ILLNESS COMMUNICATION AND COPING BEHAVIOUR IN YOUTH WITH AND
WITHOUT AUTISM SPECTRUM DISORDER

by

Kate Aubrey

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The undersigned hereby certify that they have read and recommend to the Faculty of Graduate Studies for acceptance a thesis entitled "ILLNESS COMMUNICATION AND COPING BEHAVIOUR IN YOUTH WITH AND WITHOUT AUTISM SPECTRUM DISORDER " by Kate Aubrey in partial fulfillment of the requirements for the degree of Master of Doctor of Philosophy.

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External Examiner: _____

Research Supervisor: _____

Examining Committee: _____

_____

Departmental Representative: _____

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To arrive at the simplest truth requires years of contemplation

~ Sir Isaac Newton

For my parents, Alfred and Louise Kalousek

&

Hamish Aubrey, my husband and best friend

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ABSTRACT

No previous studies have examined how those with Autism Spectrum Disorder (ASD) communicate or cope with symptoms of acute physical illness. Effective management of illness is important as it is related to an individual's overall health and has implications for the spread of disease. I hypothesized that youth with and without ASD would demonstrate important differences in illness management. In the present study, I investigated parent- and self-perceptions of illness communication and coping behaviour in high-functioning (HF) youth with and without ASD. Participants were 24 youth with HFASD and 24 age-, sex- and IQ-matched controls, aged 9 to 17 years, and one of their parents. Data related to participants' social communication, daily living skills, illness experience, and illness knowledge were also collected. Parent and self-reports of illness communication and coping behaviour were assessed using vignettes depicting characters with various ailments. Based on parent-reports, typically developing youth communicate illness using direct means (e.g., verbal reports) and utilize active (e.g., intervention-seeking) coping behaviours to manage ailments. In contrast, youth with HFASD were reported to use direct communication less frequently than controls. As such, parents of those with HFASD reported that they rely on observations of their children's sick behaviour to determine when they are ill more frequently than parents in the control group. Youth in the control group were also reported to use more passive (e.g., emotionality, self-isolation, passive adherence) means of coping when ill with acute physical ailments, when compared to parent reports. Self-reports indicated that youth with HFASD perceived themselves as having significantly more "typical" illness behaviours (e.g., utilization of direct communication and active coping strategies) than their parents reported, whereas youth and parent reports in the control group were more consistent overall. Results of this study will provide important information for parents and practitioners that may subsequently be used to help children with ASD develop strategies for communicating about and coping with illness effectively. A model, emphasizing skill deficits that may prevent youth with HFASD from managing illness effectively, was also developed. Limited insight in the domain of health behaviour may be a particularly important focus for future interventions.

LIST OF ABBREVIATIONS AND SYMBOLS USED

*	Indicates a statistically significant difference
†	Indicates a statistical difference approaching significance
χ^2	Pearson chi-square test
ABAS-II	Adaptive Behavior Assessment System, second edition
ANOVA	Analysis of variance
ASD	Autism Spectrum Disorder
r	Correlation
CCC-II	Children's Communication Checklist, second edition
CELF-4	Clinical Evaluation of Language Fundamentals, fourth edition
CPPP	Charleston Pediatric Pain Pictures
DSM-IV	Diagnostic and Statistical Manual, fourth edition
F	F distribution, Fisher's F ratio
HFASD	High-functioning individual with autism spectrum disorder
HRQOL	Health related quality of life
ID	Intellectual Disability
IQ	Intelligent Quotient
M	Mean
n	Number of cases in a sample
p	p-value for significance testings
R	Range
SE	Standard Error
SRS	Social Responsiveness Scale
SD	Standard Deviation
T	T-score (standardized score with $M = 50$, $SD = 10$)
t	Student's t-test
UTI	Urinary Tract Infection
N	Total number of cases
WASI	Wechsler Abbreviated Scale of Intelligence
VABS	Vineland Adaptive Behavior Scales
z	Mann-Whitney U test and Wilcoxon Signed-Rank test

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CHAPTER 1. INTRODUCTION

Autistic Disorder, Asperger's Disorder, and Pervasive Developmental Disorder –

Not Otherwise Specified currently comprise the autism spectrum and are described in the

Fourth Edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM;

American Psyciatric Association, 2000). In keeping with the proposed changes to diagnostic

classification in the upcoming Fifth Edition of the DSM and current terminology in the field,

I will collectively refer to these disorders as autism spectrum disorder (ASD). The key

symptom clusters in ASD are impairments in social interactions and communication, as well

as the presence of stereotypic and restrictive patterns of behaviour, interests, and activities

(Rapin, 1997). Currently, these deficits are referred to as a symptom "triad" (socialization,

communication, stereotypic/restrictive behaviour). In the Fifth Edition of the DSM,

however, the triad will be revised to reflect a "dyad" of symptoms, with communication and

socialization collapsed into one domain.

Symptoms of ASD can occur in a variety of combinations and be present to varying

degrees of severity, resulting in a great deal of heterogeneity within the spectrum. As such,

symptom severity among youth with ASD ranges from mild (e.g., youth may show subtle

signs of impairment in the two symptom domains, such as difficulty initiating or maintaining

interactions with peers) to severe (e.g., youth may not gain language ability, prefer to be

isolated from interactions with peers, or engage in excessive stereotypic behaviours, such as

rocking). Level of functioning in other areas (e.g., intellectual ability) also varies considerably

within the autism spectrum. High-functioning youth with ASD (HFASD) exhibit symptoms

in both domains, but have average to above average intellectual functioning (typically an IQ

of 70 or greater). In regards to language, youth with HFASD may experience impairments in

all domains of communication (e.g., understanding and use of language), but often struggle

significantly with social communication (i.e., communicating appropriately in social situations; Saulnier & Klin, 2007).

Previous research has also indicated that individuals with HFASD display significant impairments across all areas of adaptive functioning (i.e., everyday activities necessary to take care of oneself, communicate, and socialize with others; e.g., Klin et al., 2007; Perry, Flanagan, Geier, & Freeman, 2009), despite their average IQ. Given that one of the core deficits in ASD involves communication and socialization, it is not surprising that those with HFASD display impairments within these adaptive functioning domains. A less well-understood deficit, however, is in daily living skills. Daily living skills constitute a critical domain of adaptive behaviour, and consist of personal (e.g., dressing, grooming, bathing, personal hygiene), home or school (e.g., putting things away without reminders, cleaning with proper supplies, food preparation), and community (e.g., shopping, using community resources) skills (Harrison & Oakland, 2003). Daily living skills have been noted as "essential" to an individual's ability to function successfully and independently in the world (Liss et al., 2001), and thus contribute strongly to the prognosis of those with HFASD (Gillham, Carter, Volkmar, & Sparrow, 2000).

Although impairments in daily living skills are well documented among youth with HFASD (Harrison & Oakland, 2003; Klin et al., 2007; Perry et al., 2009), there has been no research examining how people with ASD care for themselves when ill. This is particularly problematic as 30% of children over the age of 6 years experience at least one acute physical illness within a given 4-week period (Hansen, 1993). Additionally, poor management of illness has significant implications for an individual's overall health, as well as the quality of care they receive when ill.

Given that health and safety skills (e.g., using/accessing medicines appropriately, caring for injuries, following safety rules, seeking help for illness when needed) exist within the broader arena of daily living skills (Harrison & Oakland, 2003; Sparrow, Cicchetti, & Balla, 2005), individuals with HFASD may also have impairments successfully coping with illness. Similarly, deficits in adaptive communication, which refer to skills needed for social communication (e.g., raising voice to get attention, paying attention to family discussions, giving verbal instructions), may also impact how those with HFASD communicate about illness and its symptoms. Poor ability to communicate with others may also compromise the quality of care youth receive when ill.

In the present study, I investigate parent- and self-reports of illness communication and behaviour in youth with and without HFASD. To date, no research has examined how people with ASD communicate and cope with symptoms of illness, which are two essential components in effectively managing and, ultimately, alleviating illness and its symptoms. Additionally, a number of studies have documented that children (Kuhlthau et al., 2010; Lee, Friedman, Ross-Degnan, Hibberd, & Goldmann, 2003), adolescents (Jennes-Coussens, Magill-Evans, & Koning, 2006; Kamp-Becker, Schröder, Remschmidt, & Bachmann, 2010), and adults (Saldana, Alvarez, Lobaton, & Lopez, 2009) with HFASD have lower levels of "health-related quality of life" (HRQOL). While HRQOL is a broad construct encompassing many functional domains (e.g., psychological, physical, social, environmental), two recent studies have found that adolescents with HFASD reported lower HRQOL in the "physical health" domain (e.g., physical pain/discomfort, mobility, dependence on medical treatment, energy and fatigue, sleep and rest, work capacity) compared to same-aged peers (Jennes-Coussens et al., 2006; Kamp-Becker et al., 2010). These studies indicate that those with HFASD may experience more physical health problems than healthy controls, and further

emphasize the importance of studying illness communication and coping in this population. Results of this study will provide important information for caregivers and practitioners that may be used to help youth with ASD develop strategies for communicating about and coping with illness effectively.

Illness Communication

"Mom, I have a stomachache!" Communication of illness serves several important functions, such as rousing helping behaviours in caregivers. Fortunately, everyday ailments (e.g., stomachaches, headaches, mild injuries), and the discomfort they cause, are often self-limiting, which means the sick individual is able to exercise control and terminate or ameliorate the illness through a variety of means. Hence, the interventions of others may not be necessary. However, more serious ailments, or chronic conditions associated with unremitting or recurrent discomfort, usually demand the intervention of others.

Furthermore, the need for assistance in illness is greatest for people who are vulnerable or dependent on others for their care (e.g., infants and children), and remain important for older youth who are not yet able to independently assess and treat ailments that are unknown or do not follow a predictable trajectory (Hadjistavropoulos & Craig, 2002). Because the experience of illness is inherently private, one's ability to help someone who is ill depends upon the availability of reliable and valid information concerning the presence and specific nature of the individual's physical symptoms (Craig, 1992). Therefore, one must often rely on verbal self-reports of illness, which can be combined with observations of non-verbal (e.g., facial expression, body posture) or vocal (e.g., crying, screaming) behaviours (i.e., illness expression). Furthermore, for healthcare professionals and parents to provide the best possible care, eliciting and communicating with children about symptoms and problems from the child's perspective is crucial. Through communication

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with the child, those involved with the child's care can gain insights into symptom experiences, reactions, and illness-related beliefs (Targosz, Kapur, & Creed, 2001). This information allows them to prevent or alleviate symptom distress, improve emotional well-being and satisfaction with care (Matley, 1997), and clarify any misconceptions about illness beliefs or recovery (Veldtman et al., 2000). Due to the noted importance of informing others about illness, illness communication in the present study refers to how youth notify their caregivers they are ill. From the parent's point of view, illness communication can be conceptualized as illness "detection", since it represents the means by which the parent learns of their child's illness.

Illness Communication in Typical Development

From the earliest moments of life, infants begin to communicate dissatisfaction, irritation, and discomfort. A capacity to communicate needs and states has substantial adaptive and survival value for infants, given their considerable vulnerability and dependence upon caretaking adults. The optimal model for effective childcare would involve a capacity for the infant to convey specific information about personal needs and a caretaker to readily respond to those needs (Craig, 1992). Unfortunately, infants lack the ability to convey such specific details, and caregivers instead take on a "detective" role, one that involves piecing together several aspects of the infant's behaviour (e.g., cry, facial expressions, body movements) and testing hypotheses. Unlike many other species, the signaling system is particularly important for human infants because they remain dependent and vulnerable upon caretakers for a long period of time. An important function of this signaling system is to communicate when the infant is in discomfort, especially pain. This symbiotic relationship, involving expression of distress by the infant and response to that distress by a caregiver, is addressed by the Social Communication Model of Pain (Craig, 2009).

Specifically, this model posits that the experience of pain is influenced by one's thoughts (e.g., cognitions and interpretations about what is happening), feelings, and sensations that lead to the pain expression, which can be nonverbal, verbal, or physiological. These signals serve to alert the observer or caregiver, who also contributes his/her own interpersonal and intrapersonal factors, which influence the pain assessment and management processes. For children with a developmental delay, it is less clear how cognitions impact the pain experience. Craig (2009), however, suggests that difficulty with interpreting situations may increase distress and decrease perceived sense of control, thereby affecting how pain is experienced in this population.

As children develop, their distress signaling system becomes more sophisticated and complex. Research has indicated that by the age of 5 years, children demonstrate a reduction in reflexive crying and vocalizations due to pain in favour of silence (Dubois, Bringuier, Capdevilla, & Pry, 2008). Dubois et al. (2008) suggests that this shift is due to a combination of social learning and the development of emotional control. In the course of development, preschoolers are confronted with social norms that lead them to display their painful and other emotional expressions in ways that conform to these norms. Emotional control begins between 3 and 6 years of age (Saarni, 1999) and is characterized by a decrease in the strength of emotional expression. Increased control, coupled with typical communication development, enables children to express their feelings and painful sensation with more precision using language, thereby allowing an improvement in the quality of medical care (von Baeyer, 2006).

Effective tools for the valid assessment of pain parallel this development. That is, self-report measures (e.g., numerical pain scales) are considered the "gold standard" and the most valid approach to pain measurement in children as young as 5 years of age (von Baeyer,

2006). Prior to this, direct observations of expressive behavioural indicators (e.g., crying and facial expressions) may provide a more meaningful evaluation of pain over self-report (von Baeyer & Spagrud, 2007). Given that observational pain assessment has been demonstrated to underestimate pain in children (Shavit, Kofman, Leder, Hod, & Kozer, 2008), however, self-report of physical distress should be sought in even the youngest of children.

Few studies have focused on how children verbally inform others of acute illness. However, we can learn and draw from a large body of research that has examined how children express and communicate about acute pain. Since pain and illness often co-occur, and since both transpire within a health context involving the interpretation and communication of physical symptoms, research findings on pain communication serve as an important guide for examining and developing hypotheses about how children may communicate acute illness to others.

Studies of pain communication in children have primarily focused on the words that children use to let others know they are in pain. Frank, Noble, and Liossi (2010) recently investigated the emergence of pain language in 1716 children using a parent-report questionnaire. According to their results, children begin to develop a pain vocabulary between 12 and 30 months of age, with words for pain from injury (e.g., "ow", "hurt") emerging first, followed by pain for illness ("sore", "badly"). By age 3, children begin to use more sophisticated terms such as "pain", and between age 3.5 to 4 years children begin to use sentences to describe their sensations and feelings more precisely (e.g., "I am not feeling very well"). Other researchers have reported that pain language reliably emerges around 18 months, and rapidly develops thereafter (Mills, 1989; Stanford, Chambers, & Craig, 2005). Franck et al. (2010) also investigated communicative intent following a minor pain (e.g., scrape, bruise) or illness (e.g., headache, stomach ache) for children between the ages of 1

and 6 years of age. Results indicated that descriptions of unpleasant sensations (e.g., "I feel sick", "I have a boo boo") were the most numerous throughout all age groups, followed by assistance seeking (e.g., "I want my mommy") and treatment requests (e.g., "I want medicine", "make it feel better"). This study illustrates that children as young as two years of age use purposeful language to describe physical ailments, primarily focusing on the causes of pain and requesting specific forms of assistance from parents.

Significantly less research has been conducted on the nature of adolescents' communication of pain. As adolescence represents a stage associated with increased emotionality, most research in this domain has focused on pain catastrophization (i.e., exaggerated displays of pain-related distress as a means of coping with pain) as opposed to more straightforward communication. It should be noted that pain catastrophization and communication differ, in that the former represents over-reporting of very negative aspects of pain, whereas the latter serves to inform another of one's current physical state, and is the focus of the present investigation.

Savedra, Tesler, Ward, and Wegner (1988) assessed how healthy adolescents between the ages of 13 and 17 years described the experience of pain. Findings suggested that adolescents are able to recall painful situations, and clearly describe pain, their feelings when in pain, and the strategies that help when they experience pain. For example, compared to younger children who typically only use words that describe their pain geographically (e.g., "my stomach hurts"), adolescents were explicitly descriptive about pain (e.g., "it feels like a sharp knife"). Adolescents also frequently described how they felt when in pain (e.g., "I felt like it might never go away", "I feel like I have no control over the pain"). Additionally, compared with younger children, adolescents increasingly associated pain with mental anguish (e.g., "I felt scared", "It made me nervous") in addition to the physical sensations

related to trauma or illness. This finding is consistent with cognitive developmental theory

(Piaget & Inhelder, 1969), which characterizes the thinking of adolescents as more abstract

and introspective as compared to the more concrete thinking of school-age children.

The frequency with which healthy children and adolescents purposefully

communicate their illnesses to others has not been examined. Some research in pediatric

pain, however, indicates that youth readily inform their parents when they are in pain. For

example, using the Pediatric Pain Coping Inventory, Varni et al. (1996) found "reporting pain

to a caregiver" to be one of the most common behaviours youth experiencing chronic illness

endorsed to cope with pain. Additionally, according to Lynch-Jordan, Kashikar-Zuck, and

Goldschneider (2010), verbal reports of discomfort were among the most frequent ways

caregivers described learning about pain in adolescents.

It has been suggested, however, that the frequency and type of communication used

by youth when in pain likely depends on several interacting factors related to learning and

family factors (Palermo & Chambers, 2005). Interestingly though, the ways in which parents

respond to children's reports of pain does not seem to influence the frequency of reports.

For example, several studies have failed to find a relationship between parent solicitousness

(e.g., frequent attending to pain symptoms, granting permission to avoid regular activities)

and higher frequency of pain reporting in healthy children (Jellesma, Rieffe, Terwogt, &

Westenberg, 2008) and adolescents with chronic pain (Walker, Claar, & Garber, 2002).

Youth are likely reinforced for reporting pain to caregivers in many ways, such as by

alleviation of distress or increasing closeness with a caregiver.

Illness Communication in Atypical Development

Intellectual Disability. Due to limited communication skills, children with

intellectual disabilities (ID) are not always able to verbalize and describe how they feel. In the

1990s and before, published case reports, as well as surveys of parents and clinical observation, indicated that individuals with ID do not exhibit the expected responses to painful stimuli and, in most instances, they seem to be indifferent to pain (Hennequin, Morin, & Feine, 2000). More recent literature (reviewed below), however, suggests that those with ID do feel painful sensations, but discussions remain in the scientific community concerning the quality of pain expression in this population, as results have been conflicting. For example, using an observational paradigm, Gilbert-MacLeod, Craig, Rocha, and Mathias (2000) investigated pain expression (i.e., verbal and non-verbal pain behaviour) in a heterogeneous group of children between the ages of 2 and 6 years with and without ID during unstructured play. The ID group included children with a variety of developmental disorders, such as ASD, Down syndrome, expressive language disorders, or general developmental delay. Results indicated that the behaviours exhibited by children with ID differed from those displayed by their typically developing peers. Specifically, the researchers reported that children in the ID group displayed a less intense distress response following a painful event and engaged in fewer help-seeking behaviours (e.g., running to an adult) than non-delayed children.

More recently, Breau, Finley, Camfield, and McGrath (2009) investigated facial reactions to pain following surgery for children between the ages of 5 and 12 years with an ID, such as Down syndrome. Results indicated that children with an ID demonstrated a "pain face" similar to that reported for typically developing children. Contrary to findings of Gillbert-MacLeod and colleagues, the intensity of facial expressions in the ID group was greater than those reported for the typically developing group.

Research conducted by Dubois, Capdevila, Bringuier, and Pry (2010) suggests that the type and quality of pain expression among individuals with ID depends on the

developmental abilities of the child. These researchers investigated the role of language in pain expression during post-operative acute pain among children between the ages of 5 and 18 years of age with and without an ID. Results indicated that differences in pain expression within the sample of children with ID were related to children's developmental ages in the expressive communication and socialization domains of adaptive functioning. Specifically, children who were able to verbalize their pain exhibited normative pain expression, with behavioural traits (e.g., facial actions, vocalizations, body movements, etc.) similar to those of typically developing children of the same developmental age.

By contrast, children who were unable to verbalize their pain produced pain expressions with behavioural traits that were atypical (e.g., lack of facial expressions, vocalizations, and body movements) and without a communicative goal. In general, previous research that has examined pain expression in children with ID underpins the importance of verbal communication for adequately communicating about pain. Unfortunately though, given that these studies included a heterogeneous group of children with various developmental disabilities, the generalizability of this work to specific groups, such as children with ASD, is limited.

Autism Spectrum Disorder. No research has been conducted on how youth with ASD communicate illnesses to others. Of particular relevance to the current study, however, recent investigations suggest that children with ASD express pain differently than typical children. Similar to original beliefs about pain in children with ID, children with ASD have long been described as having a "reduced pain sensitivity" or a "high threshold" for pain (Gillberg, Terenius, & Lönnerholm, 1985). The majority of these beliefs, however, have been based on clinical impressions and anecdotal observations. Moreover, the failure to identify children with ASD as a distinct group in early studies of pain in ID has made it difficult to

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isolate the experience of pain in this population. Finally, systematic investigations that have tried to uncover a physiological mechanism that may explain reduced pain sensitivity in this population have been riddled with methodological issues (e.g., poorly matched control groups, use of unreliable measures to assess pain) and have been inconclusive at best (Nagamitsu et al., 1997; Panksepp, 1979).

Nader, Oberlander, Chambers, and Craig (2004) conducted the first systematic investigation of pain expression in children with ASD. In this study, behavioural distress and facial reactions of pain in 3- to 7-year-old children with and without ASD were recorded during a painful medical procedure (i.e., venepuncture). Overall, the main results of this study showed that the children with ASD displayed greater facial reactivity during the needle phase (pain stage) of the procedure. The authors interpreted this as suggesting that those with ASD were in more pain than the typical children. However, the use of a bundling procedure (wrapping the child in a blanket for the purpose of constricting movement) for only the ASD group was part of the standard protocol of the hospital at that time and represents a limitation of the study. Furthermore, children's developmental ability was not measured and therefore the sample likely involved both children who were verbal and non-verbal.

More recently, Tordjman and colleagues (2009) examined behavioural reactivity of youth (IQ $\leq$ 80) with and without ASD between the ages of 6 and 18 years undergoing venepuncture. Behavioural pain reactivity for those with ASD was also assessed at home (by a caregiver) and at daycare (by childcare providers) using a validated pain reactivity scale. A high proportion of individuals with ASD displayed absent or reduced behavioural pain reactivity at home (68.6%), at day-care (34.2%), and during venepuncture (55.6%). Despite their low rate of reactivity during venepuncture (41.3 vs. 8.7% of controls), individuals with

ASD displayed a significantly increased heart rate in response to venepuncture and higher elevation in plasma ß-endorphin level in response to the procedure, compared to controls. These physiological markers were interpreted as indicators of high stress in the ASD group. The authors concluded that their results strongly suggest that prior reports of reduced pain sensitivity in ASD are related to differences in pain expression rather than to an insensitivity to, or high threshold for, pain. Interestingly, the widely held notion of reduced pain sensitivity in adults with schizophrenia has also been found to be related to a different mode of pain expression (e.g., flattened or inappropriate affect) than to sensory abnormalities (for a review, see Bonnot, Anderson, Cohen, Willer, & Tordjman, 2009).

Most recently, Bandstra, Johnson, Filliter, and Chambers (2012) examined self-reports of pain intensity for high-functioning youth with and without ASD in response to hypothetical pain scenarios varying in severity (low, moderate, high). Children were shown illustrations of various painful situations (e.g., pain associated with medical procedures, injuries) and asked to rate how much pain they would feel if they were the children in the pictures. Findings suggested that youth with ASD reported similar levels of pain to typical children for all of the hypothetical pain scenarios. Because this study was conducted with hypothetical pain scenarios as opposed to real pain, however, we do not know the extent to which the results would be similar in in-vivo situations.

Of particular relevance to the present study, qualitative parent reports gathered in the same study suggested that children with ASD communicate pain differently than typical children (Goodman, Aubrey, Bandstra, & Johnson, unpublished work). For example, some parents reported that their child showed reduced pain expression when hurt, while others reported hyper-reactivity to pain. There were also parental reports of children who respond atypically to pain, demonstrating anger or frustration when hurt or injured. Several parents

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also reported that their children rarely verbally communicated painful symptoms to them, making it difficult for these parents to determine when their child was experiencing pain. Parent reports of pain expression for typical children in this study did not include any of the above themes, with most parents reporting that their child would verbally communicate when s/he was in pain. Taken together, results from the above studies suggest that children with ASD experience pain similarly to typical children, but may differ qualitatively in their physical and verbal expression and communication of such pain.

Social Communication in Autism Spectrum Disorder

Research in pain expression indicates that youth with ASD presenting with a range of language abilities appear to express pain differently than typically developing controls. While developmental level and ability to communicate verbally seem to account for the quality of pain communication in ID populations, it is unlikely that these characteristics alone account for deficits in pain communication among youth with ASD. Given that high-functioning youth with ASD appear to demonstrate atypical pain expression (Bandstra et al., 2012), it is important to consider the characteristics of ASD that may impact the delivery of, and motivation for, successful communication of illness to caregivers.

There are features of the autism spectrum that may disrupt how youth with HFASD communicate illness to others. Since illness episodes often occur in a social context (e.g., the family; Litman, 1974), deficits in social communication frequently observed in ASD likely impact how children and adolescents with ASD communicate their illness symptoms to others. Poor social communication is conceptualized in the present study to be the core skill deficit accounting for atypical illness communication among youth with HFASD. Impairments in the social use of language, or pragmatics, are the hallmark of ASD (Baron-Cohen, 1988). Pragmatic impairments can include difficulty knowing how to appropriately

begin and end conversations, choosing and maintaining suitable topics, adjusting language to

meet the needs of multiple partners, recognizing non-verbal cues, being polite, coordinating

verbal and nonverbal language, and understanding non-literal aspects of language such as

metaphor and humour (Landa, 2000; Lord & Paul, 1997). Landa (2000) described pragmatic

language impairment as the "most stigmatizing and handicapping aspect" of HFASD (p.

125).

Social communication deficits in youth with HFASD have been well characterized

using standardized measures. For example, using the Children's Communication Checklist

(Second Edition; Bishop, 2006), a well-validated parent-report instrument designed to

measure pragmatic language deficits, and the Test of Pragmatic Language (Phelps-Terasaki &

Phelps-Gunn, 1992), a test administered to the child. Volden and Phillips (2010)

demonstrated that youth with HFASD scored significantly lower on language measures that

included pragmatic language when compared to typically developing controls. Poor language

initiation (e.g., failing to initiate topics of reciprocal interest) and non-verbal communication

(e.g., understanding and use of gestures and facial expressions), as well as the use of scripted

language (e.g., repeating or echoing words or sentences that others have said), characterized

the pragmatic language of youth with HFASD. Both groups showed intact structural

language skills (e.g., articulation of speech, use of grammar and vocabulary).

An underlying deficit in the ability to understand emotions may further compromise

social communication in an illness context among those with HFASD. Although illness is

often perceived and described in terms of its organic nature (e.g., physiological sensation),

the experience of illness is most commonly understood, by self as well as others, in terms of

the emotional reaction it elicits in the individual (Bowman, 2001). For example, someone

who is sick or in pain may appear sad, angry, or distressed and as a result may weep, scream,

or appear despondent. While these emotional expressions may be directly related to the pain or discomfort experienced as a result of illness or injury, they may also be related to personal perceptions of illness (e.g., self-efficacy, autonomy, optimism, expectations).

According to the Social Communication Model of Pain, the expression of emotion has a strong impact on how internal states are recognized, interpreted and responded to by others (Craig, 2009). For caregivers, emotional displays provide important information about the child's state and immediate situation, serve to evoke empathetic reactions, and may rouse helping or attentive behaviours from caregivers (Barr, Hopkins, & Green, 2000). Evidence about the emotional expression of individuals with HFASD comes from clinical observation, as well as research studies. In a laboratory setting, research about the emotion expression of individuals with HFASD has yielded conflicting results. Some research suggests that youth with HFASD do not significantly differ from controls in their ability to express emotions verbally (Jaedicke, Storoschuk, & Lord, 1994), and are also able to report examples of feeling states based on their own experience (Yirmiya, Sigman, Kasari, & Mundy, 1992). Other studies, however, have demonstrated that some youth with HFASD have difficulty identifying and describing their emotions (Samson, Huber, & Gross, 2012). In natural settings, findings are more consistent such that individuals with HFASD are observed to express emotion differently than their typically developing peers. For example, some display flattened affect (e.g., facial expression) except when highly emotionally aroused, expressing only the "highs" and the "lows" of emotional experience (Laurent & Rubin, 2004). The contrast between emotional expression in laboratory versus natural settings indicates that while verbal ability to express emotions may be intact in ASD, the quality of emotional expression is atypical. Recent studies have also provided evidence for emotion regulation deficits among HFASD populations (Jahromi, Meek, & Ober-Reynolds, 2012; Samson et al.,

2012). Poor emotional expression and difficulty regulating emotions when distressed may account for atypical pain expression among individuals with ASD, such as those reported in Goodman et al. (unpublished manuscript). Underlying impairments in emotional expression and regulation, combined with deficits in social communication skills, may compromise youths' ability to directly inform caregivers about illnesses, thereby resulting in underreporting of illnesses.

Illness Coping Behaviour

While effective illness management for children begins with communication, it does not end there. As children age they become increasingly able to engage in behaviours to make themselves feel better. Most of these behaviours have been learned by observing how family members cope with their own illnesses and how family members help the youth manage their own illnesses. These behaviours are referred to here as "illness behaviours", because they represent the actions individuals engage in when they believe they are unwell (Harding & Taylor, 2002).

It is generally accepted that illness behaviour occurs through an active process that involves interpreting symptoms, evaluating possible responses, and, finally, deciding on whether to alleviate those symptoms or simply ignore them (Harding & Taylor, 2002). Illness behaviours therefore exist along a continuum, which ranges from denial of illness at one extreme, to responses and actions that are disproportionate to physical symptoms at the other extreme. Both types of dysfunctional behaviours are of concern to health care providers. For example, denial may lead individuals to postpone diagnostic evaluation or be noncompliant with medical regimens, thereby exposing them to unnecessary risks. Preoccupation with illness, on the other hand, creates a costly burden on the healthcare system, affects work productivity, and can lead to unnecessary medical procedures

(Whitehead et al., 1992). In the centre of the continuum, however, are those behaviours that are deemed effective and proportional to the illness at hand.

Coping with Illness

An important way to conceptualize illness behaviour is in terms of coping. According to Varni (1996) coping efforts may be either adaptive or maladaptive, depending on their outcome in terms of relief of discomfort, emotional adjustment, or functional status. Thus, coping is conceptualized as a process, not as an outcome. Rosenstial and Keefe (1983) were among the first to identify a distinction between "active" coping and "passive" coping. In the pain literature, active coping has been defined as direct attempts to deal with pain and the use of active methods to regulate feelings when in pain, while passive ways of coping refer to attempts to withdraw and surrender control over pain (Reid, Gilbert, & McGrath, 1998). Active coping strategies can include things like seeking information, intervention, help or social support, by planning ahead or otherwise attempting to solve the problems caused by the stressor (Walker, Smith, Garber, & Slyke, 1997). Thus, active coping can be seen as problem-focused, as it involves direct attempts to deal with the stressor (Lazarus & Folkman, 1984). Passive strategies can involve either a disengaged way of relating to pain, or an active orientation away from the stressor, such as denial, diversion, or escape (Lazarus & Folkman, 1984). Reliance on strategies that suggest a lack of effort to regulate emotions when faced with a stressor (e.g., worry, emotionality) are also considered passive coping strategies (Reid et al., 1998).

A third distinct coping strategy that seems to be very relevant to pain and illness has been termed "accommodative" coping (Walker & Zeman, 1992). According to Reid et al. (1998), accommodative coping (also called problem-focused avoidance) includes attempts by the individual to adjust to stressful conditions. Behaviours associated with accommodative

coping are cognitive reappraisal (e.g., positive self-statements, such as "I can handle this"), behavioural distraction (e.g., engaging in an activity that keeps the individual occupied), and cognitive distraction (e.g., attempts to distract one's self by thinking about something else). Such strategies differ substantially from passive strategies as they are deliberate attempts to adjust to discomfort in the moment, as opposed to disengagement (Walker & Zeman, 1992). As such, even though accommodative coping is conceptualized as a distinct coping category, it is more homologous to active rather than passive coping (Reid et al., 1998).

Research findings from a variety of contexts (described below) suggest that active coping strategies are generally related to better psychosocial adjustment and health outcomes than passive coping, provided the individual believes s/he can have some control of the situation and has adequate coping resources (e.g., personal skills, social supports, and financial means) available (Walker, Smith, Garber, & Lewis, 2007; Lynn Walker, Smith, Garber, & Claar, 2005). If the situation is not controllable, one's perceived ability to handle/adjust to circumstances is theorized to predict how one copes with a stressor. That is, someone who believes s/he could accept and adjust to their circumstances when it is not possible to change the situation is most likely to engage in accommodative strategies. By contrast, if someone believes s/he could not adjust to unchangeable and distressing circumstances, s/he is most likely to engage in passive coping (Walker et al., 2007). Active coping is typically not adaptive unless the individual believes s/he has some sort of control over the stressor.

Coping Effectiveness

Chronic Pain and Illness Populations. The effectiveness of active- versus passive-oriented coping has been examined in a number of studies of youth with chronic illnesses or recurrent pain. Typically, active strategies (e.g., problem-solving, intervention- or help-

seeking) are associated with better psychosocial and physical outcomes and passive strategies

are associated with poorer outcomes (e.g., Holroyd, Drew, Cottrell, Romanek, & Heh, 2007;

Merlijn et al., 2003). For example, Reid et al. (1998) investigated subjective reports of coping

using the Pain Coping Questionnaire among children and adolescents with a chronic illness

or a recurrent pain condition. Results indicated that higher levels of active coping were

related to less functional disability (e.g., difficulties with various physical and social activities

when in pain) and lower emotional distress. By contrast, higher levels of passivity were

related to more emotional distress, less coping effectiveness, and higher levels of pain.

Similar results have been found in children with sickle cell disease (Gil et al., 1993; Gil,

Williams, Thompson, & Kinney, 1991), and with diabetes (Kovacs, Brent, Steinberg,

Paulauskas, & Reid, 1986), as well as children recovering from surgery (Brophy & Erickson,

1990; Reid, Chambers, McGrath, & Finley, 1997). These findings are echoed in a review on

coping with chronic pain in which Lester and Keefe (1997) concluded that "…coping efforts

which focus on thinking rationally about pain and taking concrete cognitive and behavioural

steps to control pain seem to be the most effective methods for managing chronic pain.

[Conversely] coping efforts, which lead the individual to withdraw or become passive when

dealing with pain, appear to be ineffective" (p. 89).

