



Research article

Illness representations among adolescents with attention deficit hyperactivity disorder: associations with quality of life, coping, and treatment adherence



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ABSTRACT

Research into the causes and outcomes of attention deficit hyperactivity disorder (ADHD) has been extensive, yet little is known about the perception of ADHD as a disorder and its related outcomes among diagnosed youth. The present study applied the Common-Sense Model of Illness Representations (CSM) to examine the perception of ADHD and its association with quality of life (QoL), coping strategies, and treatment adherence among 63 diagnosed adolescents (10–18 years). Adolescents recruited from clinics, parent support groups, and an educational service completed self-report measures of the key constructs. Results indicated that adolescents generally perceive their ADHD as mildly threatening; four illness beliefs (perceived impact, personal control, timeline, and coherence) are significant predictors of coping and four (perceived impact, causes, personal control, and treatment control) are that of QoL. Adolescents who perceived minimal impact, expected longer duration, had strong sense of coherence, and believed in personal control of ADHD coped with the disorder more actively. Those who made weaker attribution to psychological and environmental causes, believed in personal control and the effectiveness of behavioral treatment enjoyed better QoL. In addition, female adolescents seem to experience more difficulties in the management of ADHD than male counterparts. These findings have potentially important clinical implications, suggesting that perceptions of ADHD related to the disorder's impact, duration, coherence, and personal control, may be important for clinicians to address when caring for adolescents with the disorder.

1. Introduction

Attention-deficit hyperactivity disorder (ADHD) is a developmental disorder characterized by developmentally inappropriate levels of hyperactivity, impulsivity and inattention [1]. It is the most common childhood behavioral disorder, affecting 3%–7% of school-aged children [1, 2]. Although it is one of the most studied developmental disorders, little is known about how diagnosed children and adolescents perceive ADHD. Since research into the perception of a range of physical/mental illnesses have shown that illness beliefs are related to a number of health-related outcomes, it is surprising to see the dearth of such research in this population.

According to the Common-Sense Model of Illness Representations (CSM; also known as the Self-Regulation Model), patients' perception of their illness has important implications for their health-related outcomes [3, 4]. The model proposes that when one encounters a health threat (e.g., symptoms and diagnosis), one actively forms common-sense beliefs

about their illnesses and symptoms in order to understand and cope with the threat. The common-sense beliefs include parallel, yet interrelated, cognitive and emotional representations of the illness [3, 4]. Specifically, the CSM identifies at least five core dimensions of the cognitive representations of the illness. These dimensions are: (1) *identity*, or how the illness and its symptoms are identified and labeled; (2) *cause*, or the perceived reasons why an illness develops; (3) *timeline*, or the ideas about how long it will last; (4) *consequences*, or the emotional or functional effects on life; and (5) *control/cure*, or the extent to which a patient believes how controllable an illness is by the treatment and by themselves. Later research [9] has added two additional dimensions: (6) *emotional representations*, which comprise emotional responses towards the illness, and (7) *coherence*, or how much individuals believe they understand their illness.

Studies that have applied the CSM among adolescents with physical illnesses have demonstrated the relationships between patients' illness beliefs and the health-related outcomes. For instance, Tiggelman et al.

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[5] found that weaker sense of coherence and greater perceived impact of asthma among diagnosed adolescents were associated with greater emotional problems (i.e., anxiety, depression, stress). This study also found that greater confidence in the effectiveness of treatment is associated with less emotional problems over time. Gray and Rutter [6] found that adolescents who perceived the timeline of their chronic fatigue syndrome as acute were more likely to cope with the illness actively and those who have a strong emotional response to the illness were more likely to experience poorer quality of life. Among 126 adolescents with diabetes, Edgar and Skinner [7] found that greater perceived impact of the illness was associated with more depressive symptomatology and anxiety. Despite the emerging evidence for the utility of CSM in adolescents with physical illness, no studies have examined the utility of this framework among adolescents with mental illnesses or developmental disorders.

To our knowledge, there is only one empirical study that applied the CSM among youth diagnosed with ADHD. Among adolescents (13–17 years) who were on a long-term prescription of ADHD medication for at least 6 months, Emilsson et al. [8] reported that participants' expectation of a long course of ADHD was positively correlated with medication non-adherence; perceptions of having little understanding of ADHD and being moderately affected by ADHD were related to reduced adherence to medication; and a stronger faith in medication benefits was associated with better adherence. These findings suggest the potential utility of CSM in understanding and improving the health-related outcomes among youth with ADHD. That being said, the only outcome explored was treatment adherence [8]. Therefore, the present study aimed to extend the scope to investigate the relationship between illness beliefs and quality of life (QoL) as well as coping strategies, in addition to treatment adherence.

