of the social and emotional functioning on children with VCFS.

Overall, this study provides evidence for specific social skills deficits in children with VCFS compared to their unaffected siblings. Children with VCFS had greater difficulties labeling others' intentions and emotions as accurately as the control group. These children did not detect social problems or seek information to clarify problems as well as children without VCFS. Lastly, they had less intimate friendships than children without VCFS; however they did perceive their skills and abilities to be similar to unaffected children. This study provides the first look into an important area of deficits in children with VCFS and will lead to further research to continue to expand the understanding of the emotional and social functioning of children with VCFS.
References


Gerdes, M. et al. (1999). Cognitive and behavior profile of preschool children with...
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perspective taking, interpersonal problem solving, and interpersonal functioning.


Shprintzen, R. J., Goldberg, R. B., Lewin, M. L., Sidoti, E. J., Berkman, M. D.,


Table 1

Description of VCFS group

<table>
<thead>
<tr>
<th>No</th>
<th>Sex</th>
<th>AgeD</th>
<th>AgeP</th>
<th>Grade</th>
<th>Fail</th>
<th>SpecEd</th>
<th>EducM</th>
<th>EducF</th>
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<td>9</td>
<td>3</td>
<td>N</td>
<td>Y</td>
<td>9</td>
<td>12</td>
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<tr>
<td>2</td>
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<td>4</td>
<td>9</td>
<td>3</td>
<td>N</td>
<td>N</td>
<td>18</td>
<td>18</td>
</tr>
<tr>
<td>3</td>
<td>M</td>
<td>5</td>
<td>7</td>
<td>1</td>
<td>N</td>
<td>N</td>
<td>16</td>
<td>18</td>
</tr>
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<td>4</td>
<td>F</td>
<td>8</td>
<td>9</td>
<td>4</td>
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<td>Y</td>
<td>16</td>
<td>16</td>
</tr>
<tr>
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<td>F</td>
<td>2</td>
<td>8</td>
<td>3</td>
<td>N</td>
<td>Y</td>
<td>16</td>
<td>16</td>
</tr>
<tr>
<td>6</td>
<td>M</td>
<td>-</td>
<td>8</td>
<td>3</td>
<td>N</td>
<td>-</td>
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<td>7</td>
<td>1</td>
<td>N</td>
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<td>20</td>
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<tr>
<td>8</td>
<td>M</td>
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<td>10</td>
<td>3</td>
<td>Y</td>
<td>Y</td>
<td>12</td>
<td>12</td>
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<td>9</td>
<td>M</td>
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<td>8</td>
<td>1</td>
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<td>Y</td>
<td>14</td>
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<td>F</td>
<td>4</td>
<td>11</td>
<td>4</td>
<td>Y</td>
<td>Y</td>
<td>12</td>
<td>12</td>
</tr>
<tr>
<td>11</td>
<td>F</td>
<td>4</td>
<td>11</td>
<td>5</td>
<td>N</td>
<td>Y</td>
<td>14</td>
<td>16</td>
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</tbody>
</table>

AgeD = age of diagnosis; AgeP = present age; Grade = current grade level; SpecEd = Involvement in special education classes; Y = Yes; N = No; Fail = history of failing a grade at least once; EducM = educational level of mother; EducF = educational level of father.
Table 2

_Means and Standard Deviations of Self Perception Profile for Children_

<table>
<thead>
<tr>
<th>Subtest</th>
<th>Control M</th>
<th>Control SD</th>
<th>VCFS M</th>
<th>VCFS SD</th>
<th>F</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Scholastic Competence</td>
<td>3.04</td>
<td>.78</td>
<td>3.03</td>
<td>.52</td>
<td>.001</td>
<td>.980</td>
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<tr>
<td>Social Acceptance</td>
<td>2.85</td>
<td>.56</td>
<td>3.11</td>
<td>.50</td>
<td>1.43</td>
<td>.904</td>
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<tr>
<td>Athletic Competence</td>
<td>3.05</td>
<td>.68</td>
<td>3.01</td>
<td>.64</td>
<td>.015</td>
<td>.247</td>
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<tr>
<td>Physical Appearance</td>
<td>3.13</td>
<td>.75</td>
<td>3.08</td>
<td>.45</td>
<td>.031</td>
<td>.861</td>
</tr>
<tr>
<td>Behavioral Conduct</td>
<td>3.33</td>
<td>.72</td>
<td>3.12</td>
<td>.52</td>
<td>.63</td>
<td>.436</td>
</tr>
<tr>
<td>Global Self-Worth</td>
<td>3.31</td>
<td>.69</td>
<td>3.41</td>
<td>.47</td>
<td>.14</td>
<td>.715</td>
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</table>
### Table 3