Strategies that attempt to regulate or reduce distressful emotions (e.g., through

comfort seeking or support seeking) are associated with better physical and psychosocial

outcomes in children with hemophilia (Spitzer & Rose, 1992), asthma (Ryan-Wenger &

Walsh, 1994), and diabetes (Grey, Cameron, & Thurber, 1991). Conversely, expression of

emotions without any attempt to regulate them, such as catastrophizing (i.e., anxiety

associated with the tendency to over-emphasize the probability of a catastrophic outcome)

and externalization (e.g., frustration), are well documented to be maladaptive coping

strategies across a variety of pain and chronic illness contexts in both child and adult studies (e.g., Lynch-Jordan, Kashikar-Zuck, Goldschneider, & Jones, 2006; Sullivan et al., 2001). Finally, accommodative coping is generally considered an effective coping strategy for chronic illness populations. Specifically, behavioural distraction techniques (e.g., doing something to take one's mind off pain) seem to be related to better quality of life and greater perceived pain controllability (e.g., Huguet, Miro, & Nieto, 2009; Reid et al., 1998).

Acute Pain and Illness. While research findings regarding coping and chronic illness are important for understanding effective illness behaviour, coping with chronic illness is often confounded by coping with stress and negative emotions, which commonly accompany these conditions. No research has examined coping in children during acute illnesses, especially everyday illnesses. Although everyday illnesses are by definition not serious, they occur frequently during childhood and adolescence, and thus provide children with opportunities to learn to cope with and manage illness. There is, however, a large body of research in coping and acute pain that we can draw from.

Research in acute pediatric pain demonstrates favourable outcomes for active versus passive coping strategies. For example, Lu, Tsao, Myers, Kim, and Zeltzer (2007) examined coping style and several pain-related variables during safe experimental procedures designed to induce discomfort (i.e., cold pressor task, thermal heat task, pressure task) in a large sample of healthy children between the ages of 8 and 18 years. The researchers found that children's general pain-coping styles, as measured on the Pain Coping Questionnaire, were related to several pain variables. Specifically, the authors reported that internalizing / catastrophizing predicted higher pain intensity across the three pain tasks and higher cold pain unpleasantness. Conversely, accommodative strategies, such as distraction and positive self-statements predicted higher pain tolerance and reduced pain unpleasantness. These

results suggest that in healthy children, internalizing / catastrophizing may be conceptualized as pain-promoting strategies, and positive self-statements and behavioural distraction as pain-resistant coping strategies, within the context of laboratory pain.

Types of Coping Used by Youth

Studies of coping in response to illness and pain have found that healthy children use a variety of strategies to deal with physical distress. According to Siegel and Smith (1989), a number of factors can influence children's appraisal of illness and coping, including cognitive-developmental level, previous experiences with illness, belief in their ability to tolerate physical distress, parental support, chronicity, availability of resources in the environment to cope, and perceived controllability of the ailment by the child. Therefore, the same child might cope differently in a variety of situations.

Ryan-Wenger (1996) conducted a review of the literature (from 1987 to 1994) on coping strategies used by children and adolescents with chronic illnesses. The researchers reported that several variables, such as age and gender, were related to distinct coping behaviours. For example, several studies found that, in general, cognitive strategies such as distraction, problem-solving, social support, and relaxation were associated with older age. Young children used primarily behavioural strategies, such as behavioural distraction and venting feelings, as opposed to cognitive strategies. Ryan-Wenger (1996) suggested that this is not surprising given that coping is influenced, in part, by cognitive development (e.g., increasing attention span, problem-solving ability), increasing impulse control, as well as uptake of taught strategies by caregivers. Of the studies that examined sex differences, most indicated that more girls than boys used emotional regulation or social support; however, other studies found no sex differences on similar variables.

Finally, Ryan-Wenger (1996) found that social support was the most commonly reported coping strategy used by children in the studies reviewed. The operational definition of social support varied across studies and included strategies encompassing comfort, help, and information-seeking. None of the studies indicated from whom such support was sought, although most studies implied that it was a parent or another adult. The second most commonly identified coping strategy was active stressor modification, which included attempts to control or modify the stressor (e.g., through the use of medication, remedies, rest). Accommodative coping strategies were also used frequently, with behavioural distraction (e.g., watching TV, playing, listening to music) reportedly used more frequently than cognitive distraction (e.g., diverting attention away from pain, using humour). While most studies identified children who engaged in passive coping strategies, these children made up a small proportion of samples, suggesting that most children in the studies engaged in more active strategies to deal with their illnesses.

Coping with Illness in Autism Spectrum Disorder

No research has investigated how those with ASD cope with illness, and very little is known about how these individuals cope with stress or difficult life events more generally. As indicated above, active coping strategies help minimize dysfunction and disability, maximize personal potential and quality of life, promote recovery, and limit dependency. Due to deficits in daily living skills (discussed below), youth with HFASD may lack the necessary skills required to carry out active coping behaviours when ill and instead resort to more passive strategies and parental dependence. Poor daily living skills are conceptualized in the present study to be the core skill deficit accounting for atypical illness coping behaviour among youth with HFASD.

Daily Living Skills in Autism Spectrum Disorder. Daily living skills consist of

adaptive behaviours necessary to care for one's self (Harrison & Oakland, 2003).

Conceptually, they are differentiated from other types of adaptive behaviour, namely

communication and social skills, which are necessary to communicate and get along with

others. Daily living, communication, and social skills are all conceptualized under the

umbrella of adaptive functioning. Measures of adaptive functioning represent a gauge

reflecting real-life functioning. That is, adaptive functioning is what a person does on a day-

to-day basis as opposed to what a person is capable of doing under optimal conditions

(Tsatsanis, Saulnier, Sparrow, & Cichetti, 2011). While ability is necessary for the

performance of daily living skills, an individual's adaptive behaviour is inadequate if the

ability is not demonstrated when it is required. For example, if a person has the ability to

perform according to basic rules of safety and verbalizes the rules when asked, but seldom

follows them, his/her adaptive functioning is considered low or inadequate in this domain

(Sparrow et al., 2005).

Adaptive skills necessary for carrying out the majority of active coping behaviours

when ill are part of the "daily living" domain. According to the developers of the Adaptive

Behavior Assessment System – Second Edition (ABAS-II; Harrison & Oakland, 2003), daily

living skills are related directly to health and safety as they "encompass skills needed for

protection of health and to respond to illness and injury, including following safety rules,

using medicines, showing caution, keeping out of physical danger, etc." (p. 5).

As a group, children with HFASD display adaptive behaviour impairments across all

domains. That is, in addition to deficits in communication and socialization, those with

HFASD display poorer daily living skills than their typical peers (Perry et al., 2009). In a

study by Kenworthy, Case, Harms, Martin, and Wallace (2010), scores on ABAS-II were

examined between youth with and without HFASD. Individuals with HFASD were rated as having significantly lower adaptive behaviour ratings across all domains measured (social, communication, daily living) when compared to ratings for their IQ-matched typical peers. With regards to daily living skills, those with HFASD had deficits in personal hygiene / self-care (e.g., brushing teeth, bathing, grooming), home living (e.g., making bed, tidying room, cleaning up after self), community use (e.g., looking both ways before crossing the street, finding restroom in public places), and health and safety (e.g., caring for minor injuries, taking temperature when ill, seeking medication for an illness).

Deficits in adaptive functioning for youth with HFASD have also been found using the Vineland Adaptive Behaviour Scales (VABS; Sparrow et al., 2005), a semi-structured interview for caregivers assessing adaptive functioning across multiple domains. In a study by Saulnier and Klin (2007), the HFASD group had a mean age of 12.4 years and average IQ, but age equivalencies for adaptive behaviours as measured using the VABS were much lower for all domains of adaptive functioning. For example, the mean age equivalence for daily living skills (appropriate dressing, grooming, practicing personal hygiene or effective health care) was 6.2 years, indicating significant deficits in daily living skills.

Furthermore, there is evidence suggesting a widening gap in meeting increasing adaptive demands and expectations with age. For example, Kanne et al. (2011) investigated adaptive functioning in a large sample of 1,089 children and adolescents (aged 4 to 17 years) with ASD. Although all participants were verbal, the study included both high and lower functioning youth (mean IQ = 88). The researchers reported that standard scores on the VABS were significantly negatively correlated with age; meaning that the overall relative level of adaptive skills was lower for older children (Kanne et al., 2011). These results indicate that development of adaptive communication, socialization, and daily living skills does not keep

pace with chronological age.

The growing body of research in adaptive functioning and ASD has led to a general understanding of what is often referred to as the "autism profile" of adaptive functioning. This profile is marked by severe impairments in socialization, intermediate deficits in communication, and relative strengths in daily living skills (Bolte & Poustka, 2002). The phrase "relative strengths" should be considered with caution, as daily living skills are typically below age and cognitive expectations (Klin et al., 2007). This profile is not surprising given that the adaptive domains of communication and social functioning represent areas of functioning with which ASD symptoms interfere. It is less clear, however, why high-functioning individuals on the autism spectrum have deficits in daily living skills, and in some ways, they are puzzling deficits.

Despite their prominence in HFASD, daily living impairments are not acknowledged in the DSM-IV for Asperger's Disorder. According to the DSM-IV, "Individuals with Asperger's Disorder do not have clinically significant delays in cognitive development or in age-appropriate self-help skills [and] adaptive behaviour (other than in social interaction)" (p.81). Tsatsanis et al. (2011) reported that others have theorized that inadequate daily living skills in ASD are likely due to poor skill acquisition as opposed to poor motivation (Tsatsanis et al., 2011). Specifically, a distinction can be made between performance-based and skill-based deficits. That is, the difference between a person who is able to perform a task but does not (e.g., because of severe depression or low motivation) and a person who does not perform the task because he does not have the necessary skills. According to Tsatsanis and colleagues (2011), there is a common perception that for those with ASD, the latter is frequently the case: individuals either have not learned the specific skill or have not been explicitly taught how to apply that skill to their lives in a functional and meaningful way.

Generalization of learning is critical for successful application of daily living skills in society. It has been demonstrated, however, that those with HFASD have difficulty generalizing skills learned in one environment to another (for a review, see Whalen, 2009). For example, an individual with HFASD may struggle to apply what he has learned in a structured teaching situation (e.g., social skills training) to other similar settings or with different materials and people (e.g., at school or home). Poor skill generalization may make it difficult for those with HFASD to successfully implement learned daily living skills across a variety of contexts. Difficulties with daily living skills continue to contribute to challenges later in life, especially securing employment and living independently in adulthood (Carothers & Taylor, 2004; Eaves & Ho, 2008; Liss et al., 2001). Given that daily living skills also encompass skills related to self-care and health and safety, it is likely that individuals with HFASD will also have difficulty effectively coping with physical illnesses.

Illness Management in Autism Spectrum Disorder

Thus far, it has been argued that direct illness communication (informing another about an ailment) and active coping behaviour (problem-focused attempts to deal with ailments) are two key ingredients in identifying, treating and ultimately alleviating acute illness in youth. The term "illness management" will be used herein to refer to the combination of these factors, and to recognize both the communicative and behavioural components of effective illness management. Social communication and daily living skills were conceptualized to be core skills involved in illness communication / coping behaviour, and deficits in these skills are hypothesized to be major contributors to poor illness management.

Groden, Cautela, Prince, and Berryman (1994) theorized that specific skill deficits can significantly hamper the capabilities of individuals with ASD to deal with stress. Specifically, in their model of adaptive coping, the individual experiencing stress has access

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to situational buffers (e.g., social networks, hardiness, internal locus of control), which allow for the successful implementation of adaptive behaviours (e.g., assertiveness, problem solving, utilizing social support), leading to decreased stress. In ASD, Groden and colleagues speculated that maladaptive coping is driven by inadequate buffers (e.g., communication deficits, poor self-control, rigidity), which lead to an over reliance on maladaptive behaviours (e.g., aggression, emotionality). This is a useful model for understanding how deficits in key skills required for illness communication and coping behaviour can significantly disrupt the illness management process, and give rise to maladaptive behaviours that can impact health. The model provides a strong basis for hypothesizing that youths with ASD, who are known to have skill deficits in relevant areas, will demonstrate maladaptive coping strategies in the face of illness. Given the paucity of knowledge about illness management in ASD, it is of primary importance that we better understand this important area of functioning in youth with ASD, as well as how underlying skill deficits may effect illness management.

The Present Study: Objectives and Hypotheses

The present study is the first investigation of illness management in youth with ASD. Specifically, I examined parent- and self-perceptions of illness communication and coping behaviour in youth with and without HFASD. Although both parent- and self-reports were gathered, more emphasis was placed on parent-reports, as previous research suggests that those with HFASD may have poor insight into specific domains of their own functioning (Johnson, Filliter, & Murphy, 2009), tend to overestimate their social competence (Didehbani et al., 2012; Knott, Dunlop, & Mackay, 2006; Lerner, Calhoun, Mikami, & Reyes, 2012), and are less accurate than their typical peers at describing personal skills (Johnson et al., 2009; Koning & Magill-Evans, 2001). Furthermore, research in pediatric psychology suggests that parents are more accurate informants than children for assessing observable illness

behaviours (e.g., medical adherence, externalizing behaviours; for a review see La Greca & Lemanek, 1996).

A series of illustrated vignettes depicting hypothetical ailments was developed to gather information from parents and youth on illness communication and coping behaviour. Study methodology and the development of the vignettes and other measures are outlined in Chapter 2. Characterization data for illness (i.e., knowledge of and experience with illness) and other participant characteristics (e.g., autism severity, adaptive functioning, social communication) are also included in Chapter 2. The results of the study are presented in Chapter 3. A discussion of the research findings and suggestions for further research are included in Chapter 4. The specific objectives and hypotheses of the present study are provided below.

Objective 1: Sample Characterization

The first objective of the present study was to examine differences between the ASD and control groups with respect to autism symptom severity, social communication, and adaptive functioning abilities. This was done to ensure that members of the control group did not have symptoms congruent with a diagnosis of ASD or adaptive impairment. Illness knowledge and experience with illness were also compared between groups. There were no specific hypotheses with respect to these illness variables as they were included primarily as characterization measures.

Objective 2: Illness Communication

The second objective of the study was to examine parent- and self-reports of illness communication among youth with and without HFASD. Within this objective, there were three specific research questions: *Research Question 2.1:* Does the likelihood of reporting ailments to a caregiver differ between youth with and without HFASD? Based on previous

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research in social communication skills, it was hypothesized that youth in the ASD group would be less likely to report ailments to a caregiver compared to those in the control group. *Research Question 2.2:* Does the nature of illness communication differ between youth with and without HFASD? Specifically, I was interested in investigating how parents of youth with and without HFASD become aware of physical ailments in their children. Guided by previous research in pain expression, it was hypothesized that parents in the ASD group would be more likely to become aware of children's ailments through indirect (i.e., complaints or emotionality) or inadvertent (i.e., observing child's sick behaviour) means as opposed to through more direct means (i.e., verbal reports, showing, seeking assistance) compared to parent reports of the control youth. *Research Question 2.3:* Does insight into personal illness communication differ between youth with and without HFASD? Given that self-awareness deficits have been reported in ASD, it was hypothesized that there would be a discrepancy between self- and parent-reports of illness communication, with youth reporting a greater likelihood of communicating about illness and use of direct communication than their parents reported. No discrepancies between self- and parent-reports were anticipated for the control group.

Objective 3: Illness Coping Behaviour

The third objective of this study was to examine parent- and self-reports of illness coping behaviour within the same sample of youth with and without HFASD. Within this objective, there were three specific research questions: *Research Question 3.1:* Does the likelihood of seeking intervention for ailments differ between youth with and without HFASD? Guided by literature on daily living skills, it was hypothesized that youth in the ASD group would be less likely to seek intervention for ailments compared to those in the control group. *Research Question 3.2:* Does the nature of illness coping behaviour differ

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between youth with and without HFASD? Based on previous research in daily living skills and coping, it was hypothesized that parents in the ASD group would report more passive and less active coping strategies used by youth compared to parent reports of the control youth. *Research Question 3.3:* Does insight into personal illness coping behaviour differ between youth with and without HFASD? For the ASD group, it was hypothesized that there would be a discrepancy between self- and parent-reports of illness behaviour, with youth reporting a greater likelihood of seeking intervention and use of active coping strategies than their parents reported. No discrepancies between self- and parent-reports were anticipated for the control group.

Objective 4: Relationship Between Constructs of Interest

The final objective of the present study was to explore the relationship between illness constructs and specific characterization variables. There were two research questions associated with this objective: *Research Question 4.1:* Are social communication abilities related to illness communication? Given the proposed link between social communication and communication of illness, it was hypothesized that parents who reported better social communication skills for youth would also report more direct illness communication used by youth. *Research Question 4.2:* Are skills of daily living related to illness coping behaviour? Since daily living skills are required for adequate self-care, it was hypothesized that parents who reported better daily living skills for youth would also report greater use of active coping strategies.

CHAPTER 2. METHOD AND PROCEDURES

This study was conducted in two phases. Phase 1 involved the development of illness stimuli and measures. In Phase 2, these and other measures were used to investigate the research questions above (main study). This chapter outlines the study methodology for both phases.

Phase 1: Development of Stimuli and Measures

Participants

Expert opinions were gathered from 8 healthcare professionals (7 general practitioners, 1 nurse practitioner) and 15 parents of typically developing youth between the ages of 7 and 18 years (M= 12.3; SD = 2.4) to develop the Illness Vignettes and Illness Knowledge Interview. In order to be eligible to participate, healthcare providers had to be registered physicians or nurses who worked regularly with children and adolescents between the ages of 7 and 18 years. Additionally, only providers who practiced family medicine or general pediatrics were eligible to participate, as it was decided that they would provide the best estimates of illness and injury frequency in typically developing youth. I did not recruit clinicians who primarily work with specialized populations (e.g., cardiologists). Participating parents had to be 18 years of age or older and be the guardian of a typically developing child between the ages of 7 and 18 years of age.

Measures

Questionnaire for Healthcare Professionals. The Questionnaire for Healthcare Professionals (see Appendix B) was developed to gather expert opinions from health providers about medical conditions to comprise the Illness Vignettes. The questionnaire contained 40 relatively common childhood medical conditions; including illnesses (e.g., ear infection, tonsillitis, asthma), injuries (e.g., scrape, sprained muscle, broken limb), and

physical symptoms (diarrhea, rash, headache), that were thought to provide a range of seriousness and frequency (how often the condition occurs in childhood and adolescence). The medical conditions were gathered from the Merck Manual's Online Medical Library of Pediatric Illnesses and the Mayo Clinic's online Comprehensive Illness Guide. Although medical conditions varying in frequency and seriousness were sought, only those that were considered relatively common and benign were included so that children could realistically anticipate what they would say and do in each scenario. Therefore, medical conditions that were very serious (e.g., congenital diseases) or rare (e.g., cancers) were excluded. Additionally, names of conditions that would likely be unfamiliar to young children (e.g., psoriasis) were not included. Healthcare professionals were provided with the name of the medical condition and asked to provide their opinion on the following classification variables to help organize the vignettes: (1) *condition type* (contagious illness, non-contagious illness, injury, or symptom); (2) *condition seriousness* (low, medium, or high); and (3) *condition frequency* in childhood and adolescence (low, medium, or high).

Questionnaire for Caregivers. The Questionnaire for Caregivers (see Appendix C) was used to gather information from parents to help design a series of questions to assess youths' knowledge of specific illnesses. Caregivers were asked to provide their opinion on their child's knowledge and understanding of 24 medical conditions. Specifically, the questionnaire asked parents to indicate if they thought their children would "know about and understand" certain ailments that were thought to be common and likely understood by children (e.g., allergies, chicken pox, headache) or adolescents (e.g., concussion, strep throat, cancer), and those that were less common or considered not well understood by children or young adolescents (e.g., psoriasis, mononucleosis, meningitis). The medical conditions were gathered from the Merck Manual's Online Medical Library of Pediatric Illnesses and the

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Mayo Clinic's online Comprehensive Illness Guide. Parents were asked to answer "yes" if they believed their child knew and understood what the medical condition was and "no" if they did not. Caregivers were also asked to indicate the sex and age of their child.

Procedure

Participant Recruitment. All data collected in Phase 1 were obtained in accordance with study protocols approved by the IWK Health Centre Research Ethics Board. A research assistant visited medical clinics in the community to inform healthcare providers and/or clinic administrators about the study. Interested parties were given an envelope containing a consent form, a letter outlining the details of the study, and the Questionnaire for Healthcare Professionals. Participants were asked to mail the completed forms back to the university using a provided stamped addressed envelope. Via this method of solicitation, 21 healthcare provider questionnaires were distributed. Of these, eight were returned and used in analyses. Parents of typically developing youth who had participated in a previous study at the Johnson Laboratory at Dalhousie University, and consented to participating in future studies, were be contacted by email or telephone. The Questionnaire for Caregivers, along with a study description letter and consent form, were mailed to interested parents. A self-addressed envelope with paid postage was also provided. Healthcare providers and caregivers were also given the opportunity to complete the questionnaires online as opposed to in hard copy.

Selection of Medical Conditions to Comprise the Illness Vignettes. The 40 medical conditions on the Questionnaire for Healthcare Professionals were categorized according to type, seriousness, and frequency (classification variables) using percent agreement among healthcare professionals. Percent agreement was chosen as the means of determining reliability since it provides a clear, straightforward, and easily interpreted statistical assessment of agreement between individuals (Feinstein & Cicchetti, 1990) and is

appropriate for assessing agreement among multiple raters (Cicchetti & Feinstein, 1990; Feinstein & Cicchetti, 1990).

Percent agreement for each classification variable was determined by establishing the category that was endorsed most frequently across all 8 raters, and then calculating the percentage of raters who endorsed that category. For example, if 6 of 8 healthcare professionals agreed that a sore throat was best categorized as a "symptom", the agreement was 75% for that item. Across the 40 ailments, agreement for condition type (contagious, non-contagious, symptom, injury) ranged from 63 to 100%. Agreement for both seriousness (high, medium, low) and frequency (high, medium, low) ranged from 50 to 100%. Only ailments that received percent agreement of 75% or greater for all three classification variables were further considered. This criterion was met for 19 of the 40 ailments. The 12 medical conditions that were selected to comprise the vignettes for the present study were those that provided a sufficient range within each of the classification variables. For these 12 conditions, the average agreement among raters, across all three classification variables, was 89% (see Table 1). A detailed description of the vignettes, including scoring parameters, is provided in the Methods and Procedures section for Phase 2 of the study.

Selection of Medical Conditions to Comprise the Illness Knowledge Interview. A semi-structured interview was developed to assess illness knowledge of youth participants. The first portion of the interview was designed to assess youths' general knowledge and understanding of illness and was replicated from Perrin and Gerrity (1981). The second and third sections were designed to evaluate youths' knowledge of specific illnesses and were created based on parent reports on the Questionnaire for Caregivers.

Three questions were developed to assess youths' ability to convey their knowledge of specific illnesses or injuries using verbal means (expressive knowledge). The particular

ailments that were chosen for this section were intended to represent illnesses that would be considered easy, moderately difficult, and more difficult to define. This was done to ensure a range of complexity so that both children and older adolescents would be able to demonstrate their understanding.

The "easy", "moderate" and "difficult" ailments were chosen based on reports from the Questionnaire for Caregivers. Ailments considered by parents to be known and understood by children 7 years of age and older were classified as "easy", those that were considered to be understood by youth 12 years of age and older were classified as "moderate", and those that were thought to be understood by youth 15 years of age and older were classified as "difficult". The final three ailments chosen for the interview (i.e., cold = easy; concussion = moderate; meningitis = difficult) were those that were most frequently rated by parents to be understood by children in the different age groups. Three questions were added to the interview to assess youths' ability to identify an illness or injury based only on its symptoms (receptive knowledge). The three ailments chosen for this section of the interview (i.e., rash / chicken pox = easy; urinary tract infection = moderate; stroke = difficult) were done so in the same manner outlined above.

Phase 2: Main Study

Participants

In total, 48 children and adolescents, ages 9 – 17 years, and one parent of each, participated in Phase 2 of the study. The 24 participants (21 males) in the ASD group received an ASD diagnosis from a regional health centre (e.g., the IWK Health Centre in Halifax, Nova Scotia or the Hotel Dieu in Kingston, Ontario) or by a clinical psychologist in the community with expertise in ASD. Participants with any of the following DSM-IV diagnoses: Autistic Disorder, Pervasive Developmental Disorder - Not Otherwise Specified,

Asperger's Disorder, or a more general "ASD" diagnosis, were eligible for inclusion. All participants included in this study were administered the Autism Diagnostic Observation Schedule and/or Autism Diagnostic Interview - Revised as part of their initial diagnostic assessment or preliminary screening from previous studies. The other 24 participants (19 males) were classified as typically developing controls. Participants were excluded if they had a current diagnosis of another major psychiatric disorder or serious chronic medical condition requiring ongoing maintenance (e.g., diabetes, epilepsy). This information was gathered from parents during a screening interview to determine study eligibility. Participants were excluded if they had an estimated IQ of less than 80 (determined by the Wechsler Abbreviated Scale of Intelligence; Wechsler, 1999) or who showed difficulty with verbal language (determined by age-appropriate criterion scores on the Clinical Evaluation of Language Fundamentals, fourth edition – Screener; Semel, Wiig, Secord, 2004). The two groups were considered equivalent on age, sex and estimated full scale IQ, as there were no significant differences between groups for any of these comparisons (see Table 2). In the ASD group, 22 of the parents were female and two were male. In the control group, all parents were female. Parents and youth had to be able to read and respond to questions in English.

Measures

Participating parents were asked to complete a number of questionnaires designed to measure their child's adaptive functioning and social communication abilities, as well as their child's severity of ASD symptoms. Parents were also asked to complete a questionnaire about their child's experience with illness. Youth completed a test of intellectual functioning, a test of general language ability, and the Illness Knowledge Interview. Both parents and youth completed the Illness Vignettes. All measures are discussed below.

In total, six undergraduate students were involved in scoring of the specific measures detailed below. Two of these students served as primary scorers, while the other four were secondary scorers. The author (KA) held several formal seminars to train students on the scoring procedures, but was not directly involved in scoring. For non-standardized measures, a manual was developed containing detailed scoring instructions and examples to be referred to by students. Furthermore, students practiced scoring measures containing hypothetical data as a group and independently, prior to being permitted to score participant measures.

All measures were independently scored by a primary and secondary scorer. When discrepancies arose, they were discussed between scorers and a consensus was reached for all items. In rare instances where the primary and secondary scorer could not come to a consensus, a third rater was consulted and a decision was made. For non-standardized measures, percent agreement (i.e., the percentage of concordant ratings between primary and secondary raters) was used as a reliability estimate. Since a number of variables included in the scoring parameters (described below) occurred very infrequently, misleadingly low reliability estimates were found when Cohen's Kappa statistic was calculated for such variables. This phenomenon is known as the 'base rate problem' (Cicchetti & Feinstein, 1990; Feinstein & Cicchetti, 1990; Simon, 2006). Thus, percent agreement was chosen as an estimate of reliability instead of the more conservative Cohen's Kappa. Cicchetti and Showalter (1997) classify percent agreements as excellent (90-100%), good (80-89%), fair (70-79%), and poor (below 70%). Percent agreement for each of the non-standardized measures is discussed below.

Characterization Measures: Parent

Social Responsiveness Scale (SRS). ASD severity was measured using the SRS (Constantino & Gruber, 2005). The SRS is a parent-report questionnaire for children aged 4

to 18 years, which measures the severity of symptoms assumed to interfere with social function. Each item on the scale inquires about an observed aspect of reciprocal social behaviour that is rated on a scale from "1" (not true) to "4" (almost always true). In addition to a Total Score reflecting severity of social deficits, the SRS generates scores for five subscales. Only the Total Score was used to characterize ASD symptom severity in the present study.

Interpretation is based on a single score reflecting the sum of responses to all 65 SRS questions, whereby higher scores indicate greater severity of ASD symptoms. A total T-score of 76 or higher is considered severe and strongly associated with a clinical diagnosis of Autistic Disorder. A T-score of 60 through 75 is interpreted as within the mild to moderate range and are consistent with mild or "high-functioning" ASD, while a T-score of 59 or less suggests an absence of ASD symptoms. The SRS demonstrates strong reliability across informants, acceptable internal consistency, and correlates highly with scores on the Autism Diagnostic Interview-Revised.

Children's Communication Checklist-Second Edition (CCC-II). Youths' social communication abilities were measured using the CCC-II (Bishop, 2006). The CCC-II is a parent-report measure for children aged 4 to 17 years. The measure contains 70 items divided into 10 scales. The first four scales assess structural aspects of language: speech (e.g., "Speaks fluently and clearly, producing all the speech sounds accurately without hesitation"), syntax (e.g., "Leaves off past tense - *ed* endings on words, such as 'John kick the ball'"), semantics (e.g., "Mixes up words that sound similar, such as 'telephone for television'"), and coherence (e.g., "It is hard to make sense of what s/he is saying, even though the words are clearly spoken"). The next four scales assess aspects of communication that are impaired in children with pragmatic difficulties: inappropriate initiation (e.g., "Talks repetitively about

things that no one is interested in"), stereotyped language, (e.g., "Pronounces words in an inappropriate manner, such as mimicking a TV personality rather than speaking like those around him"), use of context (e.g., "Misses the point of jokes or puns"), and non-verbal communication (e.g., "Looks blank in a situation when most children would show a clear facial expression, such as when happy or fearful"). The final two scales assess behavioural domains relevant to ASD: social relations (e.g., "Appears anxious in the company of other children"), and interests (e.g., "Shows interest in things or activities that other people would find unusual, such as traffic lights"). The respondent is asked to rate the frequency with which a specific behaviour is observed on a scale from "0" (less than once a week or never) to "3" (several times a day or always). A General Communication Composite score can also be obtained, formed by summing the first eight (speech, syntax, semantics, coherence, inappropriate initiation, stereotyped language, use of context, non-verbal communication) scales. The General Communication Composite and the pragmatic language subscales were used to characterize social communication in the present study.

Adaptive Behavior Assessment System-Second Edition (ABAS-II). Youths' daily living abilities were measured using the ABAS-II (Harrison & Oakland, 2003). The ABAS-II is a parent report measure valid for assessing adaptive behaviour in individuals from birth to 89 years of age. Skill area scores are presented as norm-referenced scaled scores, and are aggregated into three composite scores: (1) Conceptual: consists of subscales for communication (e.g., "Ends conversations appropriately"), functional academics (e.g., "Checks for correct change after buying an item"), and self-direction (e.g., "Works independently and asks for help only when necessary"); (2) Practical: includes home living (e.g., "Puts things in their proper place when finished using them), community use (e.g., "Follows another's directions to nearby places), and health and safety (e.g., "Follows general

safety rules at home", self-care (e.g., "Washes hands with soap"); and (3) Social: includes

leisure (e.g., "Has a hobby or creative activity that requires making or building something, for

example, sewing, carpentry, or gardening"), and social (e.g., "Keeps a stable group of

friends"). A Global Adaptive Composite score is also calculated from all nine skill area

scores. The Global Adaptive Composite and the Practical subscale composite subscales were

used to characterize daily living skills in the present study.

Illness Experience Questionnaire for Parents. A questionnaire was developed for

parents to gather information about their children's and families' illness experience, as well as

their children's general health and healthcare utilization (see Appendix D).

Child's General Health and Healthcare Utilization. All parents were asked to

rate their child's physical health in the last 12 months, as well as over their lifetime using a

five-point Likert scale (1 = Excellent, 5 = Poor). Parents were also asked about the number

of healthcare provider and hospital visits their child had experienced in the last 12 months.

In order to reduce memory bias and under- or over-reporting of general healthcare

utilization, the common practice indicated by the literature is to avoid recall time frames

greater than 12 months for healthcare utilization (Bhandari & Wagner, 2006). The time

frame, however, can be extended in order to capture salient health care utilization episodes

(e.g., operation, visit to emergency department) that are less prone to memory biases

(Bhandari & Wagner, 2006). Therefore, parents were also asked to report any operations

their children had undergone, as well as the reason for these procedures.

Illness Experience. All parents were asked to list their child's health problems

during the past 12 months. As above, 12 months was chosen to help reduce memory bias

and enhance accurate recall of illness episodes. Parents were also asked to list any illnesses

that had occurred in the child's immediate family (family members living in the child's home)

during the past 12 months. Finally, parents were asked to report on any illnesses that they perceived as possibly influencing the child's understanding of illness in some way. These illnesses were not limited to family members living in the child's home, and could include individuals such as grandparents, aunts, uncles, cousins. The specific instructions for parents were as follows:

> Please list any serious illnesses or injuries, including those resulting in death or life-threatening in nature, that have occurred in your family throughout your child's life that you think might have influenced the way your child views or feels about illness. Do not include conditions that have happened to your child directly.

> Illnesses of both the child and family members were rated according to their seriousness and chronicity using a coding scheme developed by Hamsdottir and Malcarne (1998) in the following manner: (0) *none:* no illnesses reported for given time-frame (1) *not serious, not chronic:* illness not necessarily requiring doctor's attention (e.g., colds, stomachaches, pink eye, headache, ear infections); (2) *serious, not chronic:* requiring hospitalization, doctor's attention, or staying in bed for some time (e.g., childhood diseases, broken bones, tonsillitis, flu, chickenpox); (3) *not serious, chronic:* recurring problems, not very debilitating or disruptive, easily controlled through medication or lifestyle (e.g., eczema, allergies, migraines, acid reflux); (4) *serious, chronic:* diseases such as hypertension, ulcers, asthma, diabetes, multiple sclerosis, lupus, epilepsy; (5) *life-threatening and/or terminal:* such as, heart attack, stroke, cancer, paralysis, and death. The coding scheme yielded three scores of disease severity: one for child illnesses (past 12 months), one for immediate family illnesses (past 12 months), and one for serious illnesses within the extended family (lifetime).

A manual was developed containing detailed scoring instructions, as well as several examples of illnesses that would fall under each of the five organizational categories.

Although detailed scoring instructions and examples were included in the manual, scorers were encouraged to consult additional reputable sources should an illness be listed with which they were unfamiliar (e.g., the online Merck Medical Manual; American Academy of Pediatrics Online Encyclopedia). Following these guidelines, scorers could then categorize the illness appropriately.

Inter-rater Agreement. A randomly selected subsample of questionnaires (25% of full sample; n=12) was used to determine inter-rater reliability of Hamsdottir and Malcarne's coding scheme. Percent agreement (i.e., the percentage of concordant ratings between primary and secondary raters) was used as a reliability estimate. Percent agreement for the classification variables were all in the excellent range (i.e., > 90%; Cicchetti & Showalter, 1997) and were as follows: none (100%); not serious, not chronic (99%); serious, not chronic (97%); not serious, chronic (95%); serious, chronic (99%); life-threatening and terminal (99%).