Although research on the subjective experience of ADHD among diagnosed children and/or adolescents has begun to emerge, existing evidence has been limited in various ways. First, most of this work constitutes of qualitative studies, in which small sample sizes greatly diminish the generalizability of the findings [e.g., 9, 10, 11]. Second, most previous studies lacked a theoretical foundation and are limited in scope as they focused on only one or two facets (cognition or affect) of the perception of ADHD. For instance, many of these studies have examined youth's experience with medication rather than their overall perception of ADHD as a disorder. In a systematic review of literature through the lens of CSM, we observed that disproportionate amount of attention has been paid to the perceived effectiveness of medication compared with, for example, other illness beliefs that predict treatment adherence [e.g., timeline, coherence: 8], revealing limitations of the current narrow-focused research [12]. More importantly, the vast majority of the literature did not examine the potential impact of youth's perception of the disorder. Even among the few that did investigate the related impact, the qualitative design of the studies hinders the establishment of a clear relationship between the variables. Therefore, the present study initiates an exploration to address these limitations through theory-driven collection of quantitative data from adolescents diagnosed with ADHD.

The aim of the present study was to derive preliminary data for the following research questions.

1. What illness beliefs do adolescents hold about their ADHD on the CSM framework?
2. Are adolescents' perception of ADHD associated with their QoL, coping strategies, and treatment adherence? If yes, how are they related to each other?

2. Method

2.1. Participants

Sixty-three adolescents (10–18 years) were recruited from a private clinic ($n = 4$), ADHD support groups for parents ($n = 6$) and an

educational consultancy ($n = 53$) that provides coaching service for children and adolescents with ADHD in Sydney, between June and December 2016. Adolescents were eligible to participate if they: 1) received a diagnosis of ADHD from a physician or a mental health professional for at least six months; 2) were between 10 to 18 years-old; and 3) did not have a moderate-severe sensory impairment that would interfere with their ability to fill in the questionnaire. Among the participants, there were two pairs of siblings. To address analytic issues that arise from the lack of independence in those cases, the ratings of siblings from the same family were averaged, resulting in a mean score representing each pair of them as a single observation. Of the 99 parents approached about the study, 77% provided consent to their children's participation and all but one of their offspring agreed to participate. More than half of the participants were diagnosed with predominantly inattentive subtype (61.9%), followed by combined type (20.6%), and predominantly hyperactive-impulsive subtype (10.9%). A large majority of them (90.5%) were taking medications for ADHD. The sample consisted of a relatively affluent group with more than half reporting household income above AUD\$140,000. See Table 1 for the participants' characteristics.

2.2. Procedure

The researcher approached the parents in the respective clinic, ADHD support groups, and educational service, to invite them to participate in a

Table 1
Adolescent participants' characteristics (N = 63).

	Mean	SD
Age of adolescents	14.28	2.07
Duration of ADHD diagnosis (in years)	4.99	3.10
Severity of ADHD (parents' ratings on CGI-P)	15.98	6.78
	n	%
Gender of adolescents (male)	50	79.3
Number of adolescents who are born in Australia	60	95.2
Ancestry*		
Oceanian	41	65.1
North-west European	39	61.9
Southern & Eastern European	11	17.5
North-African and Middle Eastern	6	9.5
People of the Americas	3	4.8
Sub-Saharan African	2	3.2
Southern and Central Asian	1	1.6
Type of ADHD diagnosed		
Predominantly inattentive	39	61.9
Combined	13	20.6
Predominantly hyperactive-impulsive	12	19.0
Don't know	2	3.2
Sources of diagnosis of ADHD*		
Pediatrician	47	74.6
Psychologist	19	30.2
School staff	18	28.6
Psychiatrist	7	11.1
Family practitioner	5	7.9
Neurologist	5	7.9
Social worker	1	1.6
Types of current treatments for ADHD*		
Medication	57	90.5
Individual counseling/therapy	52	82.5
Behavioral treatment	29	46.0
Nutritional modification	8	12.7
Others	6	9.5
Presence of other diagnoses apart from ADHD		
Yes	31	49.2
No	35	55.6
The diagnoses among the adolescents with comorbidity*		
Anxiety disorder	17	27.0
Depression	10	15.9
Oppositional defiant disorder	8	12.7
Autism spectrum disorder	7	11.1