**Mean Scores and Standard Deviations of the Friendship Questionnaire**

<table>
<thead>
<tr>
<th>Subtest</th>
<th>Control M</th>
<th>Control SD</th>
<th>VCFS M</th>
<th>VCFS SD</th>
<th>F</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Affection</td>
<td>4.22</td>
<td>.71</td>
<td>3.76</td>
<td>1.36</td>
<td>.97</td>
<td>.336</td>
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<tr>
<td>Quarreling</td>
<td>2.54</td>
<td>.68</td>
<td>2.21</td>
<td>.87</td>
<td>.99</td>
<td>.333</td>
</tr>
<tr>
<td>Prosocial Behavior</td>
<td>3.42</td>
<td>.68</td>
<td>3.00</td>
<td>1.05</td>
<td>1.25</td>
<td>.276</td>
</tr>
<tr>
<td>Better Than-School</td>
<td>3.06</td>
<td>.57</td>
<td>2.72</td>
<td>.99</td>
<td>.93</td>
<td>.345</td>
</tr>
<tr>
<td>Warmth-Mismatch</td>
<td>3.10</td>
<td>.75</td>
<td>2.88</td>
<td>1.17</td>
<td>.26</td>
<td>.619</td>
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<tr>
<td>Antagonism</td>
<td>2.57</td>
<td>.34</td>
<td>2.58</td>
<td>1.00</td>
<td>.00</td>
<td>.996</td>
</tr>
<tr>
<td>Similarity</td>
<td>3.22</td>
<td>.90</td>
<td>3.03</td>
<td>1.15</td>
<td>.17</td>
<td>.687</td>
</tr>
<tr>
<td>Intimacy</td>
<td>2.70</td>
<td>.59</td>
<td>1.91</td>
<td>.95</td>
<td>5.53</td>
<td>.029</td>
</tr>
<tr>
<td>Competition</td>
<td>2.88</td>
<td>1.00</td>
<td>2.36</td>
<td>.97</td>
<td>1.2</td>
<td>.278</td>
</tr>
<tr>
<td>Admiration</td>
<td>2.74</td>
<td>.87</td>
<td>2.45</td>
<td>1.13</td>
<td>.36</td>
<td>.557</td>
</tr>
<tr>
<td>Better Than-Sports</td>
<td>2.65</td>
<td>1.2</td>
<td>2.30</td>
<td>1.10</td>
<td>.52</td>
<td>.479</td>
</tr>
<tr>
<td>Conflict-Mismatch</td>
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<td>.89</td>
<td>3.22</td>
<td>1.16</td>
<td>.14</td>
<td>.709</td>
</tr>
<tr>
<td>Exclusivity (of)</td>
<td>2.79</td>
<td>.75</td>
<td>2.61</td>
<td>1.10</td>
<td>.21</td>
<td>.656</td>
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<tr>
<td>Exclusivity (by)</td>
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<td>2.34</td>
<td>1.00</td>
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<td>.110</td>
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<tr>
<td>Companionship</td>
<td>2.77</td>
<td>1.17</td>
<td>1.61</td>
<td>.96</td>
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<td>.019</td>
</tr>
<tr>
<td>Better than-Friends</td>
<td>3.00</td>
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<td>2.12</td>
<td>.83</td>
<td>4.5</td>
<td>.050</td>
</tr>
</tbody>
</table>

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Table 4

*Means and Standard Deviations of All Social Skills Measures*

<table>
<thead>
<tr>
<th>Measure</th>
<th>Control M</th>
<th>SD</th>
<th>VCFS M</th>
<th>SD</th>
<th>F</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Affective Perspective Taking Task</td>
<td>16.55</td>
<td>5.91</td>
<td>9.34</td>
<td>4.23</td>
<td>10.76</td>
<td>.004</td>
</tr>
<tr>
<td>Intention Cue Discrimination Task Encoding</td>
<td>24.55</td>
<td>.69</td>
<td>31.10</td>
<td>6.79</td>
<td>10.12</td>
<td>.005</td>
</tr>
<tr>
<td>Hostile</td>
<td>.85</td>
<td>.10</td>
<td>.72</td>
<td>.21</td>
<td>3.25</td>
<td>.087</td>
</tr>
<tr>
<td>Aggressive Responses</td>
<td>.03</td>
<td>.10</td>
<td>.26</td>
<td>.30</td>
<td>5.33</td>
<td>.032</td>
</tr>
<tr>
<td>PEPSI</td>
<td>37.82</td>
<td>5.88</td>
<td>24.54</td>
<td>5.16</td>
<td>31.64</td>
<td>.001</td>
</tr>
</tbody>
</table>

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Figure Caption

*Figure 1.* Distributions of intimacy subtest scores for children with VCFS (group 1) and control group (group 2).
Figure 2. Distributions of companionship subtest scores of children with VCFS (group 1) and control group (group 2).
GROUP
Figure 3. Distributions of Affective Perspective Taking overall scores for children with VCFS (group 1) and control group (group 2).
Figure 4. Distributions of encoding errors subscale scores for children with VCFS (group 1) and control group (group 2).
Figure 5. Distributions of aggressive response subscale scores for children with VCFS (group 1) and control group (group 2).
AGGRESS

GROUP

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Figure 6. Distributions of PEPSI overall scores of children with VCFS (group 1) and control group (group 2).