Characterization Measures: Youth

Wechsler Abbreviated Scale of Intelligence (4-subtest WASI). Youths' intellectual functioning (IQ) was estimated using the WASI (Wechsler, 1999) to ensure that the ASD sample was similar in cognitive abilities to the control sample. The WASI was also completed to confirm that all participants were "high-functioning" (IQ $\geq$ 80). The WASI consists of four subtests: Vocabulary, Similarities, Block Design, and Matrix Reasoning, and yields Verbal, Performance, and Full Scale IQ scores. Although the WASI is an abbreviated scale, it has been found to correlate highly with other non-abbreviated Wecshler IQ tests (e.g., Wechsler Intelligence Scale for Children—Fourth Edition). The WASI is suitable for use with individuals 6 through 89 years of age.

Clinical Evaluation of Language Fundamentals-Fourth Edition, Screening

Test (CELF-4 Screener). Youths' basic language skills were assessed with the CELF-4

Screener (Semel, Wiig, & Secord, 2004). Given the present study's emphasis on

communication, the CELF-4 Screener was used to confirm that all participants had adequate

structural language abilities. The CELF-4 Screener is used to assess four areas of general

language ability (i.e., receptive skills, expressive skills, grammatical skills, and semantic skills).

The test was developed to identify youth at risk for language impairment and yields a

dichotomous result based on chronological age, categorizing participants as "above criterion"

or "below criterion" (i.e., at risk for language impairment). The CELF-4 Screener is suitable

for use with individuals 5 through 21 years of age.

Illness Knowledge Interview. A semi-structured interview was developed to assess

illness knowledge of youth participants (see Appendix F). The first portion of the interview

was designed to assess youths' general knowledge and understanding of illness, while the

second and third sections were designed to evaluate youths' knowledge of specific illnesses.

A standard clinical interview technique was used, such that each open-ended question was

followed with standard probes such as "What else?" and "Can you tell me more about that?"

until the interviewer was satisfied that she had accessed the full extent of the youths'

knowledge. Interviews were audio-recorded and subsequently transcribed.

General Illness Knowledge. The general knowledge portion of the interview was

replicated from Perrin and Gerrity (1981), and consisted of four questions to assess youths'

general knowledge and understanding of illness. Specifically, youth were asked about their

beliefs regarding *illness causality* (i.e., "How do people get sick?"), *symptom recognition* (i.e., "How

do people know when they are sick?"), *illness treatment* (i.e., "When people get sick, how do

they get better again?"), and *illness prevention* (i.e., "How can people try to keep/stop

themselves from getting sick?"). Perrin and Gerrity's interview was originally developed to assess general illness knowledge of healthy children between the ages of 5 and 12 years.

It was decided that the scoring rubric used by Perrin and Gerrity was not appropriate for youth who were over the age of 12 years, as it characterized children's illness knowledge using a Piagetian developmental framework. Therefore, scoring criteria were developed by establishing a set of content areas (themes) that reflected only the most important aspects of each question. The use of content areas to assess an individual's knowledge of a specific subject is common in English and language arts testing, as it allows for estimates of conceptual understanding as opposed to accumulation of knowledge or facts (Badger & Thomas, 1992).

For each of the four General Illness questions, a number of important themes were generated by the author (KA) and another Psychology graduate student. The themes chosen were intended to reflect what an ordinary adult, as opposed to a medical professional, would consider to be a good understanding of the illness concepts. Following this, the themes were presented to ten undergraduate and graduate Psychology students to gather additional input. The final content areas used to score each question were only those that were agreed upon by all members of the focus group. The themes were weighted with a score of one or two, depending on how essential the content area was considered to be. That is, content areas that were considered necessary to satisfy the question were assigned a score of two (e.g., that one must experience symptoms to know they are ill), whereas those that were deemed to be secondary, or complementary, were assigned a score of one (e.g., obtaining confirmation of illness from a healthcare professional). The participant was awarded the appropriate scores depending on how many content areas his/her answer included. The content areas varied depending on each question, and are presented in Table 3.

Specific Illness Knowledge: Expressive. Three questions were developed to assess youths' ability to convey their knowledge of specific illnesses or injuries using verbal means (expressive knowledge). The ailments that were chosen for this section were selected based on parent reports during Phase 1 of the study, and were intended to represent illnesses that would be considered easy (i.e., cold), moderately difficult (i.e., concussion), and more difficult (i.e., meningitis) to define. This was done to ensure a range of complexity so that both children and older adolescents would be able to demonstrate their understanding. For each ailment, youth were asked to define the ailment (e.g., "What is a cold?"), and its etiology (e.g., "How do people get colds?"). Scoring criteria for these questions were developed by establishing a set of content areas that had to be satisfied for both the definition and etiology questions. All content areas were worth a score of one. The content areas for each of the specific illness knowledge questions are presented in Table 4. Illness and injury characteristics (e.g., definitions, symptoms, etiologies) were gathered from the Merck Manual's Online Medical Library of Pediatric Illnesses and the Mayo Clinic's online Comprehensive Illness Guide.

Specific Illness Knowledge: Receptive. Three questions were added to the interview to assess youths' ability to identify an illness or injury based only on its symptoms (receptive knowledge). The ailments that were chosen for this section were selected based on parent reports during Phase 1 of the study, and were intended to represent illnesses that would be considered easy (i.e., chicken pox or rash), moderately difficult (i.e., urinary tract infection [UTI] = moderate), and more difficult (i.e., stroke) to identify. For example, youth were asked what might be wrong with someone if they had a given set of symptoms (e.g., red itchy spots all over one's body). If the youth did not provide the correct answer (i.e., chicken pox or rash) or responded "I don't know", they were given the opportunity to select the correct

answer from a list of four ailments (i.e., ringworm, chicken pox, lice, malaria). Only those who did not give a correct spontaneous answer were asked to respond to the multiple-choice question. Answers were scored using a 3-point scale (0 to 2) with points awarded in the following manner: 2 = spontaneous correct answer, 1 = incorrect, or no, spontaneous answer, but correct multiple-choice answer, and 0 = no response or incorrect spontaneous answer and multiple-choice answer. Therefore, total scores for receptive illness knowledge could range from 0 to 6 for each participant.

Inter-rater Agreement. A randomly selected subsample of interviews (25% of full sample; n=12) was used to determine inter-rater reliability of scoring parameters for the knowledge interview using percent agreement. Overall, as shown in Tables 3 and 4, percent agreement for the content areas of the general and expressive knowledge interview was quite good, with most themes falling in the excellent (> 90%) to good (80-89%) range (Cicchetti & Showalter, 1997). Although one answer theme fell within the poor range (< 70% agreement), it was retained for use in analyses as consensus was reached for all discrepancies between raters following a discussion. Percent agreement coefficients for the receptive knowledge section were as follows: rash (92%); UTI (92%); stroke (83%).

Primary Measures of Illness Communication and Coping Behaviour

Illness Vignettes. In order to assess parent- and self-perceptions of illness communication and behaviour, the author (KA) developed 12 vignettes that each describe a youth with a medical condition. A "vignette" is a story that provides concrete examples of people and their behaviours in certain situations. Using vignettes, participants can formulate opinions and comment on what they or another person would do or how they would react in a certain situation (Barter & Renold, 1999). Commonly, participants are presented these

standardized scenarios and then asked to answer a range of open- or closed-ended questions (Barter & Renold, 2000).

The vignettes in the present study were modeled after the Charleston Pediatric Pain Pictures (CPPP; Belter, McIntosh, Finch, & Saylor, 1988), which are a series of vignettes that describe common painful situations, accompanied by line drawings of a child in these painful situations. For each CPPP vignette, participants are asked to rate how much pain they believe they would experience in each given scenario, typically using a 5- or 10-point rating scale. The CPPP have been well-validated for use with children as young as three years of age (Belter et al., 1988) and have been effective with older youth with ASD and their parents to assess hypothetical pain ratings to various painful scenarios (Bandstra et al., 2012). Moreover, this method of employing vignettes, which facilitates the individual's ability to answer questions concerning their own understanding and representations, has been used widely in research on chronic illness (Williams & Binnie, 2002), pediatric pain (Adesman & Walco, 1992), and children's general understanding of biology (Williams & Tomie, 2000).

Similar to the CPPP, each vignette was paired with a gender-neutral drawing of a child with a neutral facial expression. The drawings were completed by a Fine Arts graduate student at the Nova Scotia College of Art & Design. A brief vignette describing the particular ailment was presented orally to the participant at the same time the drawing was presented. For example: "This is you. You have a runny nose and a sore throat. You also cough and sneeze a lot. This is because you have a cold." All the Vignettes are provided in Appendix F. The Illness Vignettes were pilot tested with five typical youth (ages 9 to 16 years) and their parents to ensure feasibility. When necessary, changes were made to the measures based on feedback from pilot participants and experimenters.

Illness Vignette Communication and Behaviour Questions. Following the brief

verbal vignette, youth were asked if they had ever experienced the ailment described. They

were then asked four additional questions (two open-ended and two closed) about what they

would say and do if they experienced the ailment tomorrow. The use of the word

"tomorrow" was included so that youth could describe what they would do, as opposed to

recalling a specific event.

The open-ended questions for each vignette were as follows: (1) Illness

communication: "How would you let someone know, or how might someone find out, if you

had . . . [name of medical condition]?", and (2) Illness behaviour: "If this happened to you

tomorrow, tell me everything you would do if you had . . . [name of medical condition]?" If

the participant made a very general statement for either question (e.g., "I would tell

someone" or "I would make it feel better"), they were asked to provide additional details

(e.g., "What exactly would you say?" or "How exactly would you make it feel better?").

Participants were also prompted as necessary (e.g., "anything else?" or "what else might you

do?") until the child indicated that they had no more information to offer (e.g., said "that's

all", "I wouldn't do anything else").

The closed questions were answered using a Likert scale (0 = very unlikely, 5 = very

likely) and were as follows: (1) Illness communication: "If this happened to you tomorrow,

how likely is it that you would let someone know this happened?" and (2) Illness behaviour:

"If this happened to you tomorrow, how likely is it that you would stop what you were doing

and try to make yourself feel better again?" Parents were asked to answer the same open- and

closed-ended questions about their children.

Illness Vignette Scoring Procedures. Coding of the open-ended questions on the

vignettes was done using content analysis. Following the steps outlined by Weber (1990), an

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emergent coding strategy was utilized, in which content categories are established following some preliminary examination of the data. During the pilot phase of the study, the responses to the vignettes from seven typically developing pilot participants aged 10 to 17 years were independently reviewed by two researchers to establish a set of content areas. The final selection of content areas contained those that both researchers agreed sufficiently captured relevant themes reflected across a number of the different vignettes and participants. An "other" category was also established so that unusual or infrequent responses could still be captured.

For the illness communication question, the content areas were organized into four broader conceptual categories based on the directness of the communication, and are as follows: direct communication, indirect communication, disengaged, and other or ambiguous communication. See Table 5 for a description of the contents units and their corresponding conceptual category.

The conceptual organization of the illness coping behaviour content areas was guided by previous research that has examined and categorized coping behaviours in the context of pediatric pain (Reid et al., 1998; Walker et al., 1997). Guided by these principles, the content areas were organized according to the broader coping categories of active, accommodative, and passive coping strategies. The "active" category was later divided into two sections, one characterizing broad or general problem-focused coping behaviours (e.g., seeking help), and the other representing more specific behaviours (e.g., wanting to visit a doctor). A fourth category termed "inattentive" was also added to capture responses indicating that the youth would not engage in any behaviours to cope with the ailment described. Finally, ailment-specific behaviours, which were defined as reports reflecting that the youth would engage in an intuitive (e.g., "go to the bathroom") or automatic (e.g., "limp", "sneeze") behaviour,

were not included in the conceptual organization as they were thought to represent intuitive or automatic reactions to illness, as opposed to specific coping strategies. See Table 6 for a description of the content areas and their corresponding conceptual categories.

Inter-rater Agreement. A randomly selected subsample of responses to the Illness Vignette questions (25% of full sample; n=12 youth vignettes, n=12 parent vignettes) was used to determine inter-rater reliability (percent agreement) of scoring parameters for the vignettes. Percent agreement coefficients for the vignettes were in the good to excellent range, ranging from 83 to 100%, with an average percent agreement of 96% (please see Table 7 for a listing of all percent agreement scores).

Procedure

Phase 2 of the investigation was conducted in Halifax, Nova Scotia or Kingston, Ontario. All data were obtained in accordance with study protocols approved by the IWK Health Centre Research Ethics Board or the Queens University Health Sciences Research Ethics Board. Study participants were recruited via poster advertisements placed in the IWK Health Centre and community. Participants who had completed a previous study at either the Johnson Laboratory at Dalhousie University or the ASD Studies Lab at Queens University were also invited to participate in the present investigation. Parents of potential participants underwent a brief screening interview over the telephone to determine if inclusion and exclusion criteria were met.

Two research assistants were present during testing; one worked with the parent and the other with the youth. Following consent, participants' general level of cognitive ability was estimated using the WASI (Wechsler, 1999). None of the participants performed below the inclusion cutoff (i.e., 80) on this measure. Participants then completed the CELF-4 Screener, the Illness Knowledge Interview, and the Illness Vignettes. Parents completed

questionnaires and the Illness Vignettes. Youth completed the knowledge interview before any other illness measures so that their answers would not be influenced by discussion of personal illness. Following completion of the study, participants were debriefed and both parents and their children were given a small honourium to thank them for their participation.

CHAPTER 3. RESULTS

Data Analysis

The research objectives of the present study were addressed using a variety of analytic techniques (described below). In keeping with statistical reporting procedures outlined in the Sixth Edition of the American Psychological Association's Publication Manual (2010), I report the exact significance level (p value) for all test statistics cited in text, unless the p value is less than .001 (i.e., $p < .001$).

Multiple statistical comparisons between the clinical and control group could not be avoided in the present investigation. Multiple comparisons increase the likelihood of committing a Type I error (i.e., rejecting the null hypothesis when it is true). There is no universally accepted solution to the issue of multiple comparisons (for discussions see Perneger, 1998; Rothman, 1990). Sometimes, a statistical correction (e.g., Bonferroni adjustment) can be applied to analyses to reduce the likelihood of Type I errors. Due to the exploratory nature of the present investigation, however, the relative risk of Type I error was determined to outweigh the risk of Type II error (i.e., failing to reject the null hypothesis when it is false; Rothman, 1990). This decision was based on discussions in the research literature suggesting that adjustments to the alpha level are too conservative and unfairly increase the risk of Type II errors (Feise, 2002). Furthermore, although this is a novel area of research, specific hypotheses based on previous research were made for each of the objectives below. Therefore, no statistical corrections were applied for planned analyses related to the research objectives. A statistical correction was applied, however, to exploratory analyses. All exploratory analyses are clearly identified below.

Objective 1: Sample Characterization

The first objective of the present study was to examine differences between the ASD and control group with respect to autism symptom severity, social communication, and adaptive functioning abilities. Illness knowledge and experience with illness were also compared between groups. Independent samples *t*-tests were used to investigate group differences for subscale and/or Total scores on the SRS, the CCC-II, and the ABAS-II. Independent and paired samples *t*-tests, as well as non-parametric statistics (i.e., Chi squared tests), were used to investigate differences between groups for illness knowledge and illness experience variables.

Objective 2: Illness Communication

The second objective of the study was to examine parent- and self-reports of illness communication among youth with and without HFASD. The three research questions associated with this objective were: Research Question 2.1: Does the likelihood of reporting ailments to a caregiver differ between youth with and without HFASD? Research Question 2.2: Does the nature of illness communication differ between youth with and without HFASD? Research Question 2.3: Does insight into personal illness communication differ between youth with and without HFASD? All data for these research questions was gathered from the illness vignettes. Exploratory analyses were also conducted to examine the likelihood that the youth would report different types of ailments (illnesses, symptoms, injuries).

Research Questions 2.1 and 2.3 involved data from closed-ended questions. To answer these questions I used a mixed 2 x 2 x 3 repeated measures Analysis of Variance (ANOVA) examining the effects of Group (ASD vs. control), Rater (parent vs. youth), and Ailment Seriousness (low, moderate, high) for mean ratings of the likelihood that youth

would report hypothetical ailments to a caregiver. When significant effects were revealed through ANOVAs, follow-up post-hoc testing was conducted using *t*-tests.

Research Questions 2.2 and 2.3 involved data from open-ended questions. To answer these questions I compared the number of times parent and youth in the ASD and control groups reported specific types of illness communication. Data were coded into several content areas that captured the range of themes reported by parents and youth. Participants were then given a count of 1 for any of the content areas and respective conceptual categories that were included in their responses. Given that there were 12 vignettes in total, counts ranged from 0 to 12 for each content area and conceptual area for each participant. Non-parametric statistics (Mann-Whitney U and Wilcoxon Signed Ranks tests) were used to examine between-group differences (i.e., ASD parent vs. control parent, ASD youth vs. control youth) and within-group differences (i.e., parent vs. youth) for these frequency counts.

An exploratory analysis to examine mean ratings of the likelihood that the youth would report different types of ailments was conducted using a 2 x 3 repeated measures ANOVA examining the effects of Group (ASD vs. control) and Ailment Type (illnesses, symptoms, injuries). Follow-up post-hoc testing was conducted using *t*-tests. A statistical adjustment (i.e., Bonferroni correction) was applied to these analyses.

Objective 3: Illness Coping Behaviour

The third objective of the study was to examine parent- and self-reports of illness coping behaviour among youth with and without HFASD. The three research questions associated with this objective were: Research Question 3.1: Does the likelihood of seeking intervention for ailments differ between youth with and without HFASD? Research Question 3.2 Does the nature of illness coping behaviour differ between youth with and

without HFASD? Research Question 3.3: Does insight into personal illness communication differ between youth with and without HFASD? Exploratory analyses were also conducted to examine the likelihood that the youth would seek intervention for different types of ailments (illnesses, symptoms, injuries), and to further examine between-group comparisons for the types of intervention (e.g., medicines, remedies, visiting a health care professional) parents reported their children used when ill. All data were gathered from the illness vignettes.

For Research Questions 3.1 and 3.3, I used a mixed 2 x 2 x 3 repeated measures ANOVA examining the effects of Group (ASD vs. control), Rater (parent vs. youth), and Ailment Seriousness (low, moderate, high) for mean ratings of the likelihood that youth would seek intervention for hypothetical ailments. When significant effects were revealed through ANOVAs, follow-up post-hoc testing was conducted using *t*-tests. For Research Questions 3.2 and 3.3, I compared the number of times that parents and youth in the ASD and control groups reported different types of coping behaviour. As above, data from open-ended questions were coded into content areas and organized conceptually according to broader coping categories. Frequency counts were then compared using non-parametric statistics (i.e., Mann-Whitney U and Wilcoxon Signed Ranks tests) to examine between-group (i.e., parent vs. parent, youth vs. youth) and within-group (i.e., parent vs. youth) differences.

Exploratory analyses to examine mean ratings of the likelihoods that the youth would seek intervention for different types of ailments were conducted using a 2 x 3 repeated measures ANOVA examining the effects of Group (ASD vs. control) and Ailment Type (illnesses, symptoms, injuries). Follow-up post-hoc testing was conducted using *t*-tests. Finally, Mann-Whitney U tests were used to examine differences between intervention types

for the ASD and control groups. A statistical adjustment (i.e., Bonferroni correction) was applied to these analyses.

Objective 4: Relationships Between Constructs of Interest

The final objective of the study was to explore the relationships between illness constructs and specific characterization variables. The two research questions associated with this objective were: Research Question 4.1: Are social communication abilities reported on the CCC-II related to illness communication? Research Question 4.2: Are skills of daily living reported on the ABAS-II related to illness coping behaviour? I used Spearman correlations to investigate the relationship between frequency counts of parent-reported direct illness communication on the vignettes and scores on the CCC-II. Spearman correlations were also used to examine the relationship between percentage values of parent-reported active coping behaviour on the vignettes and scores on the ABAS-II.

Exploratory Analyses

Given that the illness vignettes are a novel measure, I explored inter-relationships using Spearman correlations between the illness communication and behaviour content areas (frequency counts). Although these analyses were not part of the above research objectives, it was thought that they would provide important information for future refinement of the content areas and/or conceptual categories used to create the open-ended questions of the vignettes.

Objective 1: Sample Characterization

Group Differences for ASD Characterization Measures

Autism symptomology (i.e., overall symptom severity and social communication deficits) and adaptive functioning abilities were compared between groups using independent *t*-tests.

Autism Spectrum Symptom Severity. The severity of youths' autism spectrum symptoms was measured using the SRS. An independent samples *t*-test was used to compare Total scores on the SRS for the ASD and control group. Youth in the ASD group obtained significantly higher T-scores on the SRS (*M* = 78.5, *SD* = 10.4) compared to scores for those in the control group (*M*= 43.5, *SD* = 6.0), *t*(46) = 14.1, *p* < .001. Total T-scores obtained on the SRS suggest that ASD participants enrolled in the present study have a range of social deficits, ranging from mild to severe (T-score range = 55 – 90). All but one participant in the ASD group received a Total score above the suggested cut-off T-score of 60, indicating that ASD participants in the present study were reported by parents to have symptoms consistent with a diagnosis of ASD. Specifically, eight participants (33% of ASD sample) obtained a Total T-score within the "mild to moderate" range (T-score of 60 through 75) while 15 participants (62.5% of ASD sample) obtained a Total T-score within the "severe" range (T-score of 76 or higher). One participant in the ASD group scored within the "typical" range (T-score of 59 or less; participant T-score = 55)[1]. All but one participant in the control group obtained SRS Total T-scores in the typical range (T-score of 59 or less). One participant received a T-score at the very low end of the "mild to moderate" range (participant T-score = 61)[2].

   Social Communication. Youths' communication abilities were further examined using the CCC-II. Independent samples *t*-tests were used to compare scores on the CCC-II for the ASD and control group (see Figure 2). Youth with ASD obtained significantly lower scores than those in the control group across all scales of the CCC-II measuring pragmatic

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[1] Given that the SRS is not a diagnostic measure, but rather represents degree of social difficulties, this participant was not excluded from analyses. Furthermore, the obtained T-score of 55 is marginally below the SRS cutoff of 59 for the "mild to moderate" range. Finally, this participant's scores on other characterization measures (i.e., CCC-II, ABAS-II) were within 1.5 standard deviations of the ASD sample's means.
[2] This participant's scores on the CCC-II and ABAS-II indicated social communication, adaptive functioning, and structural language abilities within the average range. Therefore, the participant's data were not excluded from subsequent analyses.

communication, indicating abnormalities related to speech initiation ($t(46) = -7.1, p < .001$),

stereotyped language ($t(46) = -7.8, p < .001$), use of context ($t(46) = -9.4, p < .001$), and non-

verbal communication ($t(46) = -9.6, p < .001$). Youth with ASD also obtained significantly

lower scores than control participants on the two scales assessing behavioural domains

relevant to ASD, namely social relations ($t(46) = -8.9, p < .001$), and restricted interests ($t(46)$

$= -8.5, p < .001$).

Scores for youth with ASD were lower than those of control youth for three of the

four scales associated with structural language, indicating difficulties with spoken speech

($t(46) = -3.8, p < .001$), semantics ($t(46) = -5.5, p < .001$), and coherence ($t(46) = -4.8, p <$

$.001$). There was no difference between groups for the syntax scale ($t(46) = -1.4, p = .17$).

Scores on the General Language Composite (Total Score) were also significantly lower for

the ASD group ($M = 60.5, SD = 15.0$) when compared to the control group ($M = 101.3, SD$

$= 15.5; t(46) = -9.2, p < .001$).

Adaptive Functioning. Youths' adaptive functioning was measured using the

ABAS-II. Independent samples t-tests were used to compare scores on the ABAS-II for the

ASD and control group. Youth with ASD obtained significantly lower scaled scores

compared to youth in the control group across all subscales of the ABAS-II (see Figure 3).

That is, relative to their typical peers, youth with ASD in the present study were reported to

have difficulty with social communication ($t(46) = -8.4, p < .001$), functional academics ($t(46)$

$= -5.9, p < .001$), self-direction ($t(46) = -5.1, p < .001$), home living ($t(46) = -5.2, p < .001$),

community use ($t(46) = -5.2, p < .001$), health and safety ($t(46) = -2.2, p = .035$), self-care

($t(46) = -4.2, p < .001$), leisure ($t(46) = -6.6, p < .001$), and social skills ($t(46) = -10.5, p <$

$.001$). Youth with ASD also obtained significantly lower scores than controls on the three

composite scales that make up the ABAS-II: Conceptual ($t(46) = -8.1, p < .001$), Practical,

(t(46) = -5.2, p < .001), and Social (t(46) = -6.5, p < .001), as well as on the General Adaptive

Composite (t(46) = -7.1, p < .001).

Group Differences for Illness Characterization Variables

Illness Experience. Overall, participants in both groups were reported to be in very

good health; however, all participants had recent experience with personal or family illnesses.

Most ailments experienced by participants in the previous 12 months were not serious, but

some youth were reported to have chronic conditions (e.g., asthma) that parents described as

relatively mild.

Youths' General Health. All parents were asked to rate their children's physical

health in the last 12 months and over their lifetime using a five-point Likert scale (1 =

Excellent, 5 = Poor). By parent report, children's physical health over the past 12 months

ranged from excellent (n = 9; 37.5%) to good or very good (n = 15; 62.5%) for those in the

ASD group (*M* = 1.7, *SD* = .62). Similarly, reports of children's health over their lifetimes

ranged from excellent (n = 9; 38%) to good or very good (n = 14; 58%), with one parent

(4%) reporting her child's health to be in the fair range (*M* = 1.8, *SD* = .73). In the control

group, children's physical health over the past 12 months ranged from excellent (n = 15;

63%) to good or very good (n = 8; 33%), with one parent (4%) reporting her child's health

to be in the fair range (*M* = 1.6, *SD* = .88). All parents in the control group rated their

children's lifetime physical health to be excellent (n = 14; 58%) or good to very good (n =

10; 42%; *M* = 1.5, *SD* = .59). Independent samples *t*-tests, comparing parent ratings of

children's general health in the past 12 months and over their lifetimes, were completed for

the ASD and control group. No group differences were observed for these variables, t(46) =

.56, p = .57, t(46) = 1.5, p = .14, respectively.

Healthcare Utilization. Greater than three quarters of participants in the ASD (n =

20, 83%) and control (n = 19, 79%) groups reportedly visited a family physician due to illness in the past 12 months (M = 2.5, SD = 1.7; M = 2.6, SD = 1.9, respectively). Visits to the emergency department in the past 12 months were infrequent; the majority of youth in the ASD (n = 22; 91%) and control (n = 19; 79%) groups did not require any recent emergency intervention (M = .12, SD = .44; M = .29, SD = .62, respectively). According to parents, ten youth (41%) in the ASD group and five youth (20%) in the control group had undergone surgery at some point in their lives, with two youth in the ASD group having undergone multiple surgeries (M = .54, SD = .77; M = .21, SD = .41, respectively). For those in the ASD group, surgeries consisted of a wide range of procedures (e.g., ophthalmic surgery, tonsillectomy), as well as emergency procedures (e.g., surgery following an accident, such as a fall). In the control group, surgeries consisted only of minor procedures (e.g., tonsillectomy).

Group comparisons for the frequency of visits to a healthcare professional, emergency department, and for surgeries were analyzed using Mann-Whitney U tests. This non-parametric statistic was chosen as the data consisted of frequency counts. There were no group differences found for the number of visits to a physician (z = -.04, p = .96) or to the hospital (z = -1.2, p = .23) in the past 12 months, or for the frequency of lifetime surgeries (z = -1.6, p = .10).

Frequency and Nature of Illnesses. Parents provided information about the frequency and nature of child and family illnesses. Ninety percent of youth in the ASD (n = 22) and the control (n = 22) groups were reported to have experienced at least one illness in the past 12 months, with youth in both groups experiencing approximately two illnesses each year on average (ASD M = 2.2, SD = 1.6, control M = 2.3, SD = 1.7). All parents in the ASD group reported that at least one illness had occurred within their immediate family in

the past 12 months. The frequency of these illnesses ranged from one to 12 ($M = 3.7$, $SD =$

2.6). One parent in the ASD group, however, reported 40 ailments in the immediate family in

the last 12 months. This data point was defined as an outlier and excluded from analyses

containing this variable. The participant's data, however, was not excluded from additional

analyses, as all other characterization data was consistent with sample means. While most

parents (n = 17; 71%) in the control group reported one or more family illnesses, seven

parents (29%) reported zero illnesses within the youths' immediate family in the last 12

months. The frequency of family illnesses in the control group ranged from zero to seven (M

= 2.1, SD = 2.2). One parent in the control group, however, reported 52 ailments in the

immediate family. This data point was considered an outlier and excluded from analyses

containing this variable. The participant's data, however, was not excluded from additional

analyses, as all other characterization data was consistent with sample means. The

relationship between family size (i.e., the number of individuals living in participant's home)

and the frequency of family ailments was also examined using Pearson correlations. The

average family in the present study consisted of three to four members for the ASD (M =

3.8, SD = .98, Range = 2 to 6) and control groups (M = 3.5, SD = .72, Range = 2 to 5).

Family size was not related to ailment frequency in either group, $r(22) = .04$, $p = .80$, $r(22) =$

.21, p = .33, respectively.

Finally, 13 parents (54%) in the ASD group and 17 parents (71%) in the control

group reported at least one serious illness that may have impacted their child in some way at

some point in his/her life (M = 1.4, SD = 1.8, M = 1.0, SD = 1.0, respectively). Independent

samples t-tests comparing the frequency of youth and family illnesses in the past 12 months

were non-significant, $t(46) = -.35$, $p = .72$), $t(46) = .39$, $p = .69$, respectively. Similarly, there

was no difference found between groups for serious family illnesses, $t(46) = .90$, $p = .37$.

The nature of youth, family, and serious family illnesses were examined using criteria established by Hamsdottir and Malcarne (1998). Youth illnesses in the ASD and control groups included those that were classified as not serious and not chronic (e.g., cold, sore throat, headache, gastrointestional pain or infections); serious, but not chronic (e.g., flu, pneumonia, strep throat, bronchitis, tonsillitis); not serious, but chronic (e.g., allergies, eczema/psoriasis, migraine headaches), and serious and chronic (i.e., asthma). Illnesses in youths' immediate family over the past 12 months in both groups included those classified as not serious, not chronic (e.g., cold, sore throat, headache, stomachache, acute pain); serious, not chronic (e.g., flu, tonsillitis); not serious, but chronic (e.g., acid reflux, irritable bowel syndrome, eczema); and those that were both serious and chronic (e.g., hypertension, tonsillitis, Crohn's Disease, arteriosclerosis). In the control group, two parents reported a life-threatening or terminal illness (i.e., cancer) in the immediate family in the past 12 months.

In the ASD group, 13 parents (54%) reported that their child had experienced at least one serious family illness at some point in their lifetime that the parent believed impacted the child's understanding and perceptions of illness. Most parents (62%) reported one to two serious family illnesses, but the frequency of illnesses ranged from one to five. The reported illnesses were mainly life-threatening (e.g., cancer, heart attack/disease, stroke), and serious and chronic (e.g., Parkinson's disease, dementia, cerebral palsy). The majority of ailments (70%) were experienced by grandparents. About one quarter were parental illnesses (24%). Only two (6%) sibling illnesses were reported and both were injuries (i.e., concussion).

In the control group, 15 parents (63%) recalled a serious family illness that they believed impacted their child in some way. Most parents (60%) reported only one illness, but the frequency of ailments reported ranged from one to three. The majority of illnesses were

life-threatening or serious and chronic. Most of the illnesses (56%) were experienced by a grandparent, followed by parent (28%) and sibling (16%) illnesses. Sibling ailments were non-life threatening, and mostly consisted of surgeries. In both groups, several parents also reported the occurrence of major injuries or accidents that they believed impacted their children in some way (e.g., paralysis, amputation, brain injury).

The highest disease severity ratings for each participant were generated for child illnesses (past 12 months), immediate family illnesses (past 12 months), and serious illnesses within the extended family (lifetime). Mann-Whitney U tests were used to compare these ratings between groups. There was a difference between groups for child illnesses, whereby youth in the control group had higher ailment severity ratings than those in the ASD group ($z = -2.3$, $p = .02$). The higher frequency of asthma (classified as serious and chronic) among participants in the control group seems to account for this statistical difference. There were no between-group differences for 12 month family ($z = -1.6$, $p = .11$) or lifetime serious family ($z = -.20$, $p = .84$) illnesses (see Table 8).

Illness Knowledge. A semi-structured interview was used to assess participants' illness knowledge. All descriptive statistics for this measure can be found in Table 9. On average, participants in the ASD group received a total illness knowledge score of 19 out of 34 (57%), while those in the control group received a total score of 20 (60%).

General Illness Knowledge. Independent samples *t*-tests were completed to investigate whether youth with and without ASD differed in their knowledge of illness causality, symptom recognition, illness treatment, and illness prevention. There were no significant differences between the groups for these subscales, indicating that youth in both groups had a similar understanding of illness causality ($t(46) = -.61$, $p = .54$), illness symptoms ($t(46) = -.41$, $p = .68$), treatment of illness ($t(46) = .32$, $p = .75$), and disease

prevention ($t(46) = -1.5$, $p = .14$).

A more detailed examination of answers (content areas) revealed that the majority of youth in both groups could readily identify infectious and non-infectious disease etiology (e.g., a virus entering the body), symptoms of illness (e.g., fever, sore throat), risk factors for getting sick (e.g., sharing a drink with someone who is sick, not sleeping well), therapeutic means to recover from illness (e.g., taking medicine, resting), lifestyle factors for preventing illnesses (e.g., eating right, exercising), and disease prevention strategies (e.g., washing hands, staying away from sick people). Few participants implicated the role of the immune system in illness, or identified visiting a healthcare professional as a method to help recover from illness. Pearson chi-square tests were used to compare groups for each content area of general illness knowledge. A between-group difference was found for disease prevention strategies, with more youth in the control group reporting at least one strategy than those in the ASD group ($\chi_2 = 8.2$, $p = .005$). All other comparisons were non-significant (see Table 10).

Expressive Illness Knowledge. Independent samples *t*-tests were completed to investigate if youth with and without ASD differed in their knowledge of specific ailments (cold, concussion, meningitis). There were no significant differences between group scores for these ailments, indicating that youth in both groups had a similar understanding of the etiology of a cold ($t(46) = -.19$, $p = .85$), concussion ($t(46) = -1.3$, $p = .19$), and meningitis ($t(46) = .77$, $p = .44$). Chi-square analyses were used to compare content area scores for the ASD and control groups. There was a significant difference for the concussion area of insult content area, with more youth in the control group associating the brain as the site of injury in concussion than those in the ASD group ($\chi_2 = 6.9$, $p = .01$). All other comparisons were non-significant (see Table 11).