Note. *Participants can choose more than one options.

study investigating thoughts and feelings about ADHD. The study was approved by the Human Research Ethics Committee of the University of Sydney (Project no: 2016/173). Written informed consent was obtained from the parents of all participants. All adolescents in the study have also assented to participate. After getting parents' consent and checking the adolescent's eligibility and willingness to participate in the study, adolescents could choose to fill in the questionnaire at the site or online. The researcher explained to the parents that their offspring had to fill in the questionnaire alone so as to ensure that their responses were not affected by parents' presence. The adolescents could choose to fill in the questionnaire on their own or have the questions read out to them by the researcher. Even if the adolescent participant chose to complete the survey on his/her own, the researcher would stay with him/her until completion. In the case of online participation, a Skype meeting would be arranged with the help of parents and the questionnaires were sent to the adolescent via Skype or email. The parents also completed similar measures (which will be discussed in a subsequent paper).

2.3. Measures

The adolescents' questionnaire included the measures of their perception of ADHD, coping strategy in relation to ADHD, and QoL. The questionnaire was clear and easy to follow with a readability level of 2.6 grades and has been reviewed by an experienced pediatrician specializing in adolescents' health. Moreover, since the pediatrician recommended that the length of the questionnaire should take into account participants' difficulty in concentration, one of the instruments (i.e., the measure of coping) was shortened for this purpose.

2.3.1. Perception of ADHD

The *Brief ADHD Perception Questionnaire* [13] was developed to measure adolescents' perception of ADHD, using the participants in the current sample. Sample items included "How much does your ADHD affect your life?" and "How long do you think your ADHD will continue?". The 18-item measure is based on the *Brief Illness Perception Questionnaire* [Brief IPQ; 14], which is a 9-item questionnaire designed to rapidly assess the cognitive and emotional representations of illness. Substantial modifications targeted two of the dimensions: *Cause* and *Treatment Control*.

To assess perceived causation, the measure was changed from open-ended questions to a set of questions gauging seven etiological beliefs of ADHD on a 5-point scale (1 = not an important cause, 5 = important cause). The reasons for this change were to enable easier completion for participants and feasible comparisons between ratings of adolescents and parents. Sample items included "I have ADHD because of my genes" and "I have ADHD because I am not trying hard enough". The seven causes included in the measures were chosen according to the findings from qualitative studies that examined perceived causes among children and adolescents with ADHD [15, 16, 17]. The causes included genes, the different way their brain works, their parents' parenting practice, learning from friends, the difficulty of schoolwork, insufficient efforts, and God making them this way. In addition, an extra question was created to gauge their perception of the relative importance of nature and nurture causes. The question was, "Overall, which group of causes do you think is the most important for your ADHD? In general, there are two groups of causes. One group is related to the genes and brain processes (Option A); another group is related to the things that happen in life (for example, the way your parents raised you or learning from friends- Option B). Which group of causes do you think is more important? Or do you think both groups are equally important (Option C)?" Participants chose one of these three options.

To tailor the measure of perception of treatment control to ADHD, another modification was introduced. Two questions were created to measure perceived effectiveness of medication and behavioral treatment separately (replacing the single item that measured overall perceived treatment control).

Minor linguistic adjustments were made to the original Brief IPQ questions in order to improve the readability for the young participants. For example, the word "symptoms" was replaced with "problems"; "concerned" was replaced with "worried"; and "emotions" was replaced with "feelings". To reflect to the context of the research study, the word "illness" was replaced with "ADHD". Furthermore, to ensure the questionnaire is age-appropriate for the youth in the current study, the rating scale was reduced from 10 points of the Brief IPQ, to five points, with terms attached to each of the five rating options. The content and wording of items were reviewed by experts with extensive experience in the clinical care of children and adolescents with ADHD. The internal consistency of the scale in the current study was quite low ($\alpha = .61$), but this is to be expected due to the heterogeneity of the items and the breadth of the measure. A similar emphasis on the breadth over internal consistency is found elsewhere [e.g., 18, 19, 20].