Receptive Illness Knowledge. Independent samples *t*-tests were completed to investigate if youth with and without ASD differed in their ability to identify ailments based solely on symptoms. There were no significant differences between group scores for these ailments, indicating that youth in both groups have similar knowledge of symptoms indicative of rash ($t(46) = .67, p = .51$), UTI ($t(46) = .96, p = .34$), and stroke ($t(46) = 1.8, p = .08$).

Illness Vignettes

Frequency of Ailments Experienced

Parents were asked to report if their child had ever experienced each of the 12 hypothetical ailments that make up the illness vignettes. According to parents, all participants had experienced at least one of the mildly serious vignette ailments (cold, pink eye, rash, scrape). Specifically, parents reported that all participants had experienced a cold and a scrape, and approximately 75% had had a rash or pink eye. Similarly, all youth had reportedly experienced one or more of the moderately serious (fever, flu, strep throat, burn) vignette ailments. According to parents, all participants had had a fever and the flu, while about half of youth had had strep throat or experienced a burn. As expected, a smaller proportion of youth had experienced one or more of the most serious (asthma attack, concussion, coughing up blood, kidney infection) vignette ailments. In the ASD group, two participants had experienced either an asthma attack or concussion-like symptoms, while three participants had experienced coughing up blood. No participants in the ASD group had ever had a kidney infection. In the control group, seven participants were reported to have experienced an asthma attack, three had experienced coughing up blood, and four youth had had a kidney infection. Nine participants in the control group were reported to have experienced a concussion or had concussion like-symptoms following a head injury.

The frequencies of the mildly, moderately, and highly serious vignette ailments experienced by participants were compared between groups using independent samples *t*-tests. There were no significant differences between groups for the frequency of ailments experienced that were classified as mildly ($t(46) = -.94, p = .35$) or moderately ($t(46) = -1.2, p = .22$) serious. There was a difference between groups for ailments classified as highly serious, with participants in the ASD group ($M = .29, SD = .62$) having experienced fewer of these conditions compared to those in the control group ($M = .95, SD = 1.0$), $t(46) = -2.7, p = .008$. This finding seems to be accounted for by the higher frequency of asthma attacks and concussions experienced by participants in the control group.

Objective 2: Illness Communication

2.1: Likelihood of Reporting an Ailment

I completed group-based comparisons between parental ratings for the likelihood that youth would inform a caregiver about hypothetical ailments. In an attempt to minimize the number of analyses, some comparisons between parent and youth ratings (Question 2.3) are examined concurrently within this section. Following presentation of each vignette, parents were asked to indicate the likelihood that their child would report the given hypothetical ailment to a caregiver, using a Likert scale (0 = very unlikely, 5 = very likely). Youth were also asked to report the likelihood that they would inform a caregiver about the ailment. Scores from parents and youth were totaled across the four ailments for each seriousness level: low (cold, pink eye, rash, scrape) moderate (strep throat, stomach flu, fever, burn), and high (asthma, kidney infection, coughing up blood, concussion). Therefore, participants' scores ranged from 0 to 20 for ailments classified as mildly, moderately, and highly serious, with higher scores denoting a greater likelihood of reporting. Three average scores (total score/4), each ranging from 0 to 5, were generated for each parent and youth to

represent the mean likelihood of reporting ailments of low, moderate, and high seriousness. These average scores were used in all subsequent analyses.

A mixed 2 x 2 x 3 repeated measures ANOVA examining the effects of Group (ASD vs. control), Rater (parent vs. youth), and Ailment Seriousness (low, moderate, high) was conducted for mean ratings of the likelihood that the youth would report an ailment (as measured on a 5-point Likert scale). The descriptive statistics for these variables can be found in Table 12. These analyses revealed a significant main effect for Group ($F(1,46) = 19.4$, $p < .001$), Rater ($F(1,46) = 8.6$, $p = .005$), and Ailment Seriousness ($F(2,46) = 54.7$, $p < .001$). A significant interaction between Group and Rater was also observed ($F(1,46) = 34.1$, $p < .001$), as well as a three-way interaction between Group x Rater x Ailment Seriousness ($F(2,46) = 6.6$, $p = .002$), suggesting that mean scores varied as a function of all three variables. Two-way interactions between Group and Ailment Seriousness ($F(1,46) = 1.2$, $p = .29$) and Rater and Ailment Seriousness ($F(1,46) = .19$, $p = .82$) were not significant.

To further examine the 3-way interaction, subsequent 2 x 3 ANOVAs were conducted to examine the effects of Rater and Ailment Seriousness for the ASD and control groups separately. In the ASD group, there was a significant main effect of Rater ($F(1,46) = 22.3$, $p < .001$) and Ailment Seriousness ($F(2,46) = 27.4$, $p < .001$), as well an interaction between Rater and Seriousness ($F(2,46) = 3.5$, $p = .03$). Follow-up paired samples t-tests indicated that parent ratings were significantly higher than youth ratings for all three levels of ailment seriousness: low ($t(23) = 4.6$, $p < .001$), moderate ($t(23) = 3.8$, $p = .001$), high ($t(23) = 3.9$, $p = .001$). Furthermore, for parent ratings, there were significant differences between levels of ailment seriousness in the expected directions (high > moderate > low; $t(23) = -3.1$, $p = .005$; $t(23) = -4.2$, $p < .001$, respectively). For youth with ASD, ratings were higher for

low versus moderate ailments (t(23) = -2.3, p = .03), but did not differ for moderate versus high ailments (t(23) = -1.4, p = .17).

For the control group, there were significant main effects for Rater (F(1,46) = 15.5, p = .001) and Ailment Seriousness (F(1,46) = 29.0, p < .001). The interaction between Rater and Ailment Seriousness, however, was not significant (F(1,46) = 3.1, p = .07). Parent ratings in the control group were significantly higher for ailments classified as moderate versus low in seriousness (t(23) = -2.2, p = .03), but did not differ between moderate and high seriousness (t(23) = -1.7, p = .09). For youth ratings, however, there were significant differences between levels of ailment seriousness in the expected directions (high > moderate > low; t(23) = -3.3, p = .003; t(23) = -3.6, p = .001, respectively).

Finally, between-group post hoc comparisons indicated that parents in the control group had significantly higher ratings for ailments of low (t(46) = -6.0, p < .001), moderate (t(46) = -6.1, p < .001), and high (t(46) = -5.2, p < .001) seriousness than parents in the ASD group. However, self-ratings did not differ between groups (t(46) = .46, p = .64; t(46) = -.35, p = .72; t(46) = 1.2 p = .25, respectively).

To further investigate concordance between parent and youth ratings (Question 2.3), a mean "likelihood of reporting" score was calculated for each youth and each parent. This was done by summing each participant's scores across the 12 ailments and then calculating a mean score (total score/12). Paired samples t-tests revealed a significant difference between the overall mean parent (M = 3.5, SD = .87) and youth (M = 4.5, SD = .71) ratings for the ASD group (t(23) = 4.7, p < .001), with higher ratings reported by youth. The mean scores of parents (M = 4.7, SD = .29) and youth (M = 4.5, SD = .34) did not differ for the control group (t(23) = 2.3, p = .18).

Finally, a set of exploratory analyses examined only parental ratings of the likelihood

that youth would inform a caregiver about different *types* of ailments (i.e., illnesses, illness symptoms, injuries). Three average scores (total score/4), each ranging from 0 to 5, were generated for each parent to represent the mean likelihood of reporting illnesses, symptoms, and injuries. A mixed 2 x 3 repeated measures ANOVA, with a Greenhouse-Geisser correction, was used to examine the effects of Group (ASD vs. control) and Ailment Type (illnesses, symptoms, injuries) for mean ratings of the likelihood that the youth would report an ailment. This analysis revealed significant main effects for Group ($F(1,46) = 43.8, p <$ .001) and Ailment Type ($F(2,46) = 11.2 \, p < .001$), as well as a significant interaction between these two variables ($F(2,46) = 7.6, p = .001$).

Follow-up paired-samples *t*-tests with a Bonferroni adjustment ($\alpha = .05/6 = .008$) revealed that youth in the ASD group would be most likely to inform caregivers about injuries ($M = 3.9, SD = 1.00$) when compared to illnesses ($M = 3.0, SD = 1.11$), $t(23) = 3.2, p = .003$, but not symptoms ($M = 3.4, SD = .95$), $t(23) = 2.0, p = .11$. There was no difference between reporting symptoms and injuries ($t(23) = 1.4, p = .34$). In the control group, there were no differences between scores for the likelihood of reporting injuries ($M = 4.7, SD = .40$), compared to illnesses ($M = 4.8, SD = .23$), $t(23) = -.48, p = .63$, or symptoms ($M = 4.6, SD = .51$), $t(23) = 1.5, p = .14$. There was also no difference between reporting illnesses when compared to symptoms, $t(23) = 1.6, p = .12$.

2.2: Nature of Illness Communication

I compared the types of illness communication behaviours parents of youth in the ASD and control group reported on the vignettes. Again, comparisons between parent and youth reports (Question 2.3) are examined within this section. Parents were asked to report how they would detect each of the 12 hypothetical ailments that make up the vignettes in their own child. Similarly, youth were asked to report how they would communicate each

ailment to their caregiver. Given that these were open-ended questions, parent- and youth-reports were organized according to content areas and conceptual categories (see Table 5).

Participants' answers were organized by frequency counts. That is, participants were given a count of "1" for any of the eight content areas that were included in their responses. The same procedure was used to organize the four conceptual categories. Given that there were 12 vignettes in total, counts ranged from 0 to 12 for each content area and conceptual area for each participant. For example, a parent who reported that their child would complain about an ailment on 5 of the 12 vignettes would have a frequency count of 5 for that content area (to represent 42% of vignettes). Given that the data were in the form of counts (or frequencies), all between-group comparisons were conducted using non-parametric statistics (i.e., Mann-Whitney U and Wilcoxon Signed-Rank tests). The descriptive statistics for these variables can be found in Table 13.

Between-Group Comparisons. Mann-Whitney U tests were used to examine differences in frequency counts between the ASD and control groups for the illness communication content areas and conceptual categories. Parents in the ASD group reported detecting ailments through verbal reports ($z = -4.7, p < .001$), showing ($z = -3.4, p = .001$), and assistance seeking ($z = -2.2, p = .02$) on fewer vignettes than those in the control group. Conversely, parents of ASD youth reported detecting ailments through observing their child's sick behaviour (inadvertent signaling; $z = -4.2, p < .001$), or being unaware of an ailment ($z = -2.2, p = .02$), on more vignettes than control parents. Frequency counts did not differ between groups for complaints ($z = -.18, p = .85$), emotional reactions ($z = -1.1, p = .32$), or other/ambiguous communication ($z = -1.0, p = .32$). Parents in the ASD group reported that their children utilize Direct Communication less frequently when ill ($z = -5.2, p < .001$) and more frequent use of Disengagement ($z = -4.2, p < .001$) compared to parents in

the control group. Frequency counts for Indirect Communication did not differ between groups ($z = -1.4$, $p = .32$). Comparisons of youth frequency counts were also conducted between groups. Youth in the ASD group reported using showing less often than those in the control group ($z = -4.1$, $p = .001$). There were no other between-group differences for youth scores (all $p > .10$).

Within-Group Comparisons. Wilcoxon Signed-Rank tests were used to investigate frequency count differences between parent and youth reports for the above variables for each of the groups separately. In the ASD group, parent and youth counts differed for the following content areas: reports ($z = -3.9$, $p < .001$), complaints ($z = -2.7$, $p = .008$), emotional reactions ($z = -3.0$, $p = .002$), and inadvertent signaling ($z = -3.4$, $p = .001$), with parents reporting less reporting behaviour, but more complaints, emotional reactions, and signaling on the vignettes than youth. Parent and youth reports did not differ for shows ($z = -1.2$, $p = .24$), assistance seeking ($z = -.50$, $p = .61$), other/ambiguous ($z = -1.0$, $p = .32$), or being unaware of an ailment ($z = -.99$, $p = .32$). Parent and youth reports also differed for Direct Communication ($z = -3.7$, $p < .001$), Indirect Communication ($z = -3.1$, $p = .002$), and Disengaged ($z = -3.2$, $p = .001$). Specifically, parents reported indirect communication and disengaged behaviour more frequently, but direct communication less frequently, than youth reported.

In the control group, parent and youth frequency counts differed only for emotional reactions ($z = -3.2$, $p = .001$), with parents reporting emotional reactions on more vignettes than youth. No differences were found between raters for reports ($z = -.47$, $p = .54$), shows ($z = -.12$, $p = .90$), assistance seeking ($z = -.50$, $p = .61$), complaints ($z = -.62$, $p = .48$), and other/ambiguous ($z = -1.0$, $p = .32$), or being unaware of an ailment ($z = -1.0$, $p = .32$). For the conceptual categories, frequency counts between parents and youth differed only for

Indirect Communication ($z = -3.3$, $p < .001$), with parents reporting more Indirect

communication overall on the vignettes than youth reported. No difference between raters

was found for Direct Communication ($z = -.05$, $p = .95$) or Disengaged ($z = -.05$, $p = .96$).

Objective 3: Illness Coping Behaviour

3.1: Likelihood of Seeking Intervention for an Ailment

Group comparisons were completed for parental ratings of the likelihood that youth

would seek intervention for hypothetical ailments. In an attempt to minimize the number of

analyses, some comparisons between parent and youth ratings (Question 3.3) are examined

concurrently within this section. For each hypothetical ailment, parents were asked to

indicate the likelihood that their child would discontinue an activity and seek intervention,

using a Likert scale (0 = very unlikely, 5 = very likely). Youth were also asked to report the

likelihood that they would seek intervention for each hypothetical ailment. Scores from

parents and youth were totaled across ailments of low, moderate, and high seriousness.

Three average scores (total score/4), each ranging from 0 to 5, were generated for each

parent and youth to represent the mean likelihood of seeking intervention for ailments of

low, moderate, and high seriousness. These average scores were used in all subsequent

analyses.

A mixed 2 x 2 x 3 repeated measures ANOVA was used to examine the effects of

Group (ASD vs. control), Rater (parent vs. child), and Ailment Seriousness (low, moderate,

high) on ratings of the likelihood that youth would seek intervention for ailments. The

descriptive statistics for these variables can be found in Table 14. These analyses revealed

significant main effects for Group ($F(1,46) = 11.0$, $p = .002$) and Ailment Seriousness

($F(2,46) = 17.4$, $p < .001$), indicating that mean scores differed between groups as well as for

differing levels of ailment seriousness. No main effect was observed for Rater ($F(1,46) = .97$,

$p = .33$), however, there were significant two-way interactions between Group and Rater ($F(1,46) = 10.2$, $p = .002$) and Rater and Ailment Seriousness ($F(1,46) = 4.1$, $p = .02$), suggesting that parents and youth scores varied as a function of group, as well as ailment seriousness. The two-way interaction between Group and Ailment Seriousness ($F(2,46) = .79$, $p = .45$) and the three-way interaction between Group x Rater x Ailment Seriousness ($F(2,46) = 1.2$, $p = .31$) were not significant.

Between-groups post-hoc comparisons were used to examine the two-way interaction between Group and Rater. Independent samples t-tests indicated that parents in the control group reported a significantly higher likelihood of their children seeking intervention for ailments of low ($t(46) = -4.0$, $p < .001$), moderate ($t(46) = -3.8$, $p < .001$), and high ($t(46) = -3.7$, $p = .001$) seriousness than parents in the ASD group. However, youths' self-ratings did not differ between groups for low, moderate, or high seriousness, $t(46) = .55$, $p = .58$; $t(46) = -.39$, $p = .69$; $t(46) = 1.2$, $p = .82$, respectively.

To examine the two-way interaction between Rater and Ailment Seriousness, subsequent 2 x 3 ANOVAs examining the effects of Rater and Ailment Seriousness were conducted for the ASD and control groups separately. In the ASD group, there were significant main effects for Rater ($F(1,23) = 6.9$, $p = .01$) and Ailment Seriousness ($F(2,23) = 34.5$, $p < .001$). An interaction between Rater and Ailment Serious was also found ($F(2,23) = 3.7$, $p = .03$). Follow-up paired samples t-tests indicated that youth ratings were significantly higher than parental ratings for ailments of low ($t(23) = 3.2$, $p = .004$) and high $t(23) = 3.1$, $p = .004$) seriousness, but there was no difference at the moderate $t(23) = 1.2$, $p = .22$) level. Furthermore, for youth ratings, there were significant differences between levels of ailment seriousness in the expected directions (high > moderate > low; $t(23) = -2.3$, $p = .03$; $t(23) = -3.9$, $p = .001$, respectively). For parents, higher ratings were reported for moderate compared

to low seriousness ($t(23) = -3.6, p = .002$), but only a trend toward a significant difference

(high > moderate) for high versus moderate serious ailments ($t(23) = -2.0, p = .05$).

In the control group, there was a significant main effect for Ailment Seriousness

($F(2,23) = 31.0, p < .001$); however, the main effect for Rater ($F(1,23) = 3.3, p = .08$) and the

interaction between Rater and Ailment Seriousness ($F(2,23) = 1.3, p = .28$) were not

significant. For youth ratings, there were significant differences between levels of ailment

seriousness in the expected directions (high > moderate > low; $t(23) = -3.0, p = .006; t(23) =$

$-2.6, p = .01$, respectively). For parents, ratings were significantly higher for lesser versus

moderately serious ailments ($t(23) = -4.1, p < .001$), but did not differ between moderately

versus highly serious ailments ($t(23) = -.96, p = .34$).

To further investigate concordance between parent and youth ratings (Question 3.3),

a mean "likelihood of seeking intervention" score was calculated for each youth and each

parent. Paired samples t-tests revealed a significant difference between the overall mean

parent ($M = 3.4, SD = .88$) and youth ($M = 4.1, SD = .80$) ratings for the ASD group ($t(23)$

$= 2.6, p = .01$), with higher ratings reported by youth. The mean scores of parents ($M = 4.4,$

$SD = .59$) and youth ($M = 4.1, SD = 618$) did not differ for the control group ($t(23) = 1.8, p$

$= .08$).

Exploratory analyses examining only parental ratings of the likelihood that youth

would inform a caregiver about different *types* of ailments (i.e., illnesses, illness symptoms,

injuries) were investigated. Three average scores (total score/4), each ranging from 0 to 5,

were generated for each parent to represent the mean likelihood of reporting illnesses,

symptoms, and injuries. A mixed 2 x 3 repeated measures ANOVA examined the effects of

Group (ASD vs. control) and Ailment Type (illnesses, symptoms, injuries) for mean ratings

of the likelihood that the youth would report an ailment. This analysis revealed significant

main effects for Group ($F(1,46) = 17.8, p < .001$) and Ailment Type ($F(2,46) = 12.1, p < .001$), as well as a significant interaction between these two variables ($F(2,46) = 3.9, p = .02$).

Follow-up paired samples t-tests with a Bonferroni adjustment ($\alpha = .05/6 = .008$) revealed that youth in the ASD group would be most likely to seek intervention for injuries ($M = 3.89, SD = 1.20$), when compared to illnesses ($M = 3.42, SD = .94$; $t(23) = 2.8, p = .006$) or symptoms ($M = 3.12, SD = .87$; $t(23) = 4.4, p < .001$), however, scores between illnesses and symptoms did not differ, $t(23) = 1.7, p = .09$. No differences were found in the control group for the likelihood of seeking intervention for illnesses ($M = 4.59, SD = .54$), compared to illness symptoms ($M = 4.28, SD = .78$), $t(23) = 2.2, p = .03$, or injuries ($M = 4.34, SD = .78$);, $t(23) = 1.8, p = .08$

3.2: Nature of Illness Behaviour

I compared the types of illness coping behaviours parents of youth in the ASD and control group reported on the vignettes. As above, some comparisons between parent and youth reports (Question 3.3) are examined within this section. Parents were asked to report how their children would behave if they had each of the 12 hypothetical ailments that make up the vignettes. Similarly, youth were asked to report how they would behave if afflicted by each ailment. Given that these were open-ended questions, parent- and youth-reports were organized according to content areas and conceptual categories. Participants were given a count of "1" for any of the 13 content areas that were included in their responses. The same procedure was used to organize the five conceptual categories. Given that these data were in the form of counts (or frequencies), all between-group comparisons were conducted using non-parametric statistics (i.e., Mann-Whitney U and Wilcoxon Signed-Rank tests). The descriptive statistics for these variables can be found in Table 15.

Mann-Whitney U tests were used to examine frequency count differences between the ASD and control groups for the illness behaviour content areas and conceptual categories. Parent reports differed between the groups for the following content areas: help-seeking ($z = -4.2, p < .001$), support seeking ($z = -2.5, p = .01$), rest/relaxation ($z = -2.9, p = .003$), intervention-seeking ($z = -5.1, p < .001$), externalizing behaviour ($z = -2.6, p = .009$), self-isolation ($z = -2.3, p = .01$), and passive adherence ($z = -2.7, p = .006$). Specifically, parents in the ASD group reported that their children engage in less rest/relaxation, help, support, and intervention-seeking when ill, but display more externalizing behaviour, self-isolation, and passive adherence when ill compared to parents in the control group. Information-seeking ($z = -1.6, p = .08$), distraction ($z = -1.5, p = .10$), internalizing behaviour ($z = -1.2, p = .20$), ailment-specific behaviour ($z = -.28 p = .77$), and other/ambiguous behaviour ($z = -.03, p = .97$) did not differ between groups.

Parent reports differed between groups for the following conceptual categories: Active Coping ($z = -5.3, p < .001$), Passive Coping ($z = -3.5, p < .001$), and Inattention ($z = -4.0, p < .001$), such that frequency counts for the ASD group were lower for active coping, but higher for passive coping and inattention when compared to frequency counts for the control group. Frequency counts also differed for General Active Coping ($z = -4.2, p < .001$) and Specific Active Coping ($z = -4.5, p < .001$), with parents in the ASD group reporting fewer of both types of coping behaviours on the vignettes than parents in the control group. Frequency counts did not differ between groups for Accommodative Coping (distraction; $z = -1.5, p = .10$) or Other Coping ($z = -.19, p = .84$).

Wilcoxon Signed-Rank tests were used to investigate frequency count differences between parent and youth ratings for the above content areas and conceptual categories. In the ASD group, parent and youth frequency counts differed for the following content areas:

information-seeking (z = -2.1, p = .03), help-seeking (z = -2.2, p = .04), intervention-seeking (z = -3.6, p < .001), externalizing behaviour (z = -3.3, p = .001), internalizing behaviour (z = -3.6, p < .001), and passive adherence (z = -2.7, p = .005). Parents reported less information- and help-seeking, therapeutic intervention, but more externalizing and internalizing behaviour, and passive adherence on the vignettes than youth. Parent and youth reports did not differ for support seeking (z = -.76, p = .46), rest/relaxation (z = .00, p = 1.0), distraction (z = -1.0, p = .32), self-isolation (z = -2.0, p = .08), ailment-specific behaviour (z = -.38, p = .70), and other/ambiguous behaviour (z = -1.5, p = .13).

For the ASD group, frequency counts for parents and youth also differed for Active Coping (z = -3.8, p < .001), Passive Coping (z = -4.2, p < .001), and Inattention (z = -2.8, p = .005). Parents reported less active coping behaviour, but more passive and inattentive behaviours on the vignettes than youth. Additionally, frequency counts differed for General Active Coping (z = -2.2, p = .02) and Specific Active Coping (z = -3.2, p = .001), with parents reporting less of these active coping behaviours on the vignettes than youth. Frequency counts did not differ between raters for Accommodative Coping (distraction; z = -1.0, p = .32) or Other Coping (z = -.38, p = .70) behaviour.

In the control group, parent and youth frequency counts differed for the following content areas: information-seeking (z = -2.7, p = .005), help-seeking (z = -4.0, p < .001), support seeking (z = -.76, p = .46), intervention-seeking (z = -2.6, p = .01), internalizing behaviour (z = -3.8, p < .001), and ailment-specific behaviour (z = -2.3, p = .02). Parents reported more information-, help-, and support-seeking behaviours as well as internalizing behaviours than youth, and less therapeutic intervention and ailment-specific behaviour on the vignettes. Parent and youth counts did not differ for rest/relaxation (z = -.31, p = .75),

distraction (z = -.43, p = .66), externalizing behaviour (z = -1.8, p = .08), self-isolation (z = .00, p = 1.0), passive adherence (z = .00, p = 1.0), and other/ambiguous behaviour (z = -1.2, p = .23).

For the control group, parent and youth reports differed for Passive Coping (z = -3.8, p < .001) and Other Coping (z = -2.3, p = .007), with parents reporting more of these behaviours than youth on the vignettes. Frequency counts did not differ between raters for Active Coping (z = -.66, p = .51), Accommodative Coping (distraction; z = -1.0, p = .32), or Inattentive Coping (z = -.44, p = .65). Counts differed, however, between raters for General Active Coping (z = -4.2, p < .001) and Specific Active Coping (z = -2.2, p = .02), with parents reporting more general coping behaviours but fewer specific coping behaviours on the vignettes than youth reported.

Nature of Intervention-seeking. Due to the importance of utilizing effective interventions when ill, I further explored the nature of parent-reported intervention-seeking by youth for hypothetical ailments. Parent reports for the "intervention-seeking" content area were divided into three categories: (1) medicine/aids (over-the-counter medication or medical aids, such as pain relievers, antibiotic ointments, cough syrups, bandages etc.); (2) remedies ("home remedies" or alternative medicine to treat discomfort, such as ice, massage, tea, vitamin C etc.); and (3) healthcare professionals (requests to visit a healthcare practitioner, such as a physician, pharmacist etc.). Participants' answers were organized by frequency counts and between-group comparisons were conducted using non-parametric statistics.

Mann-Whitney U tests were used to examine differences between intervention type frequency counts for the ASD and control groups. Given that these analyses were unplanned, a Bonferroni adjustment (α = .05/12 = .004) was used. Overall, parents in the

ASD group reported fewer requests by youth for medicine/aids ($z = -4.9$, $p < .001$), remedies ($z = -4.5$, $p < .001$), and visits to a healthcare professional ($z = -3.6$, $p < .001$) for hypothetical ailments than reported by parents in the control group. I also further examined group differences for intervention type for each level of seriousness (low, moderate, high). Compared to parents of control participants, parents of youth with ASD reported less medication-seeking behaviour for hypothetical ailments classified as low ($z = -4.2$, $p < .001$), moderate ($z = -3.5$, $p < .001$), and high ($z = -3.1$, $p = .002$) in seriousness. Parents in the ASD group also reported less remedy-seeking behaviour for low ($z = -3.7$, $p < .001$) and moderately ($z = -4.1$, $p < .001$) serious ailments, but no difference was found between groups for highly serious ailments ($z = -1.7$, $p = .09$). Finally, parents in the ASD group reported fewer requests to visit a healthcare professional for highly ($z = -3.7$, $p < .001$) serious ailments, but no difference was found for less ($z = -2.2$, $p = .02$) or moderately ($z = -2.8$, $p = .005$) serious ailments (see Figure 4).

Objective 4: Relationships Between Constructs of Interest

4.1: Illness Communication and Social Communication

I used correlations to investigate the relationship between frequency counts of parent-reported direct illness communication (verbal reports, showing, assistance-seeking) and total scores on the CCC-II in the ASD group. Correlations were generated using non-parametric statistics (i.e., Spearman correlations) as frequency counts were used. No relationship was found between these variables ($r_s(22) = .18$, $p = .58$).

Due to the exploratory nature of the study, I also examined the relationship between frequency counts and the six pragmatic language subscales (initiation, scripted language, context, nonverbal communication, social relations, interests) of the CCC-II. There was a significant relationship between parent-reported direct communication frequency counts and

the context $(r_s(22) = .45, p = .02)$ and non-verbal communication $(r_s(22) = .47, p = .02)$ subscales of the CCC-II for the ASD group. That is, parents who reported that their children would use more direct communication to inform others about hypothetical ailments also reported better non-verbal and contextual communication abilities for children. Other CCC-II pragmatic subscales, including initiation $(r_s(22) = -.22, p = .31)$, scripted language $(r_s(22) = .02, p = .91)$, social relations $(r_s(22) = -.13\ p = .63)$, and interests $(r_s(22) = -.07\ p = .72)$, were not related to direct illness communication scores for the ASD group.

4.2: Illness Coping Behaviour and Daily Living Skills

I used correlations to investigate the relationship between parent-reports of general (information-, help-, support- seeking) and specific (rest/relaxation, therapeutic intervention) active coping behaviours on the vignettes and scores on the Practical Domain Composite of the ABAS-II in the ASD group. This domain was chosen as it measures daily living skills, which are skills utilized during illness self-care. Correlations were generated using non-parametric statistics (i.e., Spearman correlations) as frequency counts were used.

There was a positive relationship between specific coping behaviours counts and the scores on the Practical Domain $(r_s(22) = .54, p = .007)$. To investigate what was driving this relationship, correlations were also computed for frequency counts and subscale scores within the Practical Domain. Frequency counts were positively related to each of the four subscales. That is, parents who reported specific coping behaviours on more vignettes also reported better adaptive functioning abilities in the areas of: home living $(r_s(22) = .44, p = .03)$, community use $(r_s(22) = .48, p = .02)$, health and safety $(r_s(22) = .45, p = .03)$, and self-care $(r_s(22) = .55, p = .006)$. These correlations were significant even after controlling for age and full scale IQ. There were no relationships between general active coping frequency counts and scores on the Practical Domain $(r_s(22) = -.12, p = .46)$.

Exploratory Analyses

Given that the illness vignettes are a novel measure, I explored inter-relationships between and within the illness communication and behaviour frequency counts. Although these analyses were not part of the specified research objectives, it was thought that they would provide important information for future refinement of the content areas and/or conceptual categories. The inter-relationships between frequency counts for the illness communication and coping behaviour content areas were examined using Spearman correlations for the groups separately. Correlations were not computed for variables with very low frequencies (i.e., mean counts of 2 or less [behaviour reported on less than 17% of vignettes] for both ASD and control pairs). In keeping with this rule, the following illness communication variables were removed from analyses: complaints, unaware, and other/ambiguous, as were the following illness behaviour content areas: support seeking, accommodative coping, self-isolation, and other. The correlation coefficients between and within the communication and behaviour content areas can be found in Appendix G.

CHAPTER 4. DISCUSSION

Overview of Objectives

The primary objective of the current study was to investigate how youth with and without HFASD manage personal illness. To date, no research has examined how people with autism communicate and cope with symptoms of physical illness, which are two essential components in effectively managing and, ultimately, alleviating illness and its symptoms. Previous research indicates that youth with HFASD have significant impairments in adaptive functioning (e.g., Perry et al., 2009). Among these, impairments in daily living skills, such as dressing, grooming, and personal hygiene, appear to cause the most difficulty for individuals with HFASD, as they are essential for independent living (Harrison & Oakland, 2003). Given these deficits in daily living skills, it was hypothesized that youth with HFASD also have difficulty effectively coping with physical illnesses. Furthermore, since illness episodes often occur in a social context (e.g., within the family), deficits in social communication skills frequently observed in ASD likely influence how youth with ASD inform others they are ill. Thus, it was hypothesized that youth with HFASD report illnesses less frequently to caregivers than those without ASD and communicate illness differently than typically developing peers.

Although both parent- and self-reports were gathered in the present study, more emphasis was placed on parent-reports, as research in pediatric psychology suggests that parents are more accurate informants than children for reporting observable illness behaviours (La Greca & Lemanek, 1996). Moreover, previous studies have indicated that those with HFASD may have poor insight into specific domains of their own functioning (e.g., Johnson et al., 2009). Given these deficits in self-awareness, I was also interested in examining youths' insight into personal illness communication and behaviour, and did so by

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comparing parent- and self-reports on the vignettes. It was hypothesized that parents would report lower rates of effective illness communication and coping behaviours compared to self-reports in the ASD group, whereas smaller discrepancies were anticipated for the control group.

<div style="text-align:center">Overview of Results</div>

The results of this study indicate important differences between youth with and without HFASD in the areas of illness communication and coping behaviour. According to parent-reports on the vignettes, youth with HFASD are less likely than their typical peers to report ailments to caregivers, and utilize direct communication (e.g., reporting, showing, requesting assistance) less frequently when ill with acute physical ailments. Parents of youth with ASD reported that they detect ailments by observing their children's behaviour more often than parents in the control group did. The results also indicated that youth with HFASD are less likely than typical youth to seek intervention when ill, and utilize less active (e.g., intervention-, information-, and help-seeking) and more passive (e.g., emotionality, self-isolation) means of coping when ill with acute physical ailments. Given that these findings are based on vignettes, and thus represent hypothetical accounts of illness communication and behaviour, we do not know the extent to which the present results would map onto in vivo situations. The results suggest, however, that high-functioning youth with ASD may have difficulty managing illnesses independently.

As hypothesized, self-reports obtained from youth with HFASD about personal illness communication and behaviour were highly discrepant from parent-reports. Overall, self-reports indicated that youth with ASD perceive themselves as having significantly more "typical" coping behaviours (e.g., utilization of active coping strategies) and forms of illness communication (e.g., use of direct means to communicate illness to others) than their parents

reported, whereas the reports of youth and parents in the control group were more similar overall.

Despite the group differences described above, my data indicate that study participants with and without HFASD have had similar experiences with personal and family illnesses, suggesting that the two groups of participants were equally familiar with physical ailments. Additionally, knowledge of health and illness was comparable between groups, implying that understanding of illness and illness processes is intact for participants with HFASD. As expected, however, youth with HFASD had significant deficits in adaptive functioning and social communication abilities when compared to typical controls. Interestingly, I found some preliminary evidence for relationships between these constructs and illness communication and behaviour.

It is important to bear in mind that several of the measures (i.e., vignettes, illness knowledge interview, illness experience questionnaire) used in the present study were novel and therefore not previously validated. Consequently, interpretation of results should be done with this important caveat in mind. As discussed above, however, these measures were developed systematically and high inter-rater reliability among scorers testify to their integrity. The key findings are discussed below, followed by a proposed model of illness management in youth.

Objective 1: Sample Characterization

Autism Spectrum Disorder Characterization

As expected, when compared to typically developing peers, youth with HFASD obtained significantly higher total scores on the SRS, indicating impairments in social awareness, social information processing, capacity for reciprocal social communication, social anxiety/avoidance, and autistic preoccupations and traits. Similarly, parent reports on the

CCC-II indicated significant impairments in all aspects of pragmatic language measured. Parents also reported difficulties with several aspects of structural communication (i.e., speech, semantics, and coherence) on the CCC-II, with syntax being the only unimpaired component of structural language measured. These results are somewhat comparable with Norbury, Nash, Bishop, & Baird (2004) during the validation of the CCC-II, who reported significant structural language impairments in 32 of 46 children (70% of sample) between the ages of 4 and 17 years diagnosed with HFASD or a pragmatic language impairment, with or without autistic features. Similarly, more recent investigations have also reported structural language deficits among youth with HFASD or Asperger's Disorder (e.g., Helland, Biringer, Helland, & Heimann, 2012), suggesting that ASD affects many components of spoken communication. Scores obtained on the CELF-4 Screener, however, a direct test of verbal language (i.e., receptive, expressive, grammatical, and semantics) deficits, suggested that all participants possessed the structural language ability necessary for effective verbal illness communication (e.g., reporting an ailment).

As expected, parent-reports on the ABAS-II indicated that youth with HFASD in the present study had significant impairments in adaptive functioning. Specifically, scores on the ABAS-II suggested deficits in conceptual (communication, functional academics, self-direction), practical (home living, community use, health and safety, self-care), and social (leisure, social) adaptive skills compared to typical peers. The greatest impairments were observed in daily living skills, where the domain standard score of 74.7 was almost two standard deviations below the control group mean of 99.5. Socialization skills were also almost as low, with a domain standard score of 76.3. These results are consistent with those obtained in other studies (Kanne et al., 2011; Kenworthy et al., 2010; Klin et al., 2007; Perry

et al., 2009) and reaffirm the notion that adaptive deficits are not only present, but are substantial in high-functioning individuals with ASD.

Illness Characterization

Illness Experience. There were few between-group differences for the illness experience variables investigated. Specifically, current/past health status, healthcare utilization, and the frequency of personal illnesses were similar between groups. This suggests that youth with and without ASD have had similar opportunities to learn about illness, experience recovery, and practice illness management.

Exposure to illness also occurs indirectly, through observation of ill family members. In my sample, parents in both groups reported on average four to five illnesses within the family in the last 12 months (in addition to participant illnesses). Furthermore, most parents reported one or more serious illness experiences (e.g., cancer, death) that had occurred in their family at any time during the child's life and that they believed had contributed to their child's understanding of illness. It has been widely claimed in the literature that these indirect illness experiences represent important opportunities for children to learn about health and illness and to develop strategies for coping with physical discomfort (Walker & Zeman, 1992). This shaping is thought to occur through social learning, or learning by observation (Bandura, 1977). Given that approximately 75 to 80% of family illnesses are managed by self or family members, regardless of an individual's access to professional health services (Litman, 1974), it is not surprising that the family context provides an important domain for children to learn about how to cope with and resolve illness. Based on the information provided by parents, participants in both groups had exposure to family illnesses in the past 12 months, and the frequency of these family illnesses was similar between groups.

More participants in the control group had a chronic medical condition than those in the ASD group. This seems to be accounted for by the higher occurrence of asthma among participants in the control group. Although participants with chronic conditions were generally excluded from the present investigation, conditions that were not typically serious (e.g., migraines), or that were reported by parents to be well controlled or that infrequently produced symptoms (e.g., asthma), were not excluded. Due to the chronic nature of chronic ailments, however, these conditions were classified as more serious than acute conditions using Hamsdottir and Malcarne's (1998) scoring criteria. The seriousness and frequency of acute ailments (e.g., stomach aches, colds) over the past 12 months was similar between groups.

Given that the above illness experience data were collected via questionnaire and required parents to recall previous illness-related events, these results should be interpreted with caution. Soliciting details about previous illnesses and health-care utilization through questionnaires has been shown to yield less accurate information compared to interviews (for a review, see Bhandari & Wagner, 2006). Specifically, interviewer probing, and the use of "landmarks" (i.e., a major event, such as a holiday, to help improve respondent's ability to distinguish events occurring within a recall period), have been found to be effective techniques for eliciting more specific and detailed healthcare utilization information (Kashner, Suppes, Rush, & Altshuler, 1999). However, given that youths' experience with illness was not the main objective of the study, a questionnaire was considered to be the most feasible method to collect this information. Furthermore, in order to reduce memory bias and underreporting of general healthcare utilization and illness experience, the questionnaire only included recall time frames of 12 months or less, which is the common practice indicated by the literature (Bhandari & Wagner, 2006). The timeframe was extended,

however, in order to capture more salient healthcare experiences, such as surgeries, as they are less prone to memory biases.

Illness Knowledge. There were no between-group differences for any of the illness knowledge variables examined, and a closer inspection of participants' open-ended responses (scored using content areas) yielded few systematic qualitative differences between groups. This suggests that youth with and without ASD had similar familiarity with the illness concepts measured.

On the general portion of the interview, participants were asked four questions to assess their understanding of illness causality, illness symptomatology, treatment of illness, and disease prevention. Overall, participants' answers encompassed examples related to infectious diseases (e.g., colds, flu) more frequently than non-infectious illnesses (e.g., headache, asthma, cancer). This is not surprising given that infectious ailments, such as colds and flu, are the most common ailments children experience (Gratz, 1992). Furthermore, infectious disease etiology (e.g., virus entering body), symptoms (e.g., flu-like sensations), and prevention (e.g., washing hands), are often more concrete and easier to describe than non-infectious pathology.

Regarding illness causality, the most common answers in both groups involved coming in contact with "germs". A number of participants also reported risk factors that could predispose someone to illness. Of these risk factors, the vast majority were behavioural (i.e., something related to one's behaviour that one can control), such as being tired, being under stress, not eating your vegetables, not washing your hands, or going outside with wet hair. These risk factors have likely been learned from caregivers, grandparents, or teachers, and do not necessarily always represent sound medical knowledge. For example, catching a

cold from going outside with wet hair is a medical misconception that is often taught to children by parents or grandparents (Lee et al., 2003).

A smaller portion of participants reported environmental risk factors of illness (i.e., exposure to illness through the environment), such as "being around sick people". No participants reported biological risk factors, such as genetic predispositions, age or cultural factors; this is likely because most participants did not describe etiology related to non-infectious illnesses. Surprisingly, no participants in either group implicated the role of the immune system in illness, suggesting that youth may not have a good understanding of immune function and the body's defenses.

With regard to symptom recognition, almost all participants in both groups were able to identify at least one physical symptom that could be associated with illness. Again, most reports included symptoms of common infectious illnesses, such as those associated with a cold or flu (e.g., coughing, sneezing, fever). Few participants in either group identified confirmation from an external source (e.g., physician, thermometer), as a component of illness symptom recognition, suggesting that external confirmation is not necessary for youth to know they are unwell.

On the topic of illness treatment, all participants reported using some sort of medicine or aid to help with recovery from illness. While most participants used the word "medicine" to encompass all pharmaceutical agents, some were more specific, reporting the use of antibiotics, cough drops, or vitamin C. A number of participants in both groups also reported seeking a physician as a means to treat ailments.

Finally, with regard to illness prevention and staying healthy, all participants in the control group, and about 70% of those in the ASD group, identified at least one disease prevention strategy, such as "getting a flu shot", "washing hands", or "staying away from

sick people". These strategies likely reflect the success of various health-related campaigns in schools (e.g., hand washing visual supports) and in the media (e.g., commercials for immunization programs and clinics), or the national campaign following the 2009 H1N1 pandemic by the Public Health Agency of Canada. Understandably, fewer participants described life-style factors as a means to keep from getting sick, and those reported were similar to behavioural risk factors for the illness causality question, such as sleeping or eating well.

Seven of the 24 participants in the ASD group did not identify any disease prevention strategies compared to zero controls. This suggests that preventative measures, such as minimizing germ contamination, may be an important area for health education among youth with HFASD. Furthermore, participants in both groups could benefit from education regarding lifestyle factors related to health and prevention of illness.

The second section of the knowledge interview assessed youths' ability to convey their knowledge of specific ailments using verbal means (expressive knowledge). Worth noting is that participants in both groups obtained the highest scores for defining and describing a concussion. Almost all participants knew that a concussion was a head injury; although fewer participants in the ASD group implicated the brain specifically, compared to the control group. This is likely related to the finding that more participants in the control group (how many?) had experienced a concussion when compared to those in the ASD group (how many?). About 50% of participants in both groups reported symptoms associated with a concussion, such as dizziness or nausea. Participants' understanding of concussions may be due, in part, to recent media coverage related to head injuries in sports (e.g., hockey). Parents and/or coaches may then verbally convey this information to children.

Not surprisingly, both groups demonstrated better understanding of colds than meningitis. Most participants in both groups understood that a cold involved germ contamination, and could readily name symptoms associated with a cold. Very few participants used the word "virus" to describe a cold, and several participants incorrectly described a cold as a "bacterial infection" that could be treated with antibiotics. These results indicate that while most participants know what it is like to have a cold, they are less familiar with the specific etiology underlying respiratory illness.

Finally, very few participants knew about meningitis. Of those participants who understood something about meningitis, most could implicate something wrong with a component of the central nervous system (i.e., brain, spine, or nerves), although no participants implicated the "meninges" specifically. Very few participants knew that meningitis involved some sort of infection, and only one participant in each group correctly identified a symptom of meningitis (i.e., "headache").

The third and final section of the knowledge interview assessed participants' ability to identify an ailment only on its symptoms (receptive knowledge). As predicted, participants in both groups could spontaneously identify a rash/chicken pox based on symptoms. Roughly half of participants in both groups correctly identified a urinary tract infection (UTI) based on symptoms, and all correctly selected UTI from a list of four medical ailments. Roughly one quarter of participants in both groups correctly identified stroke, but this increased to approximately half of participants when shown the multiple choice card. Of those participants who did not correctly select the multiple choice answer, many selected heart attack instead, suggesting that most participants understood symptoms of a stroke to involve the circulatory system, but could not differentiate between heart attack and stroke.

Based on the knowledge interview and scoring rubric developed for this study, youth in both groups demonstrated average scores around 60%. This is quite poor performance overall and indicates that youth with and without ASD may benefit from more education about illness and healthy lifestyle. Given that the interview is not a validated measure of illness knowledge, however, and was designed to assess understanding of illness across a wide age-range, it is difficult to interpret the general results. There is no previous research to guide our thinking about what youth in this age range would be expected to know about illness.

Nevertheless, it is important to keep in mind that this measure was developed to compare illness knowledge between two groups, and not to necessarily validate a research tool. Moreover, to my knowledge, a well-validated measure to evaluate children and adolescents' understanding of illness has yet to be developed, and therefore this tool represents an important preliminary advancement for this field.

Objective 2: Illness Communication

2.1: Likelihood of Reporting an Ailment

As hypothesized, parents of youth with HFASD reported that their children would be less likely to inform a caregiver about a hypothetical ailment compared to reports from parents of typical youth. This finding was consistent across all levels of seriousness.

ASD Group Findings. The likelihood of informing was greatest for ailments that were considered serious (e.g., concussion, asthma attack), followed by those that were moderately serious (e.g., fever, burn), and then least serious (e.g., scrape, cold). This suggests that, according to parents, youth with ASD can distinguish between ailments of different levels of seriousness, and are most likely to inform caregivers about those ailments that are unfamiliar or more serious. However, some parents indicated that their child with HFASD

would not notify them of a serious ailment. For example, more than half the sample (58%) of parents in the ASD group reported that it would be "unlikely" or only "somewhat likely" for their child to inform a caregiver if they had symptoms associated with a kidney infection. Similarly, roughly half (55%) of parents in the ASD group reported that it would be unlikely for their child to report symptoms of an asthma attack, and two thirds indicated that they would not report symptoms of a concussion (66%) or coughing up blood (58%). These findings raise important concerns about how these youth with ASD will manage their health independently in the future given that all of these ailments can be very serious, and some (e.g., concussion, asthma attack) are potentially life threatening.

The likelihood that youth would inform a caregiver about different types of ailments was also investigated. Scores on the vignettes indicated that youth in the ASD group would be most likely to inform caregivers about injuries. The higher likelihood to report injuries may be due in part to the fact that injuries often result in tissue damage and exposure to blood, making them not only painful, but also distressing. Observing tissue damage may bring about worry, thus precipitating help-seeking behaviours (e.g., reporting).

Control Group Findings. According to parental reports in the control group, typical youth would be likely or very likely to inform a caregiver about *all* hypothetical ailments, regardless of their seriousness (low, moderate, high) or type (illness, injury, symptom). These results are comparable to findings by Varni et al. (1996), who, using the Pediatric Pain Coping Inventory (PPCI), found "reporting pain to a caregiver" to be one of the most common behaviours youth experiencing chronic illness utilized to cope with pain. Worth noting is that data obtained in the present study on the nature of youths' illness behaviours indicated that most typical youth know how to care for themselves when ill with mild or familiar ailments, and do not necessarily require help from caregivers to manage

them appropriately. This indicates that typical youth may report mild ailments for other reasons than to obtain help, such as attention, comfort, reassurance, sympathy, and special privileges that often coincide with illness, such as staying home from school. These reinforcers may bring about over-reporting of illness symptoms and/or disability that is disproportionate to physical symptoms (Whitehead et al., 1992). For example, parent solicitous behaviour (i.e., giving child positive attention, relieving the child from responsibilities, and granting special privileges) when in pain has been found to lead to higher levels of pain-related functional disability (e.g., missed school days; Brace, Smith, McCauley, & Sherry, 2000) and slower recovery from surgery (Gidron, McGrath, & Goodday, 1995) for children with recurrent pain.

Conversely, illness episodes may represent important opportunities for interaction among family members, where emotions are shared and support is rendered. Thus, sharing thoughts and feelings related to illness may foster closeness between a youth and his/her caregiver. Given that emotional reinforcers may be different for those with HFASD (e.g., preference for solitude over attention, or self-soothing over parental comfort), those with ASD may be less motivated to share the presence of ailments and this may ultimately lead to under-reporting of ailments by youth in this population.

2.2: Nature of Illness Communication

Despite four decades of pediatric pain research, very few investigations have examined the ways in which parents find out about children's minor illnesses or injuries. Thus, parental reports regarding the nature of illness communication for hypothetical ailments are an important contribution to health literature for both typical and atypical populations.

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Overall Findings. According to parents of youth with and without HFASD, the most frequent way caregivers learn about children's ailments is through direct communication (i.e., verbal reports, showing, and assistance seeking). Specifically, parents in both groups reported that youth would be most likely to use "verbal reports" to inform caregivers about the hypothetical ailments, followed by "showing", and "assistance seeking". These findings are similar to those of Lynch-Jordan et al. (2006), who found that verbal reports of discomfort were among the most frequent ways caregivers detected pain in adolescents. Similarly, given that self-report is considered to be the most valid means of describing the intensity and duration of painful sensations (von Baeyer, 2006), it is not surprising that parents reported verbal communication to be the most frequent way they learn about ailments.

Although parents reported that youth do not use showing as frequently as verbal reports, it should be noted that verbal reports and showing were positively correlated in both groups on the vignettes. That is, parents who reported that their child used more verbal reports to inform caregivers of ailments also reported that they used more showing, indicating that these two approaches may often be combined to convey richer information. Additionally, showing is only appropriate for some of the ailments depicted by the vignettes, which may have partially accounted for its lower frequency. For example, it would be possible to show a caregiver an ailment that has overt (e.g., scrape, burn, bump on head, rash, pink eye) but not covert (e.g., kidney infection, asthma attack) symptoms/results. The lower prevalence of assistance seeking reported by parents on the vignettes suggests that most youth report ailments to caregivers regardless of assistance seeking behaviour.

Between-Group Comparisons. As hypothesized, parents in the ASD group reported direct communication less frequently on the vignettes than parents in the control

group. Specifically, while parents of typical youth reported use of direct communication for 95% of the hypothetical ailments (or 11 of 12 vignettes), parents of those with ASD reported it for approximately 59% of ailments (or 7 of 12 vignettes). Furthermore, parents in the ASD group reported all forms of direct communication (i.e., verbal reports, showing, and assistance seeking) on fewer vignettes than those in the control group reported. This indicates that parents of youth with ASD believe that their children use direct means to communicate illness to caregivers less frequently than parents in the control group.

Conversely, parents in the ASD group reported using "signaling" (i.e., observing their child's sick behaviour or illness symptoms) to detect more ailments than those in the control group reported. Franck et al. (2010) refers to such behaviours as "passive expressions of distress" as they involve indirect means of signaling illness. Most signaling behaviours reported by parents in the ASD group included those that could directly be attributed to the hypothetical ailment, such as spending more time in the washroom, staying in bed, or holding a sore spot. Some parents also noted changes in their children's socio-emotional functioning, such as being more quiet or showing less interest in activities, as cues for underlying illness. These results are comparable to qualitative parent reports of children's reactions to painful events at home, which suggested that some youth with HFASD rarely report painful events to caregivers, thereby necessitating them to take notice of behaviours that may be indicative of pain (e.g., holding or rubbing a sore spot, becoming teary, walking with a limp; Goodman et al., unpublished).

Despite decreased reports of direct communication in the ASD group, very few parents believed that they would be unaware of their child's ailments. This suggests that parents of youth with HFASD in the present study are quite good at "reading" their child's sick behaviours, or noticing changes in children's socio-emotional functioning (e.g., increases

in moodiness, frustration) when ill. It is likely that these skills have developed over time, as a result of differentiating between typical behaviour and periods when behavioural and emotional cues suggested that their child was unwell. Similar experiences have been expressed by parents of children with intellectual disability, who described attunement with their children's behavioural and emotional cues as their primary means for detecting pain (Carter, McArthur, & Cunliffe, 2002).

While observing sick behaviour can act as a proxy for self-reports of illness, research indicates that reliance on behavioural cues alone can result in under-estimation of children's physical distress (von Baeyer & Spagrud, 2007). Thus, it would be beneficial for parents of youth with HFASD to be aware that observations of sick behaviour should not be used in isolation to determine children's well-being. Instead, these observations should be used to begin a dialogue between the caregiver and child about illness, and to provide an opportunity for the youth to learn how to communicate more effectively about physical symptoms.

Parent reports of verbal complaints (e.g., whining) on the vignettes were low for both groups. Franck et al. (2010), however, found that 60% of parents reported "whining or complaining more than usual" as a means for detecting minor illnesses in children between 2 and 5 years of age. Taken together, this suggests that older children and adolescents use more sophisticated verbal means to communicate ailments to caregivers than younger children, who rely more heavily on persistent complaints and whining. Increased emotional control, coupled with typical communication development, enables children to express their feelings and painful sensation with more precision using language, thereby allowing an improvement in the quality of medical care (von Baeyer, 2006).

Objective 3: Illness Coping Behaviour

3.1: Likelihood of Seeking Intervention

As hypothesized, parents of youth with HFASD were less likely to report that their children would seek intervention following a hypothetical ailment compared to parents in the control group. This finding was consistent across all hypothetical ailments, regardless of seriousness.

ASD Group Findings. According to parents in the ASD group, the likelihood of seeking intervention for youth was greatest for ailments that were considered serious, followed by those that were moderately serious, and finally least serious. Similar to above, this indicates that youth with ASD may recognize the importance of seeking intervention for ailments that are more serious. Yet, some parents reported that it would be unlikely for their children to seek intervention for more serious ailments. For example, half of parents in the ASD group reported that their child would be unlikely or only somewhat likely to seek intervention for symptoms of a kidney infection; and two thirds of parents reported it would be unlikely or somewhat likely for their children to seek intervention for coughing up blood, an asthma attack, or concussion-like symptoms.

It is also important to consider, however, that it may be unsafe to care for serious ailments independently, as often they require specialized care and involvement of a healthcare professional. For these and other serious ailments, informing a caregiver may be the safest course of action. It is particularly worrisome then, that some parents in the ASD group believe their children would be unlikely to seek intervention for or inform a caregiver about serious hypothetical ailments.

Independent of seriousness, parent scores on the vignettes indicated that youth in the ASD group would be most likely to seek intervention for hypothetical injuries. The higher

likelihood of seeking intervention for injuries is comparable to results noted above for reporting, and may indicate increased distress associated with tissue damage. Alternatively, it may denote that youth with HFASD have a better understanding of basic first aid for injuries than they do of self-care for illnesses. For example, care for a scrape or burn usually follows a standard medical regimen (e.g., washing abrasion and applying a bandage; running a burn under cold water), as opposed to more multifaceted care for an illness (e.g., resting, taking temperature, using medication or remedies, monitoring symptoms). Difficulties in executive functioning, such as poor planning skills and decreased mental flexibility, among youth with HFASD may make multi-step medical regimens particularly burdensome.

Control Group Findings. According to parent scores in the control group, the majority of caregivers believe that their children would be likely or very likely to seek intervention for all hypothetical ailments, regardless of their seriousness. With that said, statistical comparisons indicated that typical youth would be most likely to seek intervention for hypothetical ailments classified as high and moderately serious, but less likely to do so for ailments classified as least serious. Intervention for serious hypothetical ailments, however, would likely be difficult for youth to manage independently (e.g., visiting a healthcare professional). It is not surprising, therefore, that data from the present study on the nature of youths' illness behaviours suggests that intervention-seeking behaviours may be combined with help-seeking, as parent reports of these behaviours were positively correlated on the vignettes. This suggests that youth may utilize interventions with assistance from their parents, which is to be expected given the age of participants.

3.2: Nature of Illness Coping Behaviour

Overall findings. According to parent reports, the most frequent way youth with and without HFASD cope with acute physical ailments is through use of problem-focused /

active behaviours (e.g., help-seeking, resting, using medication and remedies). Although the frequency of these coping behaviours varied significantly between groups, the results overall suggest that youth with and without ASD utilize various strategies to help control or modify illness. This outcome is similar to the results of two systematic reviews conducted by Ryan-Wenger (1994; 1996), which reported that active coping strategies, such as support seeking and attempts to manage stressors, were the most commonly reported coping strategies used by healthy children and adolescents when dealing with stressors or acute/chronic illnesses. Similarly, using the Pain Response Inventory for Children, studies have found that active coping behaviours were reported more frequently than passive coping behaviours for youth with and without chronic pain (Walker et al., 1997; Huguet et al., 2009).

In the present study, parents of youth with and without HFASD reported specific active coping strategies (specific problem-focused behaviours, such as applying ice or resting) more frequently than they reported general active coping strategies (broad problem-focused behaviours, such as requesting information or help from a caregiver) on the vignettes. Given that the general coping strategies always involved seeking a caregiver, whereas the localized strategies consisted of more independent behaviours (e.g., using medicines or remedies, resting), this may suggest that youth do not always involve caregivers in their illness management, and may be more of a reflection of the age of participants as opposed to the specificity of the behaviours.

The most frequently reported specific coping behaviour on the vignettes was use of therapeutic interventions. Parents in both groups reported that their children would seek out various over-the-counter (OTC) medications (e.g., pain killers, antiseptic ointments, cold and flu medication) and remedies (e.g., hot tea, ice) to treat hypothetical ailments. Use of OTC medicines and remedies was reported more frequently for ailments that were classified as low

or moderately serious than it was for the most serious ailments. Not surprisingly, requests to visit a healthcare professional (e.g., physician) or to visit the emergency department were reported more frequently for the most serious ailments. Taken together, this illustrates that youth may recognize the benefits of OTC medications and remedies for treating more minor ailments, but that more serious ailments warrant the attention of a medical professional and/or prescription medication.

On average, rest and relaxation were only reported for one third or less of hypothetical ailments by parents in both groups. Resting was the second most frequently endorsed active coping behaviour on the Pain Response Inventory for Children by youth with and without recurrent abdominal pain (Walker et al., 1997). Given that the present study made use of vignettes that depicted ailments of differing levels of seriousness, resting may not have been equally appropriate for all hypothetical ailments. For example, although resting may bring about a more speedy recovery when ill, it may not be appropriate for very minor ailments (e.g., pink eye, rash, scrape), nor would it be the most effective method to deal with more serious ailments at the outset (e.g., kidney infection, coughing up blood, concussion).

Parental reports of support seeking on the vignettes were generally very low across both groups. This was unexpected, especially for the control group, given that support seeking was the most frequently reported behaviour in a systematic review of coping strategies that youth use when stressed (Wenger-Ryan, 1996). Similarly, using the Pain Coping Questionnaire (PCQ), social support seeking was frequently reported among youth with and without chronic pain (Huguet et al., 2009; Walker et al., 1997). It should be noted, however, that the operational definition of support seeking varied widely across these studies. For example, Wenger-Ryan noted that in the studies included in his review of the

literature, support seeking involved several dimensions, including physical comfort, social interaction, affective contact and help-seeking from caregivers. Similarly, the operational definition of social support seeking on the PCQ includes elements of emotional support, help, and information-seeking. Given that support seeking in the present study referred only to emotional or comfort-seeking behaviour, and was differentiated from help and information-seeking, the results of the present study suggest that youth with and without ASD are more likely to seek information and help from caregivers than they are emotional support for hypothetical acute ailments.

Following active coping behaviours, passive coping behaviours (e.g., emotionality, self-isolation, passive adherence to medical regimens) were the second most frequently reported behaviour on the illness vignettes by parents in both groups. Parents in both groups reported passive coping strategies more often for serious ailments than they did for those that were less serious. Given that higher perceived controllability of a stressor has been found to be a critical predictor in the effectiveness of active coping behaviours (Lazarus & Folkman, 1984), these results may indicate that youth recognize the uncertain nature of more serious ailments, and therefore resort to more passive coping behaviours. Conversely, youth may recognize and cede to parents as decision makers when things are serious, and this may be age-appropriate for some.

Accommodative behaviours (i.e., distraction) were the least-reported coping strategies on the vignettes. Since behavioural distraction (e.g., watching television, reading, playing videogames) often closely resembles youths' typical behaviours, parents may have been less likely to report these behaviours when asked about how their child behaves when confronted with the hypothetical ailments. By contrast, cognitive distraction, such as thinking about something else, may have been difficult to comment on given that it involves mental

processes that are not observable. Furthermore, engagement in accommodative behaviours may be more common way to cope with chronic as opposed to acute ailments. Recall that Walker et al. (2007) theorized that someone who believes s/he could accept and adjust to their circumstances when it is not possible to change the situation is most likely to engage in accommodative strategies. For acute ailments, adjustment to circumstances is not necessary given their time-limited nature. For this reason, distraction may not be a primary coping behaviour for acute ailments.

Between-Group Comparisons. As hypothesized, parents in the ASD group reported fewer active coping behaviours on the vignettes than parents in the control group. This finding was noted for both general and specific active coping behaviours. With respect to specific coping, parents in the ASD group reported therapeutic intervention behaviours less often on the vignettes than parents in the control group did. This difference was present across all forms of intervention (OTC medication, remedies, healthcare professional), and suggests that youth with HFASD utilize fewer pharmaceutical and non-pharmaceutical means to manage ailments than their typical peers. Qualitatively, the types of medicines and remedies parents reported also differed between groups. For example, non-pharmaceutical remedies in the ASD group were generally limited to disease prevention strategies (e.g., washing a cut, using tissues) and lifestyle factors (emphasis on increased hydration, modification to diet), while those in the control group encompassed a wider spectrum of practices, such as alternative medicines (e.g., aloe vera for a burn, ginger tablets for an upset stomach, vitamin C to boost the immune system), and treatments to naturally soothe discomfort (e.g., hot water bottle, cool cloth, warm bath, warm tea).

Use of specific problem-solving strategies has been associated with positive outcomes in the pediatric pain literature. For example, using the PPCI, Varni et al. (1996)

found that problem-solving behaviours, such as asking for medication, asking to go to the doctor, using ice for sore spots, and resting, were associated with lower self-reported depressive symptoms, anxiety, and higher self esteem among youth with chronic illness. Furthermore, Varni et al. found endorsement of "problem-solving self-efficacy" items (e.g., "Know that I can ask for something that will make the pain go away" or "Know that I can do something to make the pain or hurt feel better") was also associated with the same positive outcomes. This suggests that specific problem-solving behaviours, as well as personal belief in one's ability to engage in such behaviours (i.e., self-efficacy), may be beneficial to one's overall well-being. Not surprising, a review of the literature conducted by Jensen, Karoly, and Braver (1986) found that individuals with chronic pain who believed that they could control their pain had better functional outcomes than those who did not. This suggests that intervention-focused coping behaviours are particularly beneficial because they help manage discomfort and restore a sense of control to the individual.

Although reports of OTC medication usage were lower for less severe ailments, parents in the control group reported that their children would use or request OTC medicine for approximately three quarters of all hypothetical ailments. This high frequency of medication usage for hypothetical ailments echoes previous literature on OTC medication consumption by children and adolescents. For example, a study conducted in the United States involving 8145 young children found that 54% had been given OTC medication in the 30 days preceding the study (Kogan, Pappas, Yu, & Kotelchuck, 1994). Likewise, a survey of 8500 students aged 11–12 and 14–15 years in the UK also indicated high rates of OTC medication use, with about 20% of youth having used an OTC painkiller, cough and cold medicine, or cold-sore treatment in any one week (Dengler & Roberts, 1996). Taken

together, these results suggest that youth without ASD are comfortable using OTC medicines to help manage symptoms associated with acute ailments.

As hypothesized, parents in the ASD group reported passive coping behaviours on more vignettes than parents in the control group. This finding seemed to be driven, at least in part, by higher reports of externalizing behaviours by parents of youth with ASD. Based on inspection of the data, the majority of externalizing behaviours reported by parents included irritability, frustration, and anger. These results are comparable to qualitative parent reports of children's reactions to painful events at home, which suggested that approximately 30% of participants in the ASD sample responded to pain in ways that are characteristic of younger children, such as demonstrating anger or frustration when hurt or injured (Goodman et al., unpublished work). In addition, previous questionnaire data have indicated that externalizing behaviours are the least frequently reported coping behaviour by youth with and without chronic illness (Reid et al., 1998) and healthy adults (Huguet et al., 2009), further indicating that the higher rates of externalizing behaviour reported by parents of youth with HFASD is atypical. Increased externalizing behaviour in this population may come about due to decreased perceived control over illness, and/or as a means to alert caregivers that something is wrong and render helping behaviour. Furthermore, given that emotional regulation has been found to be compromised among youth with HFASD (Jahromi et al., 2012; Samson et al., 2012), this underlying impairment may lead to increased emotionality when faced with physical discomfort. In the current study, parent reports of internalizing behaviours did not differ between groups on the vignettes. Qualitatively, almost all internalizing behaviours reported by parents in both groups were associated with anxiety (e.g., worry, fear, panic), as opposed to sadness or depression (e.g., crying). This indicates

that worry and fear may be normal components of the illness process for some ailments, likely those that are serious or unfamiliar (Huguet et al., 2009).

Previous literature in pediatric pain indicates that youth with chronic illnesses who cope with pain through the expression of negative emotions have poorer psychosocial outcomes than those who do not (e.g., higher levels of pain, lower functional disability; Bennett-Branson & Craig, 1993; Reid et al., 1998). Reid et al. (1998) theorized that negative emotions may impair the use of more adaptive coping strategies due to decreased ability to focus attention away from pain. In this way, expression of negative emotions may hamper youths' ability to engage in more problem-focused strategies when ill.

Parent and Youth Comparisons

Parent- and self-reports of illness communication and behaviour on the vignettes were compared between raters. Systematic discrepancies were noted between raters in the ASD group, with youth ratings more closely resembling those of their typical peers than the ratings by their parents. Specifically, parents in the ASD group reported a lower likelihood of communicating about, and seeking intervention for, hypothetical ailments than youth reported. Furthermore, parents in the ASD group reported less active, but more passive, behaviour for hypothetical ailments than youth. Although some discrepancies were found between raters in the control group, there were fewer differences noted overall compared to the ASD group. Most discrepancies in the control group were found for passive behaviours, such as indirect communication and passive coping, with parents reporting more of these behaviours on the vignettes than youth. Parent- and youth-reports for more active behaviours, such as direct communication and active coping, were more consistent between raters overall.

The relationship between parent- and self-perceptions has been investigated in a variety of health-related contexts, such as health-related quality of life (Erhart, Ellert, Kurth, & Ravens-Sieberer, 2009), pain experiences (Chambers, Reid, Craig, McGrath, & Finley, 1999; Gragg et al., 1996), and pain coping behaviour (Reid et al., 1997; Reid et al., 1998), but has yielded conflicting results with respect to rater consistency. In pediatric psychology, correlations between parent- and youth- ratings on the Pain Coping Questionnaire have been found to be moderate to low, with greatest agreement for behavioural coping strategies (e.g., behavioural distraction, seeking support, problem-solving, externalizing behaviour), and poorest for cognitive strategies (e.g., positive self-statements, cognitive distraction, internalizing behaviour; Reid et al., 1997; Reid et al., 1998). This is not surprising given that cognitive strategies (e.g., positive self-statements) and internal states (e.g., anxiety, sadness) may not consistently result in overt behaviour for parents to observe; and it is likely that this would be even less so among those with ASD.

Information about agreement and discrepancies between raters guides decisions about who to consider as the most valid informant for a given construct. Research indicates, however, that concordance between parent and self-raters often varies according to child's age or developmental level, and the construct of interest, making it challenging to identify the best informant. Based on a review of the pediatric literature, La Greca (1996) suggested that parents are more accurate reporters of observable behaviours (e.g., behavioural distress, disease management, quality of life, externalizing behaviours) than children, but that self-ratings are more valid for internal states (e.g., subjective distress, health beliefs and attitudes, conceptualization of illness, internalizing behaviours). Additionally, as children age, they become more accurate at correctly reflecting upon their behaviours, making typical adolescents more accurate informants than children.

Based on La Greca's findings, some discrepancy between raters is expected in health research. The multitude of inconsistencies between raters in the ASD group of the present study, however, is clearly atypical, and suggests that youth with ASD may have limited insight into their personal illness communication and behaviour. Evidence for limited insight into specific domains of personal functioning has received some recent attention in the ASD literature. For example, Koning and Magill-Evans (2001) reported that adolescent males aged 12 to 15 years with Asperger's disorder endorsed fewer social difficulties for themselves on questionnaires than did their parents or teachers. Knott et al. (2006) reported similar parent-child discrepancies with respect to social skills and social competence for youth aged 11 to 14 years with HFASD. More recently, Johnson, et al. (2009) compared parent- and self-reports on several measures designed to assess ASD traits in high-functioning youth with ASD and typical controls. Youth with ASD reported significantly fewer autistic traits and more empathic features than their parents attributed to them. Minimal or no discrepancies between raters were noted in any of the above studies for the control groups. Moreover, youths' ratings in the ASD group were similar to youth ratings in the control group, suggesting that participants with ASD did not endorse key traits fundamental to their diagnosis.