2.3.2. Coping

A revised version of the *Coping with a Disease* [CODI; 21] was used to assess adolescents' coping with ADHD. The CODI was developed to measure the coping of children and adolescents with chronic physical health conditions. The original version of CODI consists of 28 items that represented six coping strategies. A revised version adapted for the purpose of the current study consisted of 18 items, in which the three items that had the highest factor loadings on each coping strategy were kept, based on the results of the pilot test of the questionnaire in children and adolescents (aged between eight to 18 years) with chronic physical health conditions [21]. Another modification replaced the term "illness" with "ADHD" to adapt to the context of this study.

The instructions to adolescents were "Think of the situations when you have been upset or stressed because of your ADHD. Please tell us how often you usually do the things or have this kind of thoughts related to your ADHD". The six coping strategies were "Avoidance" (e.g., "I try to ignore my ADHD"), "Cognitive-Palliative" (e.g., "I pray that my ADHD will go away"), "Emotional Reaction" (e.g., "I am angry about my ADHD"), "Acceptance" (e.g., "I have got used to my ADHD"), "Wishful Thinking" (e.g., "I want to stop having ADHD"), and "Distance" (e.g., "I don't care about my ADHD"). Adolescents indicated their rating on 5-point scales (1 = never; 5 = always). A higher score on a scale represents more frequent usage of the coping strategy.

The internal consistency of the subscales in this study ranged from unacceptable to good, i.e., Cognitive-Palliative $\alpha = .33$, Avoidance $\alpha = .55$, Distance $\alpha = .65$, Acceptance $\alpha = .79$, Emotional Reaction $\alpha = .79$, Wishful thinking $\alpha = .80$. Since an alpha of over 0.6 is considered acceptable [22, 23], only the four scales with $\alpha \geq .60$ were included in the data analysis, in order to avoid interpretation issues.

2.3.3. Quality of Life (QoL)

The *Pediatric Quality of Life Inventory – General Wellbeing Scale* [PedsQL; 24] was used to measure adolescents' QoL. The instrument was designed to assess health-related QoL in healthy and ill children and adolescents aged between eight to 25 years. It is composed of six questions on their perception of general well-being and one question on their perception of their general health. Participants indicated their ratings on a 5-point scale (0 = never; 4 = almost always). Higher scores indicate better QoL. The internal consistency of this instrument in the current study was excellent ($\alpha = .90$).

2.3.4. Treatment adherence

Two items were created to measure adherence to medications and behavioral treatments respectively. Parents indicated their rating on the questions "How much do you think your child has followed the (medication/behavioral) treatment?" on 7-point scales (1 = did not follow at all; 7 = followed completely).

2.3.5. Severity of ADHD

The *Conner's Global Index – Parent Version* [CGI-P; 25] was used to

measure the severity of ADHD symptomatology. The CGI-P is a widely used rating scale to assess symptoms of ADHD and other psychopathology in children between three and 17 years of age. Parents completed the 10-item questionnaire using 4-point scales (0 = being not at all true; 3 = being very much true). The scale had good internal consistency ($\alpha = .86$) in this study.

2.4. Statistical analysis

The data were entered and analysed using SPSS version 22 for Macintosh, with significance levels set at 0.05. Since this study has a small sample size and limited power, all analyses were conducted for exploratory purposes.

To examine the predictive value of perceptions of ADHD for coping, QoL, and treatment adherence, a series of hierarchical regressions were conducted. In each regression model, illness beliefs were entered as predictor variables in the first block and covariates were entered in the second block. In each model, the coping strategies, QoL, and adherence to treatments were used as the outcome variables. The covariates included in the analyses were age, gender, and severity of ADHD. These covariates were included based on research showing that children and adolescents' age and gender influence their perceptions of mental and physical illnesses (including ADHD) [17, 26, 27], and that the severity of illnesses influences patients' illness perception [e.g., 28].

The regression analyses of perception of ADHD predicting the outcome variables were divided into two parts. The first part involved the analyses of perceived causes in predicting the outcome variables. Only the causes that were significant predictors of the outcome variables in these initial assessments were included in the second section. In the second part, the illness beliefs were entered in the first block, the (only previously significant) perceived causes were entered in the second block, followed by covariates in the third block. The analyses were separated into these two parts because the original version of the Brief IPQ did not have a quantitative measure of the perception of causes [14]. Conducting the analysis of causes first and including only those causes that are significant predictors in the analysis of all illness beliefs would thus allow a more refined understanding of the unique predictive ability of the illness beliefs.

3. Results

3.1. Adolescents' perception of ADHD

Table 2 presents the descriptive information of adolescents' ratings on Brief ADHD Perception Questionnaire. Participants' ratings on this measure were normally distributed, except their ratings on non-biological causes. Inspection of the histograms showed that most adolescents gave the lowest ratings on the non-biological causes, suggesting that the majority perceived them as not important causes of ADHD. Moreover, inspection of the box-plots showed that there were outliers in the ratings on psychological and environmental causes (i.e., parents' parenting practice, learning from friends, and schoolwork being too hard), suggesting that a few strongly endorsed these factors. These outliers were not removed from the data analyses because such diverse belief in the psychological and environmental causes of ADHD is consistent with a previous review [12].

3.2. Correlates of adolescents' perception of ADHD

Pearson's correlations show that there were significant associations between different constructs of the illness representations (see Table 3). For instance, adolescents' perception of severe consequences of ADHD was associated with a longer expected duration, greater symptoms, higher level of worry, and stronger emotional responses to ADHD. Moreover, greater belief in personal control was correlated with fewer perceived symptoms and reduced emotional responses to the disorder.

Table 2
Descriptive statistics for adolescents' perceptions of ADHD.

Items on Brief IPQ	Rating scales	Scores
		Mean (SD)
Consequence	1 = does not affect at all, 5 = affects my life a lot	3.20 (.96)
Timeline	1 = a very short time, 5 = forever	3.52 (.88)
Personal control	1 = absolutely no control, 5 = I have all the control	2.84 (.93)
Medications control	1 = not at all, 5 = very helpful	3.74 (1.14)
Behavioral therapy control	1 = not at all, 5 = very helpful	3.07 (1.15)
Identity	1 = no symptoms at all, 5 = many serious symptoms	3.30 (.88)
Concern	1 = not at all worried, 5 = very worried	2.32 (1.17)
Coherence	1 = don't understand at all, 5 = understand very clearly	3.50 (1.01)
Emotional representations	1 = not at all affected, 5 = affected a lot	3.47 (1.13)
Cause	1 = not an important cause, 5 = a very important cause	
Parenting		1.31 (.67)
Genes		3.49 (1.26)
Brain abnormality		3.77 (1.30)
Learning from friends		1.13 (.50)
Schoolwork was too hard		1.32 (.67)
Insufficient efforts		1.46 (.87)
God made me (him/her) this way		2.17 (.87)
Overall perception of causes		n(%)
Genes and brain processes		56 (91.8)
Things that happened in life		1 (1.6)
Same importance		4 (6.6)

Several illness beliefs were associated with adolescents' etiological beliefs. For instance, greater perceived consequences of ADHD were associated with stronger beliefs in genes and brain abnormality. A longer expected duration of ADHD and stronger emotional responses to the disorder were correlated with stronger attribution to God's plan. Moreover, more perceived symptoms were associated with stronger attribution to brain abnormality. Many of adolescents' illness beliefs of ADHD were significantly correlated with outcome variables. For instance, better QoL was associated with less perceived consequences of ADHD, fewer perceived symptoms, stronger coherence of the disorder, and less emotional responses to ADHD. Greater utilization of "Acceptance" coping was associated with greater perceived personal control, fewer perceived symptoms, greater sense of coherence, and less emotional response to the disorder. Furthermore, having less faith in their personal control and stronger emotional responses to the disorder were associated with better adherence to behavioral treatment.

3.3. Creating compound variables

Since the correlation analyses showed that there were substantial associations among the constructs of illness representations and among the outcome variables, several compound variables were created. The first compound variable involves four illness beliefs. The perception of consequence had substantial positive correlations (r 's > .40) with identity, concern, and emotional responses, thus they were combined to form a variable to reflect a subjective evaluation of the impact of ADHD. The internal consistency of these four items was good ($\alpha = .72$). The second compound variable comprised four etiological beliefs. As the beliefs in insufficient efforts had moderate positive correlations (r 's > .20) with causes of parenting, learning from friends and schoolwork was too hard, they were combined to reflect their beliefs in the psychological and environmental causes of ADHD ($\alpha = .60$). Lastly, the four coping strategies were reduced to two. Since "Acceptance" and "Distance" copings

were strongly correlated with each other ($r = .47, p < .001$), they were combined to reflect a coping pattern of minimizing the disorder - believing oneself was managing the disorder well yet perceiving little problems and showing little care about ADHD ($\alpha = .70$). As “Emotional-Reaction” and “Wishful Thinking” were also strongly correlated ($r = .58, p < .001$), they were combined to reflect a coping pattern that included experiencing strong emotions to having ADHD (e.g., feeling frustrated, angry, ashamed) and wanting to stop having the disorder ($\alpha = .74$).