These studies suggest that some individuals with HFASD have limited awareness of their autism symptoms and associated features. My data suggest that these self-awareness deficits may extend beyond general symptomology to broader behavioural constructs of daily living. A tendency to inflate competence despite marked difficulties in multiple domains has also been reported in studies of children with Attention Deficit/Hyperactivity Disorder (ADHD), and is referred to as the Positive Illusory Bias (Evangelista, Owens, Golden, & Pelham, 2008; Hoza, Pelham, Dodds, & Owens, 2002; Hoza, Waschbusch, Owens, Pelham,

& Kipp, 2001). For example, Evangelista et al. (2008) found that youth with ADHD were able to accurately assess academic and social competence of others, but significantly inflated their own competence in these traits. The authors suggested that these over-estimates may be self-protective, such that individuals will attempt to hide their incompetence by bolstering reports of self-competence in order to protect against feelings of failure or inadequacy (Ohan & Johnson, 2002). Interestingly, while positive illusions in the general population have been shown to lead to more task-persistence and motivation (Taylor & Brown, 1988), positive illusions have not proven to be adaptive for children with ADHD. These children have been shown to have less task persistence and lower performance than their peers (Hoza et al., 2001).

The protective function of self-perception biases in ASD is unknown. Furthermore, associated features of the autism spectrum may contribute to perceptive biases in this population. For example, it has been suggested that the ability to attribute mental states to others (Theory of Mind) may be closely related to the ability to understand one's own mental states. Frith and Happé (1999) proposed that the same cognitive mechanisms required for attributing thoughts and feelings to others may be important for attributing mental states to the self. Some types of executive function difficulty in ASD (e.g., problems in planning and monitoring goals; Pennington & Ozonoff, 1996) may also be linked to poor abilities to reflect on personal mental states. Building on this hypothesis, Jackson, Skirrow, and Hare (2012) investigated several components of self-awareness among adults with and without Asperger's disorder using the Self-Understanding Interview, a measure of individuals' sense of self and understanding of self versus others. Of relevance to the present study, Jackson and colleagues found that those in the ASD group had a reduced sense of awareness of "self-continuity" (i.e., understating changes and stability in self over time) and "self-

distinctiveness" (awareness of uniqueness of life experiences) compared to the control group. The authors speculated that these deficits would make it particularly difficult for those with HFASD to engage in accurate self-reflection and may lead to an "over-identification" of self with others. Weakness in personal reflection and a tendency to over-identify with others helps explain reporting biases among youth with HFASD in the present study, in which reports between youth in both groups were more consistent overall than reports between parents and youth in the ASD group. These results suggest that participants with HFASD may have reported behaviours that others (e.g., siblings, caregivers, peers) engage in as opposed to reflecting and reporting on personal behaviours. They also have implications for the ability of those with HFASD to reflect on personal memories, and questions the validity of retrospective reports in this population overall.

Poor ability to reflect on mental states may help explain why children (Brown, Morris, Nida, & Baker-Ward, 2012; Bruck, London, Landa, & Goodman, 2007) and adults (Adler, Nadler, Eviater, & Shamay-Tsoory, 2009; Crane, Pring, Jukes, & Goddard, 2012) with HFASD show impairments in autobiographical memory, or the recall of personally experienced past events, compared to those without HFASD. For example, and of particular relevance to the present study, Bruck et al. (2007) reported that almost half (44%) of their sample of children with HFASD between the ages of 5 and 10 years could not recall any specific details related to a recent hospitalization due to illness (pneumonia was the most common), injury (e.g., broken bones), or medical procedures (e.g., having tubes placed in ears), compared with only 4% of those in the control group. The authors suggest that social communication deficits in ASD may also contribute to poor autobiographical memory formation as life events are generally shared with others through personal narratives. Sharing

narratives about past events provides children with an opportunity for rehearsal and cuing, which enhances memory (Craik & Tulving, 1975).

It should be noted that the discrepancies between parent- and self-reports in the ASD group may not be due entirely to atypical self-perception on the part of the youth, as argued above. For example, sibling contrast effects (i.e., when parents exaggerate differences between their typical and atypical children; Hartman, Rhee, Willcut, & Pennington, 2007) may have led parents to over-emphasize illness atypicalities. In light of previous findings (Johnson et al., 2009; Knott et al., 2006; Koning & Magill-Evans, 2001), however, the poor agreement between youth and parent ratings in the present study likely reflects atypical self-perception to a greater extent than rater bias. As such, awareness of health behaviours and improved strategies for communicating about, and coping with, illness may be a particularly important focus for future interventions with this population.

Objective 4: Relationships Between Constructs of Interest

The final objective of the study was to explore the relationships between illness constructs and specific characterization variables.

4.1: Illness Communication and Social Language Skills

In the present study, social communication skills were speculated to be a core capability related to illness communication. Overall, this hypothesis was not supported, as direct illness communication was not related to total scores on the CCC-II. A positive relationship was found, however, in the ASD group between reports of direct communication on the vignettes and the "nonverbal communication" and "context" subscales of the CCC-II. These subscales measure the extent to which parents believe their children utilize appropriate gestures, eye gaze, and facial expression during conversations (non-verbal), as well as use the environment to interpret the meaning of communication

(context). These findings suggest that the relationship between social language skills and illness communication is complex. It remains, likely, however, that social language skills are related to illness communication in some capacity since both require nonverbal behaviour (eye gaze, facial expression and gestures) and verbal behaviour (speech or spoken language) to initiate interactions, tell others what one wants, to express feelings, and to share ideas and to solve problems. Although the CCC-2 is one of the best current measures available (Volden & Phillips, 2010), it is possible that it does not sufficiently and/or sensitively capture the aspects of social communication that are related to illness communication. That is, correlations between scores on the CCC-2 with the frequency of direct communication attempts on the vignettes may not have been sensitive enough to detect the complex relationship between social communication and illness communication. More research is needed to better understand what components of social communication are particularly important for illness communication. Additionally, given that youth in the ASD group were also reported to experience some difficulties with structural language, future research could also investigate which aspects of structural language (e.g., coherence) may also be important for illness communication in high functioning youth. It is likely that both structural and social communication skills are particularly important for higher order communication about illness, such as describing physical sensations to caregiver and healthcare professionals.

4.2: Coping Behaviour and Daily Living Skills

Skills of daily living were speculated to be a core capability related to coping behaviour. A large correlation was found between specific active coping behaviours and scores on the Practical Domain of the ABAS-II in the ASD group. Furthermore, all subscales in this domain (i.e., home living, community use, health and safety, self-care) were also positively correlated. As discussed above, health and safety skills are those daily living

abilities needed for the protection of health and to respond to illness and injury, such as following safety rules, using medicines, and showing caution (Harrison & Oakland, 2009). Given that use of medicines, remedies, obtaining help from a healthcare professional, and resting when ill were included within specific active coping, it is not surprising that this conceptual category was related to the health and safety subscale of the ABAS-II. Specific active coping scores were also related to the three other subscales (home living, community use, self-care) of the Practical Domain, supporting the hypothesis that personal care when ill falls within the larger construct of general daily living abilities. Not surprisingly, subscales within each domain of the ABAS-II are often inter-correlated for individuals (Harrison & Oakland, 2009), indicating that personal, domestic, and community skills represent a relatively homogenous cluster of abilities required for independent daily living. ABAS-II scores were not related to frequency counts of general active coping on the vignettes in the ASD group, suggesting that seeking out caregivers may not necessarily be related to daily living skills.

Strengths and Limitations

Within the field of ASD research, the present study is a clinically relevant and novel research direction. This is the first study to examine illness communication and behaviour in children and adolescents with ASD. Relatively little was known about how youth communicate about illness and illness symptoms, as well as how they care for themselves when ill. Furthermore, illness knowledge and illness experiences among youth with HFASD had not been examined previously. Although a handful of previous studies have investigated pain experience and expression in individuals with ASD, most of these investigations did not distinguish between high and lower functioning individuals on the spectrum (e.g., Nader et al., 2004; Tordjman et al., 2009), or between those with ASD and other developmental

conditions (e.g., Gilbert-MacLeod et al., 2000). Moreover, these studies did not distinguish between pain resulting from injury as opposed to illness within their operational definitions of pain. Finally, although previous studies (e.g., Kanne et al., 2011; Kenworthy et al., 2010; Liss et al., 2001) using the ABAS-II with parents of youth with HFASD have reported deficits for the "health and safety" subscale of this measure, there have been no systematic investigations of the types of difficulties that contribute to impairments on this subscale. The present study, therefore, provides important contributions to the ASD literature.

The study of pain, illness, and other health-related constructs is challenging due to practical and ethical considerations. Previous studies investigating pain in youth have employed various methods, including experimental paradigms (e.g., cold pressor task; Birnie, Petter, Boerner, Noel, & Chambers, 2012), naturalistic observation (e.g., immunizations; Stanford, Chambers, Craig, McGrath, & Cassidy, 2005), and pain "diaries" for recurrent or chronic pain (Stinson, 2009). While these methods are appropriate for studying pain, it is difficult to investigate acute and every day illnesses using these strategies because illness is often unpredictable and cannot ethically be induced experimentally. In the present study, I addressed these challenges by making use of vignettes. The use of vignettes facilitated participants' ability to answer questions concerning their own understanding and representations of illness. These methods have been used in research on young children's concepts and understanding of illness (Williams & Binnie, 2002) and pain (Adesman & Walco, 1992), as well as general understanding of biology (Williams & Tomie, 2000). Also, vignettes have been used effectively with children with ASD to assess pain ratings to various painful scenarios (Bandstra et al., 2012).

Finally, the present study made use of both parent- and self-reports. Previous research in pain and pediatric psychology has been criticized (La Greca & Lemanek, 1996)

for relying on reports from a single rater, be it the child, parent/caregiver, or healthcare professional. La Greca and Lemanek (1996) recommended that multiple raters be used in pediatric research whenever possible. As discussed above, the use of multiple raters is particularly important in ASD research, as previous studies indicate that youth with ASD have self-awareness deficits.

Despite the important strengths of the present study, there are limitations. This investigation was conducted with a high-functioning sample of children and adolescents with ASD, in which each participant had an IQ greater than 80 and well-developed verbal abilities. Thus, results cannot be generalized to all youth with ASD, including those with lower IQ and/or verbal abilities. Given that our high-functioning sample of participants with ASD was reported to have poor illness communication, it is highly likely that lower functioning individuals with ASD have greater difficulties and thus may be particularly vulnerable and at risk for inadequate illness management and lack of appropriate intervention. The methods employed in the present study should be employed to investigate illness communication and behaviour in people with ASD that represent a wider range of language and intellectual abilities.

The most commonly reported theoretical and methodological limitation to using vignettes is the relationship between the vignette and "reality", or between belief (what one says they do) and action (what one actually does; Finch, 1987). Unfortunately, due to the nature of illness, real-world reporting of illness behaviours presented many methodological and ethical challenges. Furthermore, this limitation is not unique to vignettes and represents a challenge to all research methodology reliant on self-reports, including questionnaires.

The hypothetical nature of the ailments, however, is an important limitation. Due to difficulties noted above in Theory of Mind, self-reflection, and self-distinctiveness, those

with HFASD may have had a particularly difficult time reflecting upon their personal actions for each ailment. Therefore, those with HFASD may have resorted to reporting behaviours of others in their family, such as siblings, or caregivers. This type of reporting bias was reflected in the data given that reports by youth in the ASD group were more comparable to those of their typical peers than their parents. The inclusion of line drawings, depicting a youth with each ailment, was intended to anchor participants' recollections, but may have been insufficient for those with HFASD. Parental reports were used in the present study to help understand youths' illness behaviours and represent an important strength of the present study.

A research paradigm using vignettes as opposed to questionnaires was chosen because richer verbal and visual context makes them more engaging than questionnaires. Maintaining participant attention and interest was particularly important for the present study given that it involved children as young as 9 years of age. Another advantage of vignettes was that they allowed for several variables to be manipulated at once (i.e., ailment type, seriousness, frequency) in a manner that would not be possible in observation studies. Furthermore, rather than allowing or requiring respondents to come up with these variables themselves in response to simple and direct abstract questions (e.g., "what do you do when you are sick?") typical of questionnaires, the additional detail is provided in the vignette and thereby standardized across participants.

A limitation specific to the vignettes used in the present study is that they were not previously validated. As described in Chapter 2, however, the vignettes were designed using rigorous methodology to maximize internal validity, including input from healthcare professionals during measure development. The vignettes were also modeled after well validated stimuli (i.e., the Charleston Pediatric Pain Pictures); piloted prior to data collection;

and inter-rater reliability of the scoring protocol was very good. Thus, although the stimuli and coding system are novel, my data suggest that these are useful methods for future research. Further work examining the validity of these stimuli in a wider range of participants with ASD, as well as other pediatric populations, will be an important direction for future research.

Theoretical and Clinical Implications

Theoretical Implications

Models of Illness Management. It is important to consider how the current findings relate to and extend current theories that are relevant to illness communication and coping behaviour in typically developing youth and those with ASD. The results of this study, in combination with existing theories (Craig, 2009; Groden et al., 1994; Rosenstiel & Keefe, 1983), led to the development of the Model of Adaptive Illness Management (M-AIM) and a version of maladaptive management (M-MIM), both of which are specific to youth (see Figure 5). These models may serve to guide future research that examines ASD and illness, so that we can improve our understanding of how atypical illness communication and coping behaviour develop, are maintained, and may potentially be improved.

The models I propose were adapted from Groden et al. (1994; see Figure 1), who put forth a model to help explain maladaptive coping strategies used by lower functioning youth with ASD when faced with a stressor (e.g., changes in routine, inability to understand instruction). Recall that in Groden and colleagues' adaptive model of coping, they speculated that the individual experiencing a stressor has access to situational buffers (e.g., social networks, hardiness, internal locus of control), which allow for the successful implementation of adaptive behaviours (e.g., assertiveness, problem solving, utilizing social support), and subsequent reductions in stress. Groden and colleagues speculated that

maladaptive coping in ASD is driven by inadequate buffers (e.g., communication deficits, poor self-control, rigidity), which lead to an over-reliance on maladaptive behaviours (e.g., aggression, emotionality).

Figure 5 illustrates the proposed adaptive and maladaptive models of illness management. In addition to the work of Groden et al., these models also incorporate some elements of Craig's (2009) Social Communication Model of Pain and coping theory (Rosenstiel & Keefe, 1983). Recall that a distinction was made in the conceptualization of direct/active actions (i.e., direct communication, active coping) and indirect/passive actions (i.e., indirect communication, passive coping). Based on previous coping research and theory in pediatric pain (Reid et al., 1998), and the Social Communication Model, it was assumed that direct/active strategies are adaptive because they are reported to bring about favourable outcomes, such as caregiver guidance and support and decreased discomfort. Conversely, indirect/passive strategies were theorized to lead to greater distress and functional disability and were therefore considered maladaptive.

In the M-AIM, the individual experiencing illness has a range of abilities (e.g., problem solving and emotional regulation capabilities) and learned skills (e.g., well developed social communication and daily living skills) that s/he can access that allow him/her to engage in adaptive behaviours to manage the illness. For purposes of this study, abilities were defined as innate personal characteristics or competencies that typically do not change over time. By contrast, skills were defined as learned behaviours resulting from a composite of underlying abilities, techniques, and knowledge (Evreinov, 2008).

In the present investigation, adaptive illness management strategies reported for typical youth included directly informing a caregiver about the ailment and active coping strategies (e.g., seeking assistance, seeking intervention). The favourable outcomes associated

with these strategies promote recovery and thus, positively reinforce these strategies. It is assumed that this positive reinforcement increases the likelihood that the individual will engage in similar behaviours in the future, and will generalize them to new illness contexts. Additional benefits that may result from direct communication, including parental attention and support, are likely to further reinforce this strategy.

In contrast, in the M-MIM, an individual with ASD is likely to have deficits in or difficulties with the abilities and skills needed to engage in adaptive illness management strategies. As a result, youth with ASD demonstrate maladaptive behaviours much more often than those without ASD. Maladaptive behaviours can range from ignoring an ailment to becoming worried and fixated on it. It is important to note that maladaptive behaviours can be part of the normal illness process, and can co-occur with adaptive behaviours. However, in the maladaptive model, these behaviours occur in the absence of, or more frequently than, adaptive behaviours. Maladaptive behaviours lead to ineffective illness management, such as increased discomfort and little or no opportunity to practice effective coping skills. It is important to note that I have hypothesized that most parents will intervene in their child's illness management even if their child does not directly inform them about it. Based on the results of the present study, parents are often cued by their children's sick behaviours and initiate intervention for their children. When this occurs, parents become the active agents in their children's healthcare, with the youth passively adhering to the regimen. This pattern is assumed to contribute to and maintain ineffective illness communication and behaviours and, thus, may be an important target for intervention.

Due to the heterogeneity and complexity of the autism spectrum, there are many associated features of ASD that can impact youths' ability to effectively communicate about and cope with illness. Social communication and activities of daily living have already been

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discussed as central skills related to adaptive illness communication and coping behaviour. That is, poor social communication skills may decrease the likelihood of spontaneous communication about illness, such as directly informing a caregiver about an ailment, or approaching someone for help, advice, or support. It is likely that poor social communication also negatively impacts other aspects of verbal interactions when ill, including ability to describe or answer questions about symptoms. Deficits in daily living skills, such as caring for injuries, using medicines, taking temperature, and swallowing pills may affect an individual's ability to care for him/herself independently. Although it is not fully understood why daily living skills are so limited among those with HFASD, deficits in executive function (Hart & Bean, 2010) and challenges with acquiring or generalizing novel skills (Tsatsanis et al., 2011) may be contributors. Not knowing how to approach a task, such as caring for a sore throat, can lead to confusion and frustration, unsuccessful illness management, and decreased confidence in one's abilities.

Deficits in social communication and daily living skills that affect illness management can be conceptualized as resulting from underlying differences/deficits in abilities that are common in ASD. In Chapter 1, I discussed how poor understanding of emotions and difficulty expressing emotions would adversely impact youths' ability to inform others of personal illnesses. According to the Social Communication Model of Pain, the expression of emotion has a strong impact on how internal states are recognized, interpreted and responded to by others (Craig, 2009). Given the emotional nature of illness, social communication skills may be particularly hampered in an illness context. Theory of Mind deficits may represent another underlying ability impacting illness communication. As discussed above, Theory of Mind, or the ability to attribute mental states to others, is generally poor in those with HFASD (Tager-Flusberg, 2007). Youth with ASD may not

understand that others feel differently than they do, and therefore may not readily communicate symptoms of illness if they think that caregivers already know what they are feeling. As outlined above, parental detection of ailments may also reinforce poor illness reporting given that caregiver intervention does not depend on reporting behaviour by youth when ill.

Other cognitive deficits, such as poor executive function (e.g., difficulties with planning, impulse control, inhibition, shifting set, initiation and monitoring of action) may impact an individual's ability to carry out the actions necessary to manage ailments. For example, Harding and Taylor (2002) described illness management as a dynamic process, characterized by making choices, identifying a plan of action and alternatives, and implementing the plan and revising it accordingly. This process may be problematic for individuals with executive dysfunction. In addition, difficulty regulating emotions during stressful situations may contribute to reliance on passive coping strategies, particularly those related to avoidance of emotional expression or atypical expression of emotion. According to Mazefsky, Pelphrey, and Dahl (2012), emotion regulation processes in typically developing individuals modulate the intensity and timing of both positive and negative responses to fit the situation. Recent research suggests a failure to do so in HFASD (Samson et al., 2012), resulting in increased negative affect, as well as rapidly escalating and seemingly out-of-proportion reactions to stimuli (Baker, 2008). These behaviours can be quite impairing given that they may further impede engagement in direct communication and active coping behaviours to manage illness.

Poor social learning abilities, or learning through observation, in ASD may hamper illness management skills. According to social learning theory (Bandura, 1977) children and adults learn a wide range of behaviours by inadvertently observing others and then imitating

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the observed behaviour. In an illness context, parental modeling has been found to influence children's pain behaviour (Osborne, Hatcher, & Richtsmeier, 1989; Palermo & Chambers, 2005; Veek et al., 2012). Research, however, has documented children with autism display significant deficits in the fundamental skills necessary for observational learning (for a review, see Taylor & DeQuinzio, 2012). To learn by observation, a child will need to attend to and observe the modeler, make complex discriminations of another person's actions and their outcomes, and after a delay in time, imitate some properties of the modeled behaviour (or not). Thus, attending, delayed imitation, and the discrimination of contingencies, are specific skills that seem to be required for observational learning to occur. For children with ASD, these skills are often deficient or delayed, which will invariably impede learning in environments that rely heavily on observational learning. As a result, those with ASD may be particularly disadvantaged as compared to their typical peers when it comes to learning and reproducing strategies to illness management.

Given that there were no between-group differences with respect to illness knowledge in the present investigation, general understanding of illness and illness processes were not theorized to contribute to maladaptive illness management in the model. Instead, illness knowledge can be conceptualized as a relative strength for those with ASD when compared to the ability and skill deficits that likely contribute to maladaptive illness communication and behaviours. More research is needed to better understand factors beyond social communication and daily living skills that may hamper successful execution of active illness management strategies. Given the paucity of research that has been conducted in ASD and coping to date, studies examining relationships between personal coping preference (i.e., active versus passive) and other constructs of interest (e.g., executive

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function, emotional regulation) may be particularly important next steps to better understanding coping in this population.

Although both models incorporate caregiver involvement, the key difference between them is that in the M-AIM, the youth seeks the support of the caregiver and is an active participant in his / her care. Collaboration between the caregiver and youth allow the youth to gain new skills and refine previously learned ones. This process leads to personal mastery and further increases the likelihood that the youth will engage in adaptive behaviours again. By contrast, in the M-MIM, caregiver intervention is not solicited by the youth, but rather occurs when the parent suspects that his / her child is ill. Furthermore, intervention in the M-MIM is generated by the parent and is passively adhered to by the youth, without adding the behaviour(s) into his / her coping repertoire. Deficits in social learning discussed above may disrupt youths' ability to consolidate and reproduce skills into their coping repertoires. Due to social learning deficits, caregivers may resort to direct instruction and active coaching, which are typically not how young children are taught to manage illness. Direct instruction of illness behaviours can be time consuming, however, and youth with HFASD may acquire illness management strategies at much slower rates than their typical counterparts. Poor generalization of skills may also impede the learning process (Whalen, 2009). That is, even when rules are taught or interventions for specific symptoms are learned, these may not generalize from one instance of illness to another.

In addition to the aforementioned skills and abilities, motivation to engage in self-care behaviours is a central component of illness management. Specifically, poor motivation to manage illness would decrease the likelihood of doing so, even if the individual has the necessary skills and abilities. Moreover, motivational biases may account for variability

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between direct / indirect communication and active / passive behaviour among typical

youth, who presumably have adequate skills and abilities to effectively manage illness.

Low motivation, in addition to poor skill acquisition, may be an important contributor to

daily living skill deficits among youth with HFASD. Koegel and colleagues have investigated

the motivational biases of children with ASD, and have reported that learning the

contingencies between response and reinforcers is very difficult for this population, and that

repeatedly responding incorrectly significantly reduces children's responsivity, participation,

and enthusiasm for persisting with a task (Koegel, Singh, & Koegel, 2010; Koegel & Egel,

1979). Youth with HFASD may be less sensitive to the social (e.g., embarrassment, appearing

childish) and personal (e.g., conforming to parental expectations, not attracting a life partner)

consequences that can result from caregiver dependence, and therefore may not seek out

opportunities to gain independence and individuate from caregivers. Finally, excessive

caregiver-directed illness management will likely decrease youths' motivation to perform

these behaviours independently over time.

An important future direction of this research is to investigate the contributions of

motivational biases to illness management among youth with and without HFASD. As an

initial step, youths' perceptions about, and interest in taking charge of, their own health (e.g.,

through interviews, questionnaires, vignettes) could be investigated. Research in behavioural

medicine may provide a good starting point for this line of inquiry. The role of motivation in

the initiation and maintenance of healthy lifestyle behaviours (e.g., exercise, weight loss,

smoking cessation) has been a focus of recent research (Williams, Herzog, & Simmons, 2011

Webber, Tate, Ward, & Bowling, 2010). There is also a large body of research that has

investigated motivation and self-management of chronic illness (e.g., diabetes; Bjorg, Bru, &

Bjorg, 2011) and rehabilitation (e.g., cardiac rehabilitation; Sweet, Tulloch, Fortier, Pipe, &

Reid, 2011). This research could be extended to examine motivation in the context of adaptive and maladaptive illness management, as suggested by the M-AIM and M-MIM. For example, participants could be divided on the basis of illness management motivation (high versus low) and then compared in the areas of illness communication (direct versus indirect) and coping behaviour (active versus passive). Relationships between motivation and illness behaviour and communication could also be examined. If findings indicate low motivation to manage illness among youth with HFASD, and relationships between motivation and illness communication and behaviour, novel intervention approaches for increasing motivation to carry out such strategies may be useful for improving illness management in ASD.

Pain Sensitivity. Illness communication results from the present study also provide support for the hypothesis that youth with ASD may express physical discomfort differently than those without ASD. Until recently, there was a prevailing belief that individuals with developmental disabilities have a "reduced pain sensitivity" or a "high threshold" for pain (Panksepp, 1979). This conviction was initially founded on anecdotal evidence, but later research has found conflicting results regarding reduced pain sensitivity in ASD (Gillberg et al., 1985; Nagamitsu et al., 1997). Tordjman et al. (2009) was the first to provide evidence that reports of lower pain sensitivity in ASD were likely related to differences in pain expression rather than to an insensitivity to, or high threshold for, pain. Although the present study did not investigate physiological experiences of discomfort associated with illness, parent reports gathered in this study further support the hypothesis that youth with HFASD communicate physical discomfort differently than their typical peers. More research is needed to understand how those with ASD experience pain and discomfort associated with illness. A well controlled study using safe experimental procedures designed to induce mild discomfort (i.e., cold pressor task, thermal heat task, pressure task) may be a promising

future direction of research for examining sensory experiences among youth with HFASD.

Sensory experiences likely have a significant impact on the initiation and maintenance of

illness management strategies in individuals with and without ASD.

Clinical Implications

The results of this study have important implications for youth with ASD, as well as

the individuals who care for them. My findings suggest that those with HFASD are less

likely, compared to their typical peers, to notify caregivers when they feel ill, or to engage in

appropriate self-care behaviours to care for themselves when ill. It is particularly alarming

that some parents of youth with HFASD believe that their children would not inform them

about even very serious ailments, such as a head injury, coughing up blood, or an asthma

attack. Similarly, some youth with HFASD seem to have significant difficulties caring for

even very minor ailments, such as cold symptoms, a rash, or a scrape. These findings indicate

that improving communication about illness and developing effective strategies for managing

illness are important targets for remediation in youth with HFASD. As highlighted in the M-

MIM, helping youth cultivate more adaptive behaviours when ill necessitates a multi-pronged

process. For example, assessing and considering the role of daily living and social

communication skills, as well as underlying ability deficits (e.g., cognitive differences, poor

ability to regulate emotions), are critical to developing a comprehensive remediation strategy.

Efforts to improve motivation and a sense of pride in illness management can also be

targeted in treatment. Due to the nature and heterogeneity of the autism spectrum, profiles

of ability, skill, and motivational deficits will vary by individual and therefore intervention

approaches should be individualized as necessary. Remediation efforts are beyond the scope

of this study, as more research is needed to better understand the contributions of various

components of the proposed maladaptive model. However, based on our knowledge to date,

some key strategies that may be helpful for improving illness management are discussed below. It will also be important for caregivers and health care providers who work with children on the autism spectrum to be aware of differences between how youth with and without ASD communicate about and cope with illness. The clinical implications for youth with HFASD, caregivers, and healthcare providers are discussed below.

Youth. According to Attwood (2007), "there may be two ways to acquire a skill - intuition or instruction" (p. 91). Typical children acquire many skills without being consciously aware of them, they learn instinctively. In ASD, it is these instincts that are deficient and therefore those with ASD must often rely on either direct instruction or meticulous intellectual reasoning to acquire a skill. Consequently, daily living skills are an important target for remediation in youth with ASD, and programs already targeting these abilities should include a module dedicated to illness management. To date, applied behaviour analysis (ABA) has been used to improve communication and social skills of children with ASD (for a review, see Virues-Ortega, 2010). ABA uses techniques based on the traditional theory of behaviourism to modify behaviours to bring about meaningful and positive change. Daily living skills can also be taught using ABA principles and specific teaching strategies, such as visual supports (e.g., line drawings, photographs, video-based materials; Pierce & Schreibman, 1994; Shipley-Benamou, Lutzker, & Taubman, 2002), and computer-based training (Ramdoss et al., 2011). Although research on the effectiveness of these strategies for improving daily living skills is generally favourable (Pierce & Schreibman, 1994; Ramdoss et al., 2011; Shipley-Benamou et al., 2002), most studies have been conducted with lower functioning individuals on the autism spectrum (e.g., those with intellectual delay). For higher functioning youth, Drahota, Wood, Sze, and Dyke (2011) suggested that daily living skills are rarely targeted in treatment. The phenomenon of "diagnostic overshadowing"

(Reiss, Levitan, & Szyszko, 1982) may cause clinicians to overlook deficits in daily living skills among individuals with HFASD, and focus solely on the core symptoms of their developmental disability, such as poor social reciprocity. While targeting core symptoms may foster daily living skills indirectly, youth with HFASD would likely benefit from more intensive remediation of daily living skills since they are an important contributor to challenges later in life, especially securing employment and living independently in adulthood (Carothers & Taylor, 2004; Eaves & Ho, 2008; Liss et al., 2001).

To my knowledge, only one study has investigated intervention for daily living skills among high-functioning youth with ASD. Participants in this study took part in a confidence-building treatment program based on cognitive behavioural principles (Drahota et al., 2011); daily living skills were targeted in treatment using techniques to foster children's independence and self-help skills. Parents of children who participated in treatment reported increases in children's total and personal daily living skills, and reduced involvement in their children's private daily routines, compared to waitlist controls. The authors reported that their results indicate that cognitive behavioural therapy may yield increased independence and improve daily living skills among children with ASD. Unfortunately, safety / illness management skills were not directly targeted specifically in this intervention.

Scripts, such as Social Stories® (Gray, 1995), may be a particularly beneficial strategy to teach younger children with ASD appropriate illness management. A script is a short story with specific characteristics that describe a situation, concept, or skill (usually social) using a format that is meaningful for individuals with ASD (Reynhout & Carter, 2006). Scripts have been found to be effective teaching tools for both lower and higher functioning youth with ASD (for a review, see Styles, 2011), and represent strategies that parents can use with their children at home (Hutchins & Prelock, 2006). Reynhout and Carter (2006) have outlined

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some specific formal aspects and guidelines for constructing scripts to use with individuals with ASD. Moreover, Tarnai and Wolfe (2008) have adapted these instructions to create scripts to teach youth with ASD skills related to health and hygiene, and sexual health. These may be an excellent starting point for teaching high-functioning youth with ASD how to effectively communicate about and cope with illness.

Caregivers. My results suggest that parents of youth with HFASD in the present study appear to be sensitive to signs of illness in their children. By relying solely on overt indicators of illness, however, caregivers have to achieve a difficult balance between potentially misinterpreting and treating non-illness behaviours as signs of illness, and inadvertently neglecting signs or symptoms indicative of illness or an underlying health problem. Consequently, caregivers are likely to adopt either a high- or low-risk approach to potential health problems, with some erring on the side of caution at all times, and others choosing to "wait and see". Given that there are risks associated with both approaches (i.e., exposing children to unnecessary medical procedures or ignoring early signs of a serious health problem), parents should be encouraged to teach their children about effective illness management. Furthermore, some parents may have difficulty reading their child's cues, especially when the child is young. For these reasons, communication about illness could be taught using scripts, and facilitated with rating scales (e.g., numerical rating scales, Faces Pain Scale; Hicks, Baeyer, Spafford, Korlaar, & Goodenough, 2001; Jensen et al., 1986) so children can rate the intensity of their pain or discomfort. Rating scales, such as the one used in the present study, have been found to be effective ways for typical children as young as 5 years to rate the intensity of pain (von Baeyer, 2006), and have successfully been used with youth with HFASD (Bandstra et al., 2012).

The importance of teaching daily living skills, including self-care when ill, to children with HFASD has already been emphasized. Many parents, however, report difficulty teaching daily living skills to children with ASD, finding it easier to perform such tasks for their children (Koegel & Egel, 1979). According to Drahota et al. (2011), it may be necessary for parents of children with ASD to provide extensive care for their children at young ages and throughout childhood. This need early in life may make it difficult for parents to recognize when their child is developmentally ready to perform some daily living skills independently. Further, due to poor skill acquisition, fluctuations in motivation, and limited perspective-taking (e.g., for social norms regarding developmentally appropriate independent behaviours, such as when peers begin dressing without parental assistance), children with ASD are unlikely to resist their parents' efforts to do these tasks for them. Together, these factors create barriers to independence and reinforce dependency in youth with HFASD. Caregivers can help foster their children's development of daily living skill using a two pronged approach targeting critical skill and motivational deficits. To address skill deficits, caregivers can teach children daily living skills using strategies such as direct modeling, scripts, shaping, or chaining. There is an extensive literature for parents on teaching adaptive skills to young children. For example, *Steps to Independence* (Baker & Brightman, 2004), is a step-by-step guide for teaching everyday skills to children with special needs and has been a popular resource for parents for more than 20 years.

Drahota and colleagues (2011) suggest that possible strategies to increase motivation and self-efficacy include reframing the idea of performing new daily living skills independently. This can be done by highlighting increased responsibility and self-efficacy as a result of mastering new skills (e.g., "being able to wash a cut and put a bandage on means that you are becoming a big boy!"); emphasizing social norms (e.g., "kids your age think it is

really cool to do stuff for themselves instead of having mom or dad help"); and using praise (e.g., "I'm really proud of you for cleaning your own cut!").

The challenge of helping youth move from dependence to independence in their illness management is not unique to ASD. Negotiating the process of transitioning from pediatric- to adult-centered care is a reality for youth with chronic illness and has become an important topic in healthcare (Kennedy, Sloman, Douglass, & Sawyer, 2007). As a result, increasing numbers of pediatric and adult hospitals are engaging in processes to promote the continuity of care for young people with chronic illness (Wood, Reiss, Ferris, Edwards, & Merrick, 2010). Increasing evidence shows that adverse health consequences (e.g., poor medication adherence) occur when inadequate transition arrangements are in place (Pai & Ostendorf, 2011).

The Shared Management Model (Kieckhefer & Trahms, 2000), developed in Seattle, Washington, offers a good framework for helping parents of youth with ASD foster independent management of illness. The model emphasizes a gradual shift in responsibility where the leadership for care is shifted from the health professional to the caregiver then ultimately to the youth. As the child ages, they actively participate in their health care in an age-appropriate manner. For example, a young child who takes insulin can retrieve his/her insulin from the refrigerator and give it to the parent who will administer it.

The Hospital for Sick Children in Toronto, Ontario has developed a transition program based on the Shared Management Model to assist caregivers and providers with healthcare transition issues in youth. The program, called "Good 2 Go", has several resources available online that may be helpful for caregivers of children with HFASD. These resources include parent and youth readiness checklists, customized health "passports" outlining youths' medical information, aids to communicate about illness clearly and

concisely (e.g., tips to describe a medical condition in 3 sentences or less), appointment checklists detailing items (e.g., health card, medication list) to bring when visiting a healthcare professional, glossaries of common medical terms (e.g., blood draw, adherence), and timelines outlining youths' progression to healthcare independence.