3.4. Relationship between individuals' characteristics and perception of ADHD

Pearson's correlations show that an increase in age was related to greater perceived impact of ADHD ($r = .26, p = .042$), stronger attribution to genes ($r = .30, p = .021$), and weaker attribution to God's plan ($r_s = -.27, p = .038$). Gender differences were observed on only one illness belief: male participants perceived less impact of ADHD than female participants ($M_{diff} = -.64, t(57) = -2.88, p = .006, d = .90$). A higher household income was correlated with shorter expected duration of ADHD and a stronger endorsement of the cause of brain abnormality ($r_s = .35, p = .01$).

Longer duration of ADHD diagnosis was associated with reduced faith in behavioral treatments ($r = -.27, p = .038$). More severe ADHD symptoms were associated with perceiving reduced personal control. Adolescents with comorbid disorders had a greater sense of understanding of ADHD than those without comorbidity ($M_{diff} = .52, t(61) = 2.94, p = .005, d = .54$). Adolescents whose parents were diagnosed with ADHD attributed ADHD to genes more than those whose parents were not diagnosed with the disorder ($M_{diff} = .99, t(59) = 2.24, p = .029, d = .90$). Lastly, adolescents who were taking medication, perceived higher effectiveness of medication ($M_{diff} = -1.37, t(59) = -2.99, p = .004, d = 1.41$) than those who were not taking medication.

3.5. Relationships between perception of ADHD and QoL

Table 4 presents the results of regression analyses in which etiological beliefs served as predictors of various outcome variables and Table 5 presents the results of illness beliefs serving as the predictors (with only the significant etiological beliefs from the first analysis included). First, results indicate that adolescents' etiological beliefs of ADHD (and relevant covariates) significantly predicted QoL, $R^2 = .347, F(6,52) = 4.61, p = .001$. However, only covariates and weaker belief in the psychological and environmental causes were significant predictor of better QoL (physiological causes did not amount to significance). Second, participants' illness beliefs about ADHD (and their belief in psychological and environmental causes entered in the second step) significantly predicted their QoL, explaining 49.7% of variance; two illness beliefs (reduced perceived impact and weaker belief in the psychological and environmental causes) were significant predictors of better quality of life in this model. However, once an outlier¹ was removed, the analysis produced quite different results (see Table 5 for a comparison). Adolescents' illness beliefs still significantly predicted QoL, explaining 60.3% of variance. Four significant variables, three illness beliefs (weaker belief in the psychological and environmental causes, greater perceived control, and higher perceived effectiveness of behavioral treatment) and one covariate (having a less severe ADHD) predicted better QoL.

3.6. Relationships between perception of ADHD and coping

Adolescents' etiological beliefs significantly predicted their minimization of the disorder, $R^2 = .401, F(6,52) = 5.80, p < .001$. Only weaker belief in the psychological and environmental causes was a significant predictor of this coping. Adolescents' illness beliefs significantly

predicted their minimization of ADHD, explaining 63.0% of variance. In the full model, longer perceived duration of ADHD, greater perceived personal control, a stronger sense of coherence, reduced perceived impact, and being a male adolescent were significant predictors of this coping.

Adolescents' perception of causes did not significantly predict their use of “Reactive-Wishful” coping, $R^2 = .184, F(6,52) = 1.95, p = .090$. However, their illness beliefs significantly predicted their “Reactive-Wishful” coping, explaining 31.1% of variance. Two illness beliefs (a weaker sense of coherence and greater perceived impact) were significant predictors of this coping.

3.7. Relationships between perception of ADHD and treatment adherence

Adolescents' etiological beliefs did not significantly predict adherence to medication, $R^2 = .042, F(6,46) = .34, p = .913$. Likewise, their illness beliefs about ADHD did not significantly predict such adherence to medication,² $R^2 = .129, F(9,43) = .71, p = .697$. The analysis of the relationship between their perception of ADHD and adherence to behavioral treatments was not performed because less than half of the participants (46%) were receiving such treatments.