The website also has several suggestions for easy interventions to help promote independence, such as encouraging youth to book their own appointments, write down questions they would like to ask the healthcare provider, and practice "taking the lead" when speaking with providers and pharmacists. These and other resources can be found on the Hospital for Sick Children's website: http://www.sickkids.ca/Good2Go. Successful interactions between youth and healthcare providers will depend heavily on sufficient preparation at home, involving scripts and rehearsal of learned skills prior to visiting the physician.

Healthcare Professionals. Finally, the results of the present study have important implications for physicians and other healthcare professionals who work with youth on the autism spectrum. Studies suggest that pediatric providers report feeling ill-prepared to meet the needs of their patients with ASD and express a desire for further education and training (Boreman, Thomasgard, Fernandez, & Coury, 2007; Heidgerken, Geffken, Modi, & Frakey, 2005). Recently, Major, Peacock, Ruben, Thomas, and Weitzman (2013), in partnership with the Centers for Disease Control and Prevention, have proposed a curriculum to help improve ASD education during pediatric residency in the United States. Proposed topics to be covered in the case-based curriculum include early warning signs of ASD, ASD screening, assessment and diagnosis, early intervention, and treatments for ASD. Not surprisingly, a discussion of the complexities of delivering primary medical care (e.g., for acute illness) to children and adolescents with ASD is not included in the training modules. In light of results

from the present study, however, healthcare providers, especially general practitioners, should be made aware of the significant difficulties their patients with ASD may have managing illnesses independently.

To my knowledge, two resources have been published to assist healthcare professionals deliver effective medical care to children and adolescents on the spectrum. Morton-Cooper's (2004) book, *Health Care and the Autism Spectrum: A Guide for Health Professionals, Parents and Carers,* outlines the characteristics of ASD and provides suggestions (e.g., providing a safe environment, showing sensitivity to sensory issues, maintaining a clear sense of structure, involving the family in care) for healthcare professionals when conducting routine and non-routine health assessments / procedures with those with ASD. Similarly, Volkmar and Wiesner's (2004) book, *Healthcare for Children on the Autism Spectrum: A Guide to Medical, Nutritional, and Behavioral Issues*, suggests ways to modify a typical health care encounter, such as visits to a physician's office, the emergency room, or dentist, to accommodate the needs of an individual with ASD. Unfortunately, these books are largely focused on lower functioning / non-verbal patients, and do not highlight challenges experienced by higher functioning youth, who may appear more typical to a physician who has limited ASD experience / expertise, that can seriously affect their medical care.

Autism Speaks, the world's largest ASD advocacy organization, has also developed a number of "tool kits" containing empirically supported information for parents and healthcare providers caring for children with high or low functioning ASD. Two of these resources focus on health interventions, specifically blood work and dental care. The information and techniques (e.g., relaxation and distraction, visual supports, first-then, reinforcement) presented, however, also apply to other aspects of a healthcare, such as

undergoing physical exams, and hospitalization. Caregiver and provider tool kits are available

on Autism Speaks' website: http://www.autismspeaks.org/family-services/tool-kits.

Beyond coping with medical procedures, it is important for healthcare providers to

be aware that children, adolescents, and even adults with HFASD may have significant

difficulties with several other components of illness management, such as initiating contact

with healthcare providers, describing symptoms, compliance with medication and treatment

instructions, administration of medicines, and pain management. Additionally, poor self-

awareness of personal care behaviour and limited self-advocacy skills may predispose

adolescents with HFASD to agree to comply with medical regimens they cannot manage.

For all these reasons, healthcare providers should tailor their practice to protect the safety

and wellbeing of these vulnerable youth.

Overall Conclusions

This study is an important first step in understanding how youth with ASD

communicate and cope with illness. Until now, no research had examined the experience of

illness in youth with ASD. Previous studies examining how those with ASD respond to pain

have suggested that youth with ASD have a unique way of conveying physical distress to

others. Beyond this, little was known about how those with ASD respond to physical

distress. Results of the present study suggest that high-functioning youth with ASD

communicate and behave differently than typical youth do when ill. Specifically, they are less

likely to inform caregivers about ailments and have difficulties caring for ailments

independently. Although youth with ASD were reported to engage in these behaviours

sometimes, they do so less frequently than those without ASD, reserving these behaviours

for more serious ailments. Conversely, typical youth appear to engage in a two-pronged

process for dealing with ailments consisting of: (1) directly reporting ailments to caregivers;

and (2) and engaging in one or more active coping behaviours. This process appears to be uninfluenced by the seriousness of the ailment, suggesting that youth without ASD have well-learned and rehearsed strategies for managing illnesses.

Active coping behaviours, particularly intervention-seeking when ill, can be conceptualized under the broader umbrella of daily living skills. These skills represent age-appropriate behaviours necessary for people to live independently and to function safely and appropriately in daily life. Although it is well documented that those with HFASD have significant deficits in daily living skills, the extent of these deficits in the illness domain was unknown until now. Some support was found for a relationship between direct illness communication and social communication ability in the ASD group. More research is needed to better understand how social communication and other common deficits/differences influence illness reporting behaviour in youth with ASD. Illness knowledge and the frequency and nature of personal illness history were similar between groups, suggesting that both sets of participants have had similar opportunities to learn and practice illness management strategies in the past.

When asked to report on illness behaviours using hypothetical scenarios, there were greater systematic differences overall between youth and parent reports for the ASD group compared to the typical group, suggesting that those with ASD might have limited insight into how they behave when ill. Moreover, the pattern of discrepancies between parent and youth reports is consistent with findings from previous studies suggesting that those with HFASD overestimate their competence across multiple domains of functioning, including managing illness. It also underpins the importance of utilizing multiple raters when working with youth with ASD as self-reports may be misleading due to poor self-awareness and a tendency to perceive functioning and behavior as typical. Enhancing insight into personal

illness management behaviours may be an important focus for interventions targeting daily living behaviours.

The findings of this study provide the foundation for future studies of illness communication and coping. The proposed models of adaptive and maladaptive illness management provide a framework for guiding future research. The current findings also offer a starting point for discussions amongst relevant stakeholders, such as caregivers and healthcare professionals. The results indicate that effective illness management should be incorporated into intervention strategies for people with ASD. The proposed maladaptive model also provides potential targets for improving illness communication and behaviour for individuals on the spectrum. With the right supports in place, those with HFASD may be able to develop knowledge and skills to advocate for themselves in healthcare settings, maintain health-promoting behaviours, and utilize healthcare services appropriately and successfully.

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Table 1

List of Ailments Included in Vignettes and Health Professional Percent Agreement Coefficients for
Classification Variables (n = 8)

Ailment	Classification (% agreement)	Seriousness (% agreement)	Frequency (% agreement)
Cold	Illness: Contagious (100)	Low (100)	High (100)
Pink Eye	Illness: Contagious (100)	Low (88)	High (88)
Strep Throat	Illness: Contagious (100)	Medium (88)	High (88)
Influenza (flu)	Illness: Contagious (100)	Medium (75)	Low (88)
Asthma Attack	Illness: Non-contagious (100)	High (100)	Medium (88)
Kidney Infection	Illness: Non-contagious (100)	High (75)	Low (88)
Scrape	Injury (100)	Low (100)	High (75)
Burn	Injury (100)	Medium (75)	Medium (88)
Concussion	Injury (100)	High (100)	Low (88)
Skin Rash	Symptom (100)	Low (100)	Medium (75)
Fever	Symptom (100)	Medium (75)	High (100)
Coughing up blood	Symptom (100)	High (75)	Low (100)

Table 2

Sex, Age, and Estimated IQ for Autism Spectrum Disorder and Control Groups

| | | ASD (n=24) | Control (n=24) | Inferential Statistics | | | |
				Statistic Type	*df*	Value	*p*-value
Sex	Male	21	19	Pearson Chi Square	1(N=48)	.44	.70
	Female	3	5				
Age (in years)	M	13.8	13.4	Independent Samples *t*-Test	46	.63	.53
	SD	2.6	2.5				
	Min	9.3	9.4				
	Max	17.8	17.5				
Estimated IQ	M	112.4	113.4	Independent Samples *t*-Test	46	-.24	.82
	SD	13.3	13.7				
	Min	88.0	89.0				
	Max	139.0	144.0				

Table 3

Scoring Parameters for the General Knowledge Section of Illness Interview and Percent Agreement Coefficients

Context	Questions	Answer Themes	Score	Percent Agreement
Illness causality	How does someone get sick?	Insult to the body (e.g., virus, disease, vitamin deficiency)	2	92
		Identification of a risk factor (e.g., weak immune system, stress)	1	83
		Insult is able to overtake body's defenses (e.g., immune system)	2	100
Symptom recognition	How does someone know they are sick?	Symptom recognition (e.g., fever, soreness)	2	100
		Symptoms are out of the ordinary (e.g., feels different)	1	75
Illness treatment	When someone gets sick, how do they get better again?	Seek information (e.g., seeing a doctor, taking temperature)	2	90
		Therapeutic engagement (e.g., taking medicine, rest)	2	100
Illness prevention	How can someone try to keep him/herself from becoming sick?	Lifestyle factor (e.g., eating well, getting rest)	2	80
		Disease prevention strategy (e.g., washing hands, flu shot)	2	80
		Total	**16**	**89**

Table 4

Scoring Parameters for the Expressive Knowledge Section of the Illness Interview and Percent Agreement Coefficients

Ailment	Questions	Answer Themes	Score	Percent Agreement
Cold	What is a cold? How do people get colds?	Insult (e.g., infection, virus)	1	62
		Area of insult (any component of respiratory system)	1	90
		Process (e.g., not washing hands, sharing drinks)	1	100
		Symptom (e.g., cough, sneeze)	1	100
Concussion	What is a concussion? How do people get concussions?	Insult (e.g., injury, trauma, bruising)	1	92
		Area of insult (e.g., brain, head)	1	100
		Process (e.g., hitting head, a blow to the head)	1	92
		Symptom (e.g., dizzy, headache)	1	92
Meningitis	What is meningitis? How do people get meningitis?	Insult (e.g., inflammation, infection, virus)	1	90
		Area of insult (e.g., brain, spine)	1	90
		Process (e.g., infection, living in a dorm)	1	100
		Symptom (e.g., stiff neck, fever)	1	100
		Total	**12**	**92**

Table 5

Content Areas and Broader Conceptual Categories for Youths' Illness Communication

Conceptual Category	Content area	Definition How parent learns of ailment
Direct Communication	Report	Child's verbal report
	Show	Child showing a physical feature associated with the ailment (e.g., scrape, rash, blood)
	Seek assistance	Child seeking information or making a request related to the ailment
Indirect Communication	Complain	Child's whining, complaints, or "acting like a baby"
	Emotional reaction	Child's yelling, screaming, anger or frustration (may be inadvertent)
Disengaged	Inadvertent signaling	Child's inadvertent sick behaviour (e.g., staying in bed, sneezing)
	Unaware	Parent not likely learn about the ailment
Other	Other or ambiguous	Means not captured by above categories

Table 6

Content Areas and Broader Conceptual Categories for Youths' Illness Coping Behaviour

Conceptual Category	Content area	Definition
Active: *General*	Information-seeking	Child seeks information from someone (e.g., parent) or other source (e.g., internet)
	Help-seeking	Child seeks help from parent or other individual
	Support Seeking	Child seeks emotional support or comfort
Active: *Specific*	Rest or Relaxation	Child decreases activity level
	Therapeutic Intervention	Child requests (or uses) one of three intervention therapies: (1) visit a healthcare professional; (2) Medication (e.g., Tylenol) or aid (e.g., bandage); (3) Remedy (e.g., tea) or alternative medication (e.g., vitamin)
Accommodative	Distraction	Child diverts attention away from ailment by thinking about something or engaging in an activity
Passive	Externalization	Child is angry, frustrated, or rude
	Internalization	Child is worried or panics
	Self-Isolation	Child prefers or tries to be alone
	Passive Adherence	Child follows parental directions but makes no independent attempts to deal with the ailment
Inattentive	Ignore Ailment	Child does not acknowledge ailment or makes no attempts to cope with ailment
Other	Ailment-Specific Behaviour	Child engages in automatic or intuitive behaviour
	Other or Ambiguous	Child behaves in a way not captured by above categories

Table 7

Content Areas, Broader Conceptual Categories, and Percent Agreement Coefficients for Youths' Illness Behaviour

Illness Communication

Conceptual Category	Content area	% Agreement Parent Vignettes	% Agreement Youth Vignettes
Direct Communication	Report	95	95
	Show	94	97
	Assistance seeking	97	99
Indirect Communication	Complaints	96	97
	Emotional reaction	97	99
Disengaged	Inadvertent signaling	93	88
	Unaware	100	100
Other	Other or ambiguous	99	92

Illness Coping Behaviour

Conceptual Category	Content area	% Agreement Parent Vignettes	% Agreement Youth Vignettes
Active: *General*	Information-seeking	94	100
	Help-seeking	83	94
	Support seeking	99	99
Active: *Specific*	Rest or relaxation	98	96
	Therapeutic intervention	93	99
Accommodative	Staying positive	100	99
	Distraction	98	97
Passive	Externalizing	94	100
	Internalizing	94	100
	Self-isolation	99	100
	Follows directions	89	94
Inattention	Ignore ailment	89	97
Other	Ailment-specific behaviour	89	94
	Other or ambiguous	83	88

Table 8

Frequencies and Proportions of the Seriousness and Chronicity of Youth and Family Illnesses

		ASD (n=24)		Control (n=24)	
		n	%	n	%
Youth illnesses (past 12 months)	None	2	8.3	2	8.3
	Not serious, not chronic	12	50.0	6	25.0
	Serious, not chronic	9	37.5	11	45.8
	Not serious, chronic	1	4.2	4	20.9
	Serious, chronic	0	0.0	0	0.0
	Life-threatening or terminal	0	0.0	0	0.0
Family illnesses (past 12 months)	None	0	0.0	7	29.2
	Not serious, not chronic	3	12.5	1	4.2
	Serious, not chronic	10	41.7	9	37.5
	Not serious, chronic	6	25.0	3	12.5
	Serious, chronic	5	20.8	2	8.3
	Life-threatening or terminal	0	0.0	2	8.3
Serious family illnesses (lifetime)	None	11	45.8	9	37.5
	Not serious, not chronic	0	0.0	0	0.0
	Serious, not chronic	0	0.0	2	8.3
	Not serious, chronic	0	0.0	0	0.0
	Serious, chronic	1	4.2	3	12.5
	Life-threatening or terminal	12	50.0	10	41.7

Note. Proportions represent the most serious ailment reported by parents for each cluster. Categorization and scoring of ailments is as follows: (0) *none* no illness reported; (1) *not serious, not chronic* illnesses not typically requiring doctors' attention;(2) *serious, not chronic* requires substantial intervention; (3) *not serious, chronic* recurring problems, not very debilitating, or easily controlled; (4) *serious, chronic* diseases such as hypertension, diabetes; (5) *life-threatening/ terminal* fatal or near fatal conditions or death.

Table 9

Means and Standard Deviations for Autism Spectrum and Control Groups on the Illness Knowledge Task

	ASD (n=24) M (SD)	ASD (n=24) Range	Control (n=24) M (SD)	Control (n=24) Range
General illness knowledge (total score = 16)	10.0 (2.0)	6 - 14	10.6 (1.8)	6 - 14
Illness causality (score = 5)	2.2 (1.0)	0 - 4	2.3 (0.9)	1 - 3
Symptom recognition (score = 3)	2.3 (.62)	1 - 3	2.4 (0.7)	1 - 3
Illness treatment (score = 4)	2.6 (0.9)	2 - 4	2.5 (0.9)	2 - 4
Illness prevention (score = 4)	2.9 (1.2)	0 - 4	3.4 (0.9)	2 - 4
Expressive illness knowledge (total score = 12)	5.3 (2.7)	1 - 11	5.6 (1.4)	3 - 9
Definition and etiology of a cold (score = 4)	2.0 (0.8)	1 - 3	2.1 (0.7)	1 - 4
Definition and etiology of a concussion (score = 4)	2.6 (1.5)	0 - 4	3.0 (0.8)	1 - 4
Definition and etiology of meningitis (score = 4)	0.7 (1.2)	0 - 4	0.4 (1.0)	0 - 3
Receptive illness knowledge (total score = 6)	4.0 (1.1)	1 - 6	4.2 (1.1)	1 - 6
Identification of a rash based on symptoms (score = 2)	1.8 (0.4)	0 - 2	1.8 (0.4)	0 - 2
Identification of a urinary tract infection based on symptoms (score = 2)	1.4 (0.6)	0 - 2	1.3 (0.6)	0 - 2
Identification of a stroke based on symptoms (score = 2)	0.7 (0.8)	0 - 2	1.1 (0.9)	0 - 2
Total Illness Knowledge (score = 34)	19.3 (4.5)	11 - 28	20.3 (2.7)	15 - 25

Comparisons between groups (of total scores only) were conducted using independent samples *t*-tests and were all non-significant ($p > .10$)

Table 10

General Illness Knowledge: Content Areas and Chi Square Test Results

Item Description	ASD (n=24)	Control (n=24)	χ^2
How does some someone get sick (illness causality)?			
Insult to body (e.g., virus)	18	15	0.87
Identification of a risk factor (e.g., stress)	15	20	2.64
Insult able to overtake body's defenses (e.g., immune system)	1	3	1.10
How does someone know they are sick (symptom recognition)?			
Symptom recognition (e.g., fever)	22	20	0.76
Symptoms are out of ordinary (e.g., feels different)	11	17	3.11
When someone is sick, how do they get better again (treatment)?			
Seek information (e.g., see a physician)	7	6	0.11
Therapeutic engagement (e.g., rest)	24	24	0.00
How can someone try to keep him/herself from becoming sick (prevention)?			
Lifestyle factor (e.g., eat well)	16	17	1.10
Disease prevention (e.g., wash hands)	17	24	8.20*

* = ASD versus control differ at $p < .01$

Note. Degrees of freedom = 1 for each chi-square analysis. In cases were the chi-square test could not be interpreted due to low "expected cell frequencies", Fisher's Exact Test p-value was used to determine statistical significance.

Table 11

Expressive Illness Knowledge: Content Areas and Chi-Square Results

Item Description	ASD (n=24)	Control (n=24)	χ^2
What is a cold? How do people get colds?			
Insult to body (e.g., virus)	8	8	0.00
Area of insult (e.g., respiratory system)	6	6	0.00
Process (e.g., sharing drinks)	19	16	0.95
Symptom (e.g., sneeze)	17	21	2.02
What is a concussion? How do people get concussions?			
Insult (e.g., injury)	16	16	0.00
Area of insult (e.g., head)	18	24	6.90*
Process (e.g., hitting head)	17	21	2.02
Symptom (e.g., dizzy)	11	12	0.83
What is meningitis? How do people get meningitis?			
Insult (e.g., inflammation)	4	4	0.00
Area of insult (e.g., brain)	6	3	1.21
Process (e.g., infection)	5	1	3.10
Symptom (e.g., stiff neck)	1	2	0.36

* = ASD versus control differ at $p < .01$

Note. Degrees of freedom = 1 for each chi-square analysis. In cases were the chi-square test could not be interpreted due to low "expected cell frequencies", Fisher's Exact Test *p*-value was used to determine statistical significance.

Table 12

Descriptive Statistics for Average Ratings of the Likelihood Youth would Report a Hypothetical Ailment at Differing Levels of Seriousness

		ASD (n=24)			Control (n=24)		
		M	SD	Range	M	SD	Range
Parent	Low	3.1*†	1.1	1.3 – 5.0	4.5†	.54	3.3 - 5.0
	Moderate	3.5*†	.95	1.3 – 5.0	4.8	.36	3.5 - 5.0
	High	3.9*†	.81	1.7 – 5.0	4.9	.16	4.5 - 5.0
Youth	Low	4.2	.85	1.7 - 5.0	4.1	.52	3.0 - 5.0
	Moderate	4.4	.87	1.5 - 5.0	4.6	.49	3.2 - 5.0
	High	4.6	.63	2.5 - 5.0	4.8	.33	4.0 - 5.0

* = ASD versus control differ at $p < .01$; † = Parent versus youth differ at $p < .01$

Note. Scale ranges from 1 – 5; higher scores = greater likelihood of reporting.

Table 13

Descriptive Statistics for Content Areas and Conceptual Categories for Parent and Youth Ratings of Youths'
Illness Communication

	ASD (n=24)		Control (n=24)	
	Parent M % (SD)	Youth M % (SD)	Parent M % (SD)	Youth M % (SD)
Direct Communication	59*† (.21)	88 (.19)	95 (.14)	96 (.07)
Report	50*† (.21)	82 (.20)	88 (.16)	91 (.13)
Show	8* (.08)	11* (.11)	25 (.18)	23 (.13)
Assistance seeking	7 (.11)	6 (.09)	18 (.17)	10 (.16)
Indirect Communication	30† (.26)	7 (.18)	20† (.22)	2 (.04)
Complaints	9 (.13)	0 (.02)	8 (.13)	0 (.02)
Emotional reaction	25† (.21)	6 (.19)	13† (.14)	2 (.04)
Disengaged	36*† (.23)	12 (.18)	9 (.10)	8 (.11)
Inadvertent signaling	32*† (.20)	10 (.17)	8 (.13)	8 (.10)
Unaware	4 (.08)	2 (.04)	1 (.05)	0 (.02)
Other or Ambiguous	2 (.06)	0 (.01)	2 (.05)	0 (.02)

* = ASD versus control differ at $p < .05$; † = Parent versus youth differ a $p < .05$

Note. Categories are not mutually exclusive. For ease of presentation, frequency counts were converted into percent values to represent the average number of vignettes that a behaviour was reported. For example, a parent who reported that their child would complain about an ailment on 5 of the 12 vignettes would have 41.7 percent for this behaviour.

Table 14

Descriptive Statistics for Average Ratings of the Likelihood Youth would Seek Intervention for a Hypothetical Ailment at Different Levels of Seriousness

| | | ASD (n=24) | | | Control (n=24) | | |
		M	SD	Range	M	SD	Range
Parent	Low	2.9*†	1.1	1.3 -	3.9	.83	2.0 - 5.0
	Moderate	3.5*	1.1	1.0 -	4.6†	.74	2.0 - 5.0
	High	3.9*†	.90	1.5 -	4.7	.55	3.5 - 5.0
Youth	Low	3.8	1.0	2.3 -	3.7	.63	2.3 - 5.0
	Moderate	4.0	.99	1.5 -	4.1	.80	2.0 - 5.0
	High	4.5	.99	2.5 -	4.5	.71	2.0 - 5.0

* = ASD versus control differ at $p < .01$; † = Parent versus youth differ at $p < .01$

Note. Scale ranges from 1 – 5; higher scores = greater likelihood of seeking intervention

Table 15

Descriptive Statistics for Content Areas and Conceptual Categories for Parent and Youth Ratings of Youths'
Illness Coping Behaviour

	ASD (n=24)		Control (n=24)	
	Parent	Youth	Parent	Youth
	M % (SD)	M % (SD)	M % (SD)	M % (SD)
Active Coping	60*[†] (.23)	85 (.15)	93 (.09)	95 (.07)
Active: General	28*[†] (.19)	15 (.19)	59[†] (.18)	17 (.19)
Information-seeking	15[†] (.13)	7 (.14)	24[†] (.18)	10 (.16)
Help-seeking	14*[†] (.15)	7 (.13)	41[†] (.21)	8 (.12)
Support Seeking	2* (.05)	1 (.03)	6[†] (.08)	0 (.00)
Active: Specific	48*[†] (.26)	76* (.25)	81[†] (.15)	93 (.12)
Rest or Relaxation	20* (.13)	20 (.19)	33 (.16)	35 (.18)
Intervention-seeking	29*[†] (.23)	66* (.27)	72[†] (.17)	80 (.18)
Accommodative Coping	6 (.07)	2 (.05)	6 (.07)	9 (.11)
Passive Coping	42*[†] (.27)	10 (.06)	25[†] (.19)	5 (.06)
Externalizing	23*[†] (.28)	1 (.03)	6 (.13)	2 (.04)
Internalizing	25[†] (.23)	2 (.04)	18[†] (.19)	2 (.03)
Self-Isolation	6* (.11)	2 (.03)	.01 (.01)	0 (.02)
Passive Adherence	15*[†] (.13)	0 (.03)	3 (.11)	2 (.03)
Inattention	11* (.14)	10* (.13)	.6 (.02)	1 (.03)
Other	9 (.11)	12 (.13)	8[†] (.21)	19 (.08)
Ailment-Specific	9 (.11)	11 (.12)	7[†] (.08)	18 (.21)
Other or Ambiguous	1 (.06)	0 (.01)	2 (.05)	0 (.02)

* = ASD versus control differ at $p < .05$; [†] = Parent versus youth differ a $p < .05$

Note. Categories are not mutually exclusive. For ease of presentation, frequency counts were
converted into percent values to represent the average number of vignettes that a behaviour
was reported. For example, a parent who reported that their child would seek intervention for
an ailment on 9 of the 12 vignettes would have 75 percent for this behaviour.

Adaptive Model

Exhibited by persons with good coping strategies

Stressors
(promotion, death, separation, birth of a sibling, pain)

↓

Buffers
(social networks, hardiness, internal locus of control)

↓

Adaptive Behaviors
(assertiveness, socializing, exercise)

↓

Reinforcement

↓

Stress Reduction

Maladaptive Model

Exhibited by persons with poor coping strategies, especially by individuals with developmental disabilities

Stressors
(taking criticism, changes, inability to understand instruction)

↓

Inability to Use Buffers
(lack of friends, communication deficits, lack of self-control)

↓

Maladaptive Behaviors
(aggression, self-injury, stereotypic behaviors)

↓

Punishment

↓

Increased Stress

Figure 1. Adaptive and Maladaptive Coping Models in Autism. Reprinted from *The impact of stress and anxiety on individuals with autism and developmental disabilities* (p. 182), by J. Groden, 1994. In E. Schopler & G.B. Mesibov (Eds.), Behavioral issues in autism. New York: Plenum Press.
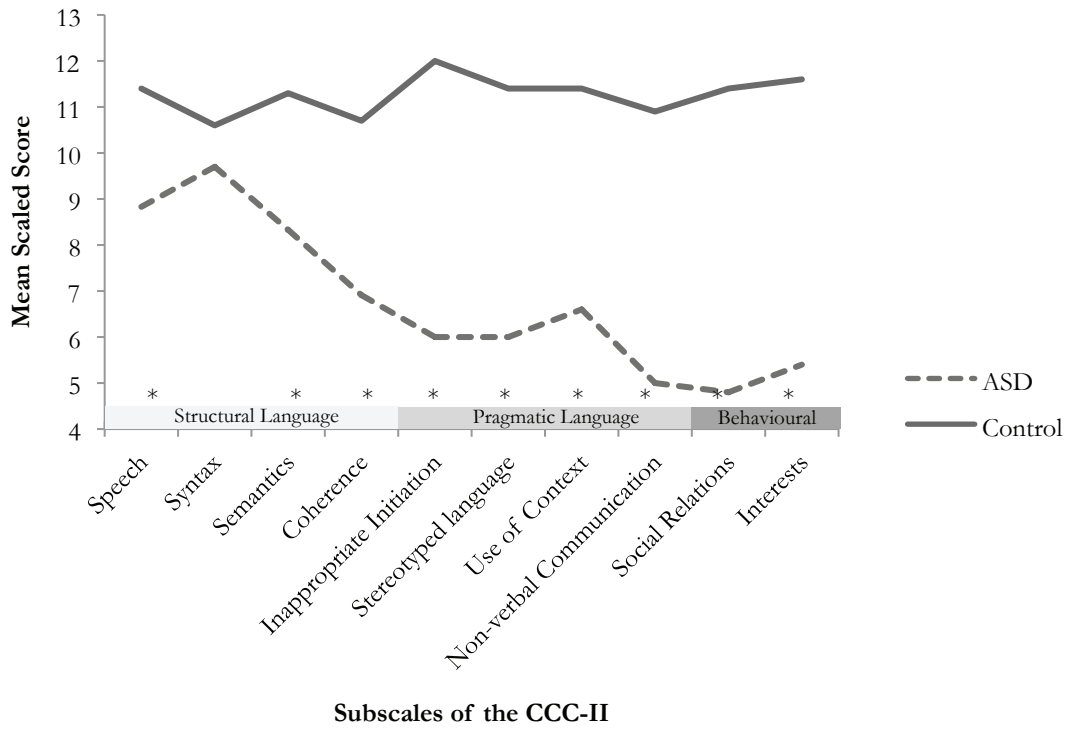
Figure 2. Mean Subscale Scores for the Children's Communication Checklist, Second Edition, (CCC-II) in the Autism Spectrum and Control Groups

* = ASD versus control differ at *p* < 001.
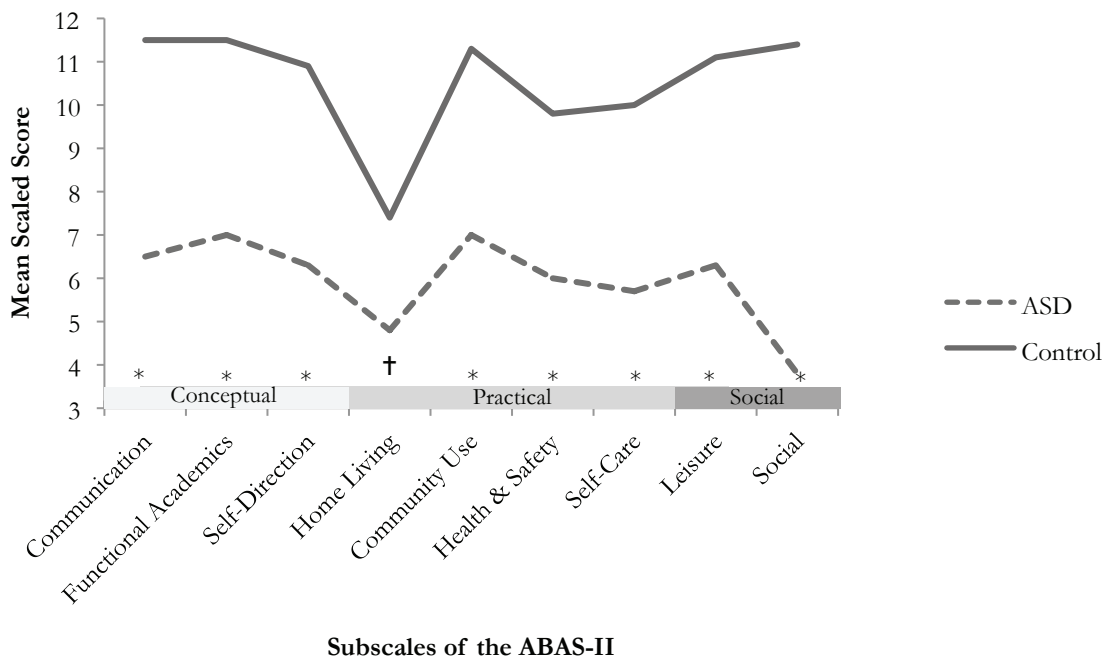
Figure 3. Mean Subscale Scores for the Adaptive Behavior Assessment System, Second Edition, (ABAS-II) in the Autism Spectrum and Control Groups

* = ASD versus control differ at $p < .001$; † = ASD versus control differ at $p < .05$
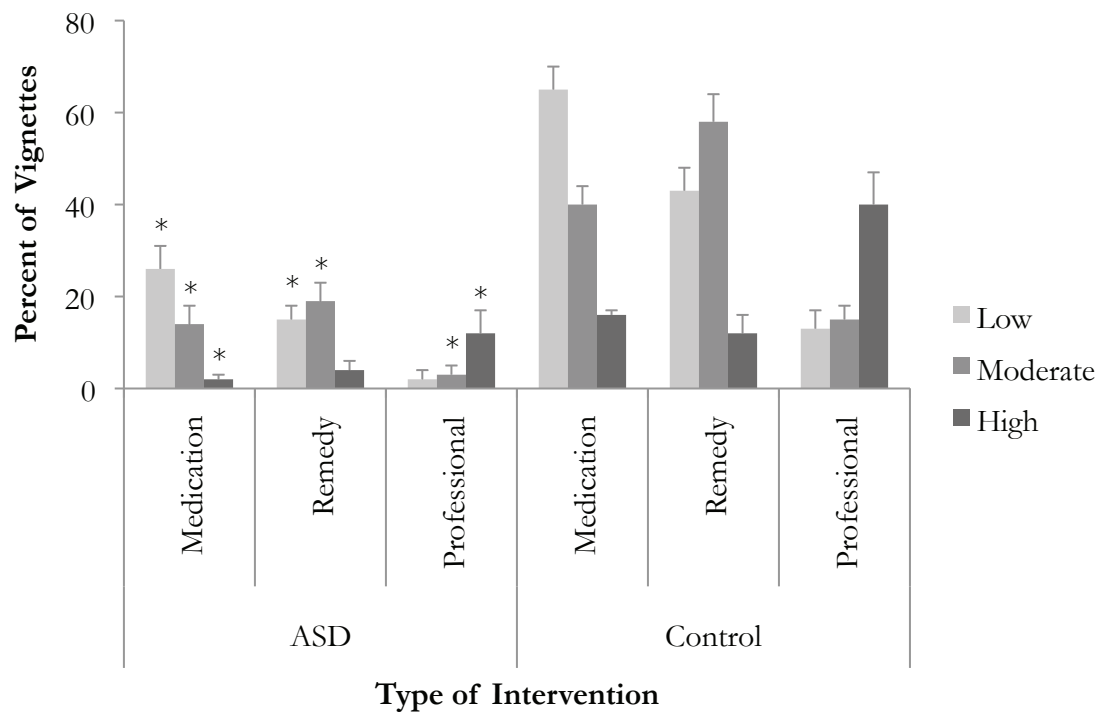
Figure 4. Intervention Types Reported by Parents in the Autism Spectrum and Control Groups on the Vignettes

* = ASD versus control differ at *p* < .004

Note. Categories are not mutually exclusive. "Low", "Moderate", "High" refer to ailment seriousness. For ease of presentation, frequency counts were converted into percent values to represent the average number of vignettes that a behaviour was reported. For example, a parent who reported that their child would use medication for an ailment on 4 of the 12 vignettes would have 33 percent for this behaviour.
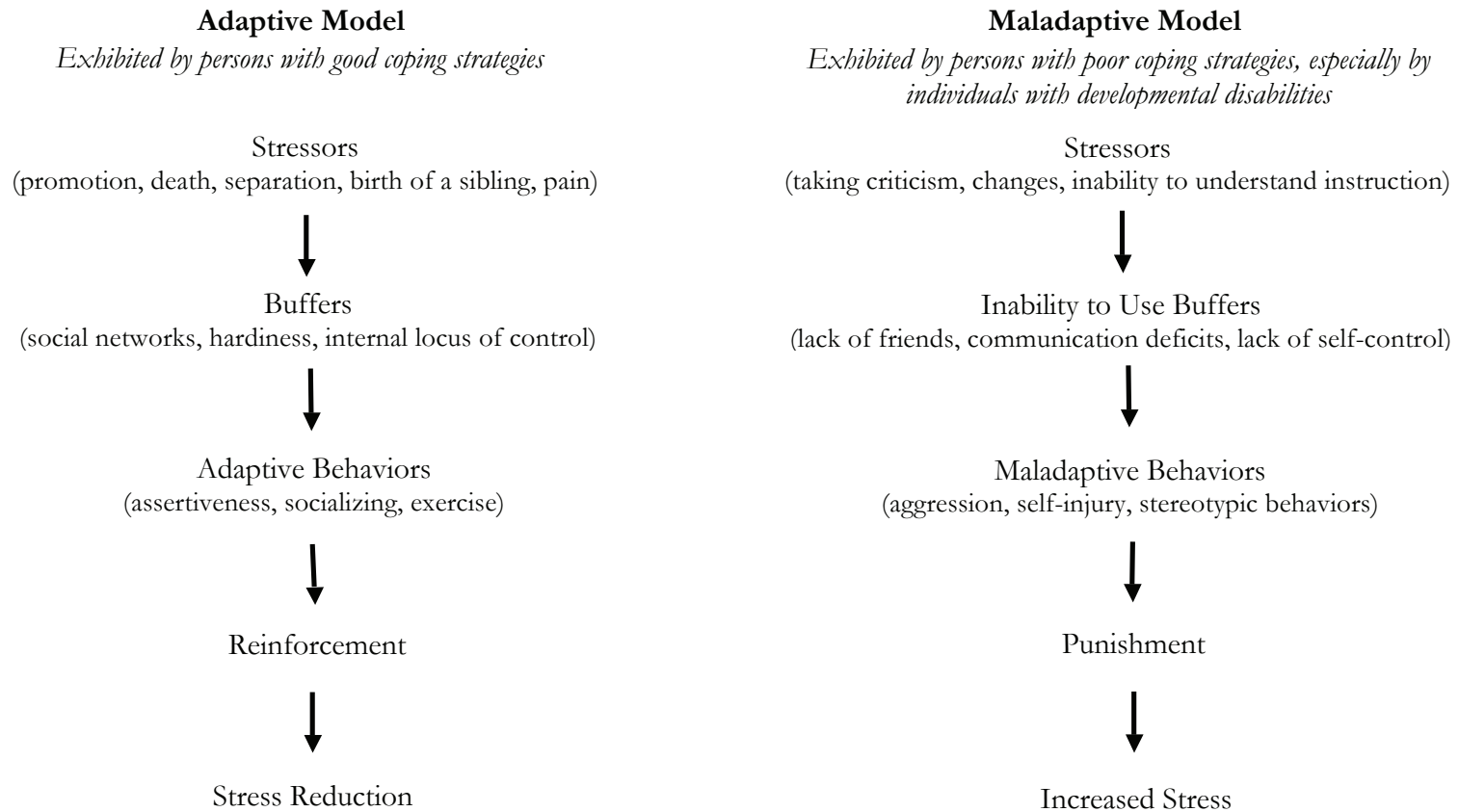
Model of Adaptive Illness Management (M-AIM)

Exhibited by those who have sufficient critical skills and resourcefulness to manage ailment

Ailment

Critical Skills, Abilities, and Resourcefulness
Sufficient abilities (e.g., problem solving, emotional regulation); well-developed social communication and daily living skills; previously learned coping strategies

Adaptive Behaviours
e.g., inform caregiver, seek assistance, seek intervention, rest

Motivation

Effective Outcomes
Decreased discomfort, stable emotions, personal mastery of skills

Skills gained or refined

Reinforcement
Physical (positive outcomes) and social (e.g., caregiver attention) reinforcers lead to increased likelihood of engaging in adaptive behaviours in future

Model of Maladaptive Illness Management (M-MIM)

Exhibited by those who have insufficient skills and resourcefulness to manage ailment, including, but not limited to, individuals with autism spectrum disorder

Ailment

Limitations in Critical Skills, Abilities, and Resourcefulness
Poor abilities (e.g., emotional regulation, Theory of Mind); Deficits in communication and daily living skills; limited repertoire of coping strategies or inability to generalize these

Maladaptive Behaviours
e.g., ignore symptoms, increased emotionality and irritability

Caregiver Intervention
Unsolicited involvement of caregiver and passive adherence by youth to medical regimen

Ineffective Outcomes
Increased discomfort, deregulated emotions, lack of mastery in skills

Motivation

Reinforcement
Positive outcome leads to increased reliance on maladaptive behaviours and dependency on caregiver intervention

Figure 5. Models of Adaptive and Maladaptive Illness Management Among Youth. Adapted from *The impact of stress and anxiety on individuals with autism and developmental disabilities* (p. 182), by J. Groden, 1994. In E. Schopler & G.B. Mesibov (Eds.), Behavioral issues in autism. New York: Plenum Pre ss.

QUESTIONNAIRE FOR HEALTHCARE PROFESSIONALS

<u>Instructions:</u>

Please answer the following questions about youth illnesses, injuries, and physical symptoms. Each question will present the name of a medical condition and then ask you to evaluate the condition with respect to condition type, severity, and frequency for children and adolescents between the ages of **5 and 16 years of age**. Please check the box to answer. We are aware that there may be categories other than the ones listed below; however, for purposes of this study**, please do your best to classify each condition in only one of the categories provided**. We have also included four questions about your background to help us generally describe the healthcare providers that took part in this study.

<u>Background questions</u>

1. Can you read, write, and speak fluently in English?
   ☐ Yes
   ☐ No

2. Are you a licensed physician (i.e., have received a Doctor of Medicine degree) or a registered nurse?
   ☐ Yes
   ☐ No

3. Please select the age ranges of the children and adolescents you regularly work with in a medical context (check all that apply):
   ☐ 5 to 7 year olds
   ☐ 8 to 10 year olds
   ☐ 11 to 14 year olds
   ☐ 15 to 16 year olds

4. Please indicate your medical specialty:

   ☐ General Practice   ☐ Pediatrics   ☐ Family Medicine

   Other: _____

Illness / injury / physical symptom questions:

5. <u>Sore Throat</u> (excluding strep throat, tonsillitis, and other very painful infections)

    a) How would you best **classify** this condition?
      ☐ Contagious Illness   ☐ Non-Contagious Illness   ☐ Injury   ☐ Symptom

    b) How would you rate the **seriousness** of this condition?
      ☐ Low   ☐ Moderate   ☐ High

    c) How would you rate the **frequency** of this condition in youths (5 to 16 years)?
      ☐ Low   ☐ Moderate   ☐ High

6. <u>Head Lice</u>

    a) How would you best **classify** this condition?
      ☐ Contagious Illness   ☐ Non-Contagious Illness   ☐ Injury   ☐ Symptom

    b) How would you rate the **seriousness** of this condition?
      ☐ Low   ☐ Moderate   ☐ High

    c) How would you rate the **frequency** of this condition in youths (5 to 16 years)?
      ☐ Low   ☐ Moderate   ☐ High

7. <u>Pink Eye</u> (conjunctivitis)

    a) How would you best **classify** this condition?
      ☐ Contagious Illness   ☐ Non-Contagious Illness   ☐ Injury   ☐ Symptom

    b) How would you rate the **seriousness** of this condition?
      ☐ Low   ☐ Moderate   ☐ High

    c) How would you rate the **frequency** of this condition in youths (5 to 16 years)?
      ☐ Low   ☐ Moderate   ☐ High

8. <u>Common Cold</u>

    a) How would you best **classify** this condition?
      ☐ Contagious Illness   ☐ Non-Contagious Illness   ☐ Injury   ☐ Symptom

    b) How would you rate the **seriousness** of this condition?
      ☐ Low   ☐ Moderate   ☐ High

    c) How would you rate the **frequency** of this condition in youths (5 to 16 years)?
      ☐ Low   ☐ Moderate   ☐ High

9. <u>Bronchitis</u>

    a) How would you best **classify** this condition?
       ☐ Contagious Illness   ☐ Non-Contagious Illness   ☐ Injury   ☐ Symptom

    b) How would you rate the **seriousness** of this condition?
       ☐ Low   ☐ Moderate   ☐ High

    c) How would you rate the **frequency** of this condition in youths (5 to 16 years)?
       ☐ Low   ☐ Moderate   ☐ High

10. <u>Stomach Flu</u>

    a) How would you best **classify** this condition?
       ☐ Contagious Illness   ☐ Non-Contagious Illness   ☐ Injury   ☐ Symptom

    b) How would you rate the **seriousness** of this condition?
       ☐ Low   ☐ Moderate   ☐ High

    c) How would you rate the **frequency** of this condition in youths (5 to 16 years)?
       ☐ Low   ☐ Moderate   ☐ High

11. <u>Mild Sunburn</u>

    a) How would you best **classify** this condition?
       ☐ Contagious Illness   ☐ Non-Contagious Illness   ☐ Injury   ☐ Symptom

    b) How would you rate the **seriousness** of this condition?
       ☐ Low   ☐ Moderate   ☐ High

    c) How would you rate the **frequency** of this condition in youths (5 to 16 years)?
       ☐ Low   ☐ Moderate   ☐ High

12. <u>Tonsillitis</u>

    a) How would you best **classify** this condition?
       ☐ Contagious Illness   ☐ Non-Contagious Illness   ☐ Injury   ☐ Symptom

    b) How would you rate the **seriousness** of this condition?
       ☐ Low   ☐ Moderate   ☐ High

    c) How would you rate the **frequency** of this condition in youths (5 to 16 years)?
       ☐ Low   ☐ Moderate   ☐ High

13. <u>Skin Rash</u> (contact dermatitis)

    a) How would you best **classify** this condition?
       ☐ Contagious Illness   ☐ Non-Contagious Illness   ☐ Injury   ☐ Symptom

b) How would you rate the **seriousness** of this condition?
☐ Low ☐ Moderate ☐ High

c) How would you rate the **frequency** of this condition in youths (5 to 16 years)?
☐ Low ☐ Moderate ☐ High

14. <u>Seasonal Allergies</u>

a) How would you best **classify** this condition?
☐ Contagious Illness ☐ Non-Contagious Illness ☐ Injury ☐ Symptom

b) How would you rate the **seriousness** of this condition?
☐ Low ☐ Moderate ☐ High

c) How would you rate the **frequency** of this condition in youths (5 to 16 years)?
☐ Low ☐ Moderate ☐ High

15. <u>Headache</u> (excluding migraine)

a) How would you best **classify** this condition?
☐ Contagious Illness ☐ Non-Contagious Illness ☐ Injury ☐ Symptom

b) How would you rate the **seriousness** of this condition?
☐ Low ☐ Moderate ☐ High

c) How would you rate the **frequency** of this condition in youths (5 to 16 years)?
☐ Low ☐ Moderate ☐ High

16. <u>Ear Infection</u> (otitis media)

a) How would you best **classify** this condition?
☐ Contagious Illness ☐ Non-Contagious Illness ☐ Injury ☐ Symptom

b) How would you rate the **seriousness** of this condition?
☐ Low ☐ Moderate ☐ High

c) How would you rate the **frequency** of this condition in youths (5 to 16 years)?
☐ Low ☐ Moderate ☐ High

17. <u>Asthma Attack</u>

a) How would you best **classify** this condition?
☐ Contagious Illness ☐ Non-Contagious Illness ☐ Injury ☐ Symptom

b) How would you rate the **seriousness** of this condition?
☐ Low ☐ Moderate ☐ High

c) How would you rate the **frequency** of this condition in youths (5 to 16 years)?
☐ Low ☐ Moderate ☐ High

18. <u>Bruise</u> (contusion)

   a) How would you best **classify** this condition?
     ☐ Contagious Illness   ☐ Non-Contagious Illness   ☐ Injury   ☐ Symptom

   b) How would you rate the **seriousness** of this condition?
     ☐ Low   ☐ Moderate   ☐ High

   c) How would you rate the **frequency** of this condition in youths (5 to 16 years)?
     ☐ Low   ☐ Moderate   ☐ High

19. <u>Concussion</u>

   a) How would you best **classify** this condition?
     ☐ Contagious Illness   ☐ Non-Contagious Illness   ☐ Injury   ☐ Symptom

   b) How would you rate the **seriousness** of this condition?
     ☐ Low   ☐ Moderate   ☐ High

   c) How would you rate the **frequency** of this condition in youths (5 to 16 years)?
     ☐ Low   ☐ Moderate   ☐ High

20. <u>Superficial Scrape</u>

   a) How would you best **classify** this condition?
     ☐ Contagious Illness   ☐ Non-Contagious Illness   ☐ Injury   ☐ Symptom

   b) How would you rate the **seriousness** of this condition?
     ☐ Low   ☐ Moderate   ☐ High

   c) How would you rate the **frequency** of this condition in youths (5 to 16 years)?
     ☐ Low   ☐ Moderate   ☐ High

21. <u>Nausea</u>

   a) How would you best **classify** this condition?
     ☐ Contagious Illness   ☐ Non-Contagious Illness   ☐ Injury   ☐ Symptom

   b) How would you rate the **seriousness** of this condition?
     ☐ Low   ☐ Moderate   ☐ High

   c) How would you rate the **frequency** of this condition in youths (5 to 16 years)?
     ☐ Low   ☐ Moderate   ☐ High

22. <u>Urinary Tract Infection</u>

   a) How would you best **classify** this condition?
     ☐ Contagious Illness   ☐ Non-Contagious Illness   ☐ Injury   ☐ Symptom

b) How would you rate the **seriousness** of this condition?
☐ Low   ☐ Moderate   ☐ High

c) How would you rate the **frequency** of this condition in youths (5 to 16 years)?
☐ Low   ☐ Moderate   ☐ High

23. Runny Nose

a) How would you best **classify** this condition?
☐ Contagious Illness   ☐ Non-Contagious Illness   ☐ Injury   ☐ Symptom

b) How would you rate the **seriousness** of this condition?
☐ Low   ☐ Moderate   ☐ High

c) How would you rate the **frequency** of this condition in youths (5 to 16 years)?
☐ Low   ☐ Moderate   ☐ High

24. Frostbite

a) How would you best **classify** this condition?
☐ Contagious Illness   ☐ Non-Contagious Illness   ☐ Injury   ☐ Symptom

b) How would you rate the **seriousness** of this condition?
☐ Low   ☐ Moderate   ☐ High

c) How would you rate the **frequency** of this condition in youths (5 to 16 years)?
☐ Low   ☐ Moderate   ☐ High

25. Nosebleed

a) How would you best **classify** this condition?
☐ Contagious Illness   ☐ Non-Contagious Illness   ☐ Injury   ☐ Symptom

b) How would you rate the **seriousness** of this condition?
☐ Low   ☐ Moderate   ☐ High

c) How would you rate the **frequency** of this condition in youths (5 to 16 years)?
☐ Low   ☐ Moderate   ☐ High

26. Vomiting

a) How would you best **classify** this condition?
☐ Contagious Illness   ☐ Non-Contagious Illness   ☐ Injury   ☐ Symptom

b) How would you rate the **seriousness** of this condition?
☐ Low   ☐ Moderate   ☐ High

c) How would you rate the **frequency** of this condition in youths (5 to 16 years)?
☐ Low   ☐ Moderate   ☐ High

27. <u>Chest Pain</u>

   a) How would you best **classify** this condition?
     ☐ Contagious Illness   ☐ Non-Contagious Illness   ☐ Injury   ☐ Symptom

   b) How would you rate the **seriousness** of this condition?
     ☐ Low   ☐ Moderate   ☐ High

   c) How would you rate the **frequency** of this condition in youths (5 to 16 years)?
     ☐ Low   ☐ Moderate   ☐ High

28. <u>Swollen Lymph Nodes in Neck</u>

   a) How would you best **classify** this condition?
     ☐ Contagious Illness   ☐ Non-Contagious Illness   ☐ Injury   ☐ Symptom

   b) How would you rate the **seriousness** of this condition?
     ☐ Low   ☐ Moderate   ☐ High

   c) How would you rate the **frequency** of this condition in youths (5 to 16 years)?
     ☐ Low   ☐ Moderate   ☐ High

29. <u>Spitting Up Blood</u>

   a) How would you best **classify** this condition?
     ☐ Contagious Illness   ☐ Non-Contagious Illness   ☐ Injury   ☐ Symptom

   b) How would you rate the **seriousness** of this condition?
     ☐ Low   ☐ Moderate   ☐ High

   c) How would you rate the **frequency** of this condition in youths (5 to 16 years)?
     ☐ Low   ☐ Moderate   ☐ High

30. <u>Strep Throat</u>

   a) How would you best **classify** this condition?
     ☐ Contagious Illness   ☐ Non-Contagious Illness   ☐ Injury   ☐ Symptom

   b) How would you rate the **seriousness** of this condition?
     ☐ Low   ☐ Moderate   ☐ High

   c) How would you rate the **frequency** of this condition in youths (5 to 16 years)?
     ☐ Low   ☐ Moderate   ☐ High

31. <u>Burn</u>

   a) How would you best **classify** this condition?
     ☐ Contagious Illness   ☐ Non-Contagious Illness   ☐ Injury   ☐ Symptom

b) How would you rate the **seriousness** of this condition?
◻ Low   ◻ Moderate   ◻ High

c) How would you rate the **frequency** of this condition in youths (5 to 16 years)?
◻ Low   ◻ Moderate   ◻ High

32. <u>Broken Limb</u>

a) How would you best **classify** this condition?
◻ Contagious Illness   ◻ Non-Contagious Illness   ◻ Injury   ◻ Symptom

b) How would you rate the **seriousness** of this condition?
◻ Low   ◻ Moderate   ◻ High

c) How would you rate the **frequency** of this condition in youths (5 to 16 years)?
◻ Low   ◻ Moderate   ◻ High

33. <u>Fever</u>

a) How would you best **classify** this condition?
◻ Contagious Illness   ◻ Non-Contagious Illness   ◻ Injury   ◻ Symptom

b) How would you rate the **seriousness** of this condition?
◻ Low   ◻ Moderate   ◻ High

c) How would you rate the **frequency** of this condition in youths (5 to 16 years)?
◻ Low   ◻ Moderate   ◻ High

34. <u>Dizziness</u>

a) How would you best **classify** this condition?
◻ Contagious Illness   ◻ Non-Contagious Illness   ◻ Injury   ◻ Symptom

b) How would you rate the **seriousness** of this condition?
◻ Low   ◻ Moderate   ◻ High

c) How would you rate the **frequency** of this condition in youths (5 to 16 years)?
◻ Low   ◻ Moderate   ◻ High

35. <u>Kidney Infection</u>

a) How would you best **classify** this condition?
◻ Contagious Illness   ◻ Non-Contagious Illness   ◻ Injury   ◻ Symptom

b) How would you rate the **seriousness** of this condition?
◻ Low   ◻ Moderate   ◻ High

c) How would you rate the **frequency** of this condition in youths (5 to 16 years)?
◻ Low   ◻ Moderate   ◻ High

36. <u>Chicken Pox</u>

    a) How would you best **classify** this condition?
    ☐ Contagious Illness   ☐ Non-Contagious Illness   ☐ Injury   ☐ Symptom

    b) How would you rate the **seriousness** of this condition?
    ☐ Low   ☐ Moderate   ☐ High

    c) How would you rate the **frequency** of this condition in youths (5 to 16 years)?
    ☐ Low   ☐ Moderate   ☐ High

37. <u>Sprained / Pulled Muscle</u>

    a) How would you best **classify** this condition?
    ☐ Contagious Illness   ☐ Non-Contagious Illness   ☐ Injury   ☐ Symptom

    b) How would you rate the **seriousness** of this condition?
    ☐ Low   ☐ Moderate   ☐ High

    c) How would you rate the **frequency** of this condition in youths (5 to 16 years)?
    ☐ Low   ☐ Moderate   ☐ High

38. <u>Loss of Appetite</u>

    a) How would you best **classify** this condition?
    ☐ Contagious Illness   ☐ Non-Contagious Illness   ☐ Injury   ☐ Symptom

    b) How would you rate the **seriousness** of this condition?
    ☐ Low   ☐ Moderate   ☐ High

    c) How would you rate the **frequency** of this condition in youths (5 to 16 years)?
    ☐ Low   ☐ Moderate   ☐ High

39. <u>Nose Bleed</u>

    a) How would you best **classify** this condition?
    ☐ Contagious Illness   ☐ Non-Contagious Illness   ☐ Injury   ☐ Symptom

    b) How would you rate the **seriousness** of this condition?
    ☐ Low   ☐ Moderate   ☐ High

    c) How would you rate the **frequency** of this condition in youths (5 to 16 years)?
    ☐ Low   ☐ Moderate   ☐ High

APPENDIX C

QUESTIONNAIRE FOR CAREGIVERS

<u>Instructions:</u>

Please answer the following questions about the types of illnesses you believe your child knows about and understands. Please fill out a separate questionnaire for each of your children between the ages of 5 and 21 years of age.

<u>Demographic Questions:</u>

1. Are you over the age of 18?   Yes   No

2. Can you read, write, and speak in English?   Yes   No

3. Please fill out the age and sex of the child you are completing the questionnaire for:

    Child: Age: ___   Sex: Male   Female

Illness Knowledge Question:

4. Please indicate if you think your child would know **about and understand what the following conditions are:**

a) Allergies	☐ Yes	☐ No	m) Common Cold	☐ Yes	☐ No
b) Asthma	☐ Yes	☐ No	n) Concussion	☐ Yes	☐ No
c) Leukemia	☐ Yes	☐ No	o) Pink Eye	☐ Yes	☐ No
d) Bladder Infection	☐ Yes	☐ No	p) Respiratory Flu	☐ Yes	☐ No
e) Meningitis	☐ Yes	☐ No	q) Sore Throat	☐ Yes	☐ No
f) Broken Limb	☐ Yes	☐ No	r) Ear Infection	☐ Yes	☐ No
g) Bronchitis	☐ Yes	☐ No	s) Strep Throat	☐ Yes	☐ No
h) Skin Rash	☐ Yes	☐ No	t) Psoriasis	☐ Yes	☐ No
i) Stroke	☐ Yes	☐ No	u) Toothache	☐ Yes	☐ No
j) Heart attack	☐ Yes	☐ No	v) Headache	☐ Yes	☐ No
k) Chicken Pox	☐ Yes	☐ No	w) Mono	☐ Yes	☐ No
l) Kidney Infection	☐ Yes	☐ No	x) Cancer	☐ Yes	☐ No

APPENDIX D

CHILD ILLNESS QUESTIONNAIRE FOR PARENTS

For reasons of confidentiality, please do not include your child's name or your family name anywhere on this questionnaire.

The following questions are about your child and family's health and experience with illness and injury as well as the nature of your child's health care visits (e.g., to doctor, hospital, etc.). We would like to gather this information so that we can describe the general health background and illness experiences of families and children taking part in this study.

Since it is sometimes difficult to remember details about events that happened in your family a long time ago, some people find it helpful to answer all the questions they can initially, and then look back at them at a later date to see if they remember anything new.

Since family illness is very personal, you do not have to answer any questions or provide any details that you feel uncomfortable sharing. Please note, however, that all of your answers will be confidential.

Questionnaire completed by:

◻ Mother   ◻ Father   ◻ Other:_____

Please answer the following questions about your child that is taking part in this study

Child Illness Experience

1. How would you rate your child's physical health overall in the past **12 MONTHS**?

◻   1 Excellent   ◻   2 Very Good   ◻   3 Good   ◻   4 Fair   ◻   5 Poor

2. In general, how would you rate your child's physical health over his/her **LIFETIME**?

◻   1 Excellent   ◻   2 Very Good   ◻   3 Good   ◻   4 Fair   ◻   5 Poor

3. In the space below, please list any illnesses or injuries that your child has experienced in the last **12 MONTHS**. Please also record the severity of the condition by checking either the Mild, Moderate, or Severe box.

If the same illness/injury occurred more than once in the 12 month period, please list each occurrence separately. If you do not know the name of the condition, or are unsure, please just describe the symptoms.

a) Name of condition:_____   ☐ Mild   ☐ Moderate   ☐ Severe

b) Name of condition:_____   ☐ Mild   ☐ Moderate   ☐ Severe

c) Name of condition:_____   ☐ Mild   ☐ Moderate   ☐ Severe

d) Name of condition:_____   ☐ Mild   ☐ Moderate   ☐ Severe

e) Name of condition:_____   ☐ Mild   ☐ Moderate   ☐ Severe

f) Name of condition:_____   ☐ Mild   ☐ Moderate   ☐ Severe

g) Name of condition:_____   ☐ Mild   ☐ Moderate   ☐ Severe

h) Name of condition:_____   ☐ Mild   ☐ Moderate   ☐ Severe

4. Please list any illnesses or injuries that anyone who is currently living in your home (including yourself, but not including the child participating in the study) has experienced in the last **12 MONTHS**. Please also record the family member who experienced the condition by checking the appropriate box below.

If the same illness/injury occurred more than once in the 12 month period, please list each occurrence separately. If you do not know the name of the condition, or are unsure, please just describe the symptoms.

a) Name of condition:_____   ☐ Parent   ☐ Child   ☐ Other

b) Name of condition:_____   ☐ Parent   ☐ Child   ☐ Other

c) Name of condition:_____   ☐ Parent   ☐ Child   ☐ Other

d) Name of condition:_____   ☐ Parent   ☐ Child   ☐ Other

e) Name of condition:_____   ☐ Parent   ☐ Child   ☐ Other

f) Name of condition:_____   ☐ Parent   ☐ Child   ☐ Other

g) Name of condition:_____   ☐ Parent   ☐ Child   ☐ Other

h) Name of condition:_____   ☐ Parent   ☐ Child   ☐ Other

5. Please list any illnesses or injuries, including those resulting in death or life-threatening in nature, that have occurred in your extended family throughout your child's life (even if you have listed them above) that you think might have influenced the way your child views or feels about illness. Do not include conditions that have happened to your child directly.

   Please also record the family member who experienced the condition by checking the appropriate box below.

   a) Name of condition:_____   Family member:_____

   b) Name of condition:_____   Family member:_____

   c) Name of condition:_____   Family member:_____

   d) Name of condition:_____   Family member:_____

   e) Name of condition:_____   Family member:_____

   f) Name of condition:_____   Family member:_____

   g) Name of condition:_____   Family member:_____

   h) Name of condition:_____   Family member:_____

Healthcare Usage

6. How many times has your child seen a doctor or other health care professional about his/her health in the last 12 MONTHS?

   _____ Time(s)

7. How many times has your child been to the hospital emergency room about his/her health in the last **12 MONTHS**?

   _____ Time(s)

8. Has your child **EVER** had surgery?

   ☐ YES   ☐ NO (finish)

9. In the space(s) below, please provide the reason for each surgery as well as his/her age at the time.

   a) Surgery details _____   Age _____

   b) Surgery details _____   Age _____

ILLNESS KNOWLEDGE: SEMI-STRUCTURED INTERVIEW WITH YOUTH

<u>Materials</u>

☑ Audio Recorder   ☑ Pen / Pencil   ☑ Multiple Choice Scale

<u>Instructions</u>

With the participant sitting at a table across from you say: **I am going to ask you some questions about health and illness. I will be voice recording your responses because sometimes I can't write fast enough to keep up with everything you will say. I will listen to the recording later so I can write down anything I missed.**

Do you have any questions before we begin?

Turn the audio recorder on. Say the ID of the participant and the activity. For example, say participant ID 1008, illness knowledge interview with youth, START.

> At the end of every open-ended question youths should be asked if they have any additional information to provide. This prompt could be any of the following: "Anything else?", "Any other ideas?", "Does anything else come to mind when you think about [restate question]?" Mark a (p) on the answer sheet where you provided a prompt.

<u>General Knowledge Questions</u>

1. All people get sick once in a while. How do people know when they are sick?

_____

_____

_____

2. How do people get sick?

_____

_____

_____

3. How can people try to keep/stop themselves from getting sick?

_____

_____

_____

4. When people are sick, how do they get better again?

_____

_____

_____

Expressive Knowledge Questions

5. a) What is a cold?

_____

_____

_____

   b) How do people get colds?

_____

_____

_____

6. a) What is a concussion?

_____

_____

_____

   b) How do people get concussions?

_____

_____

_____

7. a) What is meningitis?

_____

_____

_____

   b) How do people get meningitis?

_____

_____

_____

I am now going to ask you to tell me what sickness someone might have if they experience the following things (can use "symptoms" with older participants).

If the participant provides the WRONG response, does not provide a spontaneous response, or says "I don't know" to any of the questions, present the laminated multiple choice options. Read the multiple-choice options to the participant and ask him/her to choose the condition that best fits the symptoms. Record the multiple-choice answer in the space below each question.

* The asterisk indicates the correct answer

8. **What could be wrong with someone if they have a red itchy spots all over their body?** (chicken pox)

    Answer given: _____

    a) Correct answer given? ☐ YES   ☐ NO (go to part b)

    b) Multiple choice answer:

A ☐	B ☐	C ☐	D ☐
Ringworm	Chicken Pox*	Lice	Malaria

9. **What could be wrong with someone if they feel like they always have to go pee, and have intense pain when they do pee?** (bladder/kidney infection/UTI)

    Answer given: _____

    a) Correct answer given? ☐ YES   ☐ NO (go to part b)

    b) Multiple choice answer:

A ☐	B ☐	C ☐	D ☐
Food Poisoning	Upset Stomach	Celiac Disease	Bladder Infection*

10. What could be wrong with someone if their face or arm becomes numb, and they feel dizzy and have trouble speaking? (stroke)

Answer given: _____

a) Correct answer given?   ☐ YES   ☐ NO (go to part b)

b) Multiple choice answer:

A ☐   B ☐   C ☐   D ☐
Heart Attack   Strep Throat   Stroke*   Epilepsy

Before you turn off the recorder, Say the ID of the participant and that the activity has ended. For example, say participant ID 1008, illness knowledge interview with youth, FINISH.

ILLNESS VIGNETTE STIMULI

Injury: Scrape
"This is you. Your knee is cut and bleeding. This is because you have a scrape."

Illness: Cold
"This is you. You have a runny nose, a sore throat, and sneeze a lot. This is because you have a cold."
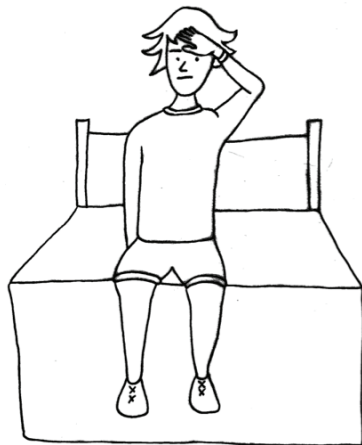
Symptom: Fever
"This is you. You feel warm and sweaty, but sometimes you also feel cold. This is because you have a fever."

Illness: Strep Throat
"This is you. You have a very sore throat and swollen neck glands. This is because you have strep throat."

Injury: Concussion

"This is you. You have hit your head very hard and you feel dizzy. This is because you have a concussion, which is a serious head injury."

Illness: Pink Eye

"This is you. You have sore, red eyes that have discharge in them. This is because you have pink eye, which is a contagious eye infection."

Illness: Asthma Attack

"This is you. You are coughing and wheezing, and having trouble breathing. This is because you are having an asthma attack."

Symptom: Rash

"This is you. You have red, itchy bumps on your body. This is because you have a rash."

Illness: Stomach Flu

"This is you. You have stomach cramps, a fever, and are vomiting. This is because you have a stomach flu"

Illness: Kidney Infection

"This is you. You have a sore lower back and a fever. It also hurts when you pee. This is because you have a kidney infection. The kidneys are responsible for producing your pee."

Symptom: Cough up Blood

"This is you. You have just coughed up blood."

Injury: Burn

"This is you. You have blistered, sore, red skin. This is because you have burned yourself."

Inter-correlations Between Illness Communication and Behaviour Content Areas for Parent-Reports on the Illness Vignettes

Content Area	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16
Direct																
(1) Report	--	**.40**	.02	-	**-.54**	**-.53**	-	.24	.18	-	**.41**	**.52**	**-.71**	.23	-	-
(2) Show	**.45**	--	.38	-	.10	-.16	-	.11	.27	**-**	.38	.17	-.13	.02	-	-
(3) Assistance	.09	.00	--	-	.10	-.13	-	.04	.30	-	.25	.20	-.26	.02	-	-
Indirect																
(4) Complaints	-	-	-	--	-	-	-	-	-	-	-	-	-	-	-	-
(5) Emotional	-.04	.13	.21	-	--	**.46**	-	-.17	-.39	-	-.31	-.30	**.54**	.26	-	**-**
Disengaged																
(6) Signaling	**-.56**	**-.52**	-.08	-	-.33	--	-	-.09	-.09	-	-.04	-.31	**.76**	.11	-	-
(7) Unaware	-	-	-	-	-	-	--	-	-	-	-	-	-	-	-	-
Active: General																
(8) Information	.06	.01	.11	-	.22	-.32	-	--	-.17	-	.16	-.19	-.19	**.40**	-	-
(9) Help	.16	.16	.39	-	.12	-.14	-	-.10	--	-	.25	**.51**	-.16	-.21	-	-
(10) Support	-	-	-	-	-	-	-	-	-	--	-	-	-	**-**	-	-
Active: Specific																
(11) Rest	-.07	-.35	-.19	-	**-.53**	.36	-	-.12	-.04	-	--	.16	-.19	.01	-	-
(12) Intervention	.06	.12	.03	-	-.02	-.02	-	.18	**.48**	-	.38	--	**-.51**	-.23	-	-
Passive																
(13) Externalize	-.10	-.05	.06	**-**	**.56**	-.05	-	-.03	-.23	-	**-.54**	-.37	--	-.00	-	-
(14) Internalize	.05	.16	.33	-	**.76**	-.21	**-**	.25	.25	-	-.29	.23	**.46**	--	-	-
(15) Self-isolate	-	-	-	-	-	-	-	-	-	-	-	-	-	-	--	-
(16) Passive Inattention	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	--

Note. These are Spearman correlation coefficients for variables within the ASD and control groups. The data for these variables are given in Tables 13 and 15. Those in boldface are significant at *p* < .05. Frequency counts for the control group are above diagonal, and frequency counts for the ASD group are below the diagonal. "-" single dashes denote variables with frequency counts of less than 2 (behaviour reported on less that 17 percent of vignettes) across both ASD and control pairs that were not included in analyses.