4. Discussion

The current exploratory study presents the perception of ADHD among diagnosed youth using the CSM framework. It provides a deeper understanding of the relationships between illness representations, QoL, coping, and treatment adherence, among them. Overall, a number of our findings are novel and/or fall out of step with the research conducted among people with mental/physical illnesses. Thus, this study demonstrates the unique role of perception of ADHD in relation to the health-related outcomes among diagnosed adolescents that are distinctive from the perception of other types of illnesses/disorders.

4.1. Adolescents' perception of ADHD and its correlates

The adolescents in the present study generally perceive their ADHD as mildly threatening. They think the disorder have a moderate level of impact on their lives, will last for a medium-term, and have a moderate impact on their emotions. They think they have a moderate amount of symptoms of ADHD, an average sense of coherence of the disorder, and they believe they have relatively little control over it. Most of them attribute ADHD to biological causes, however, a few of them strongly believe in psychological and environmental causes. They also believe medications and behavioural treatment have modest effectiveness.

Our data indicate that adolescents' perception of ADHD is associated with a number of factors – their experience with medication, the presence of comorbidity, and parental ADHD. Their medication status is related to their faith in the treatment effectiveness. Specifically, adolescents who are taking medication rate it as more effective than those who are not. Moreover, the presence of comorbidity is related to their sense understanding of ADHD. Adolescents who have comorbid disorder(s) have a more coherent understanding of the disorder than those who have ADHD alone. Additionally, the presence of ADHD in parents is linked with adolescents' etiological beliefs. Those whose parents are diagnosed with ADHD are more likely to endorse biological causes of the disorder than those whose parents are not diagnosed. Lastly, our study replicated previous findings that older adolescents are more likely to attribute ADHD to genes than younger ones, yet all favoured a biological explanation [e.g., 15,17].

² The removal of an outlier ($N = 1$) that had Studentized Deleted Residuals of < -4.0 produced similar results in the model predicting the adherence to medication, $R^2 = .276, F(9,42) = 1.78, p = .101$.

¹ One participant had Studentized Deleted Residuals < -4.0 .

4.2. Relationships between perception of ADHD, QoL, and coping

Adolescents' illness beliefs about ADHD were significantly associated with their QoL and coping strategies, thus supporting key assumptions of CSM [3, 4]. Specifically, four illness beliefs (perceived timeline, impact, personal control, coherence) are significant determinants of coping and four (perceived impact, causes, personal control, and treatment control) are predictors of QoL. In particular, it should be noted that adolescents' illness beliefs explained large portions of variance of their QoL and active coping. The specific role of each illness belief is discussed below.

4.3. Subjective evaluation of impact of ADHD

The present study has found that perception of impact of ADHD is associated with QoL. Adolescents who perceive reduced impact of ADHD experience better QoL (before removing an outlier), in line with previous findings among youth with ADHD [29] and people with mental illnesses [e.g., 30] indicating that perception of greater consequences and symptoms are related to greater depressive and anxious symptoms.

Surprisingly, adolescents who perceive greater impact cope with ADHD more passively ("Reactive-Wishful" coping is considered a passive coping as it involves wishful thinking patterns³). Likewise, those who perceive minimal impact cope with the disorder more actively. These findings are inconsistent with research in people with mental illnesses that showed that greater perceived consequences are associated with more effortful attempts to cope [33]. Such discrepancy may be explained as the prediction was deduced from a zero-order correlation [33], whereas the present finding controlled for additional variables. That said, the conflicting findings might imply that perceived impact plays a different role in youth with ADHD and mood disorders. We postulate that minimal perceived impact may be viewed as more controllable among adolescents with ADHD, as perceived impact and personal control were negatively correlated with each other in the current study. Having stronger faith in personal control may thus foster more active coping.

4.4. Personal control

Having faith in personal control seems to be beneficial to not only adolescents' management of the disorder, but also their experience of QoL. Adolescents who perceive having greater personal control over the ADHD symptoms seem to cope with the disorder more actively and enjoy better QoL, in line with the findings among people with mental illnesses [34, 35, 36].

Unfortunately, as adolescents in this sample perceived a moderate extent of impact and limited personal control, these two perceptions appear to be undermining coping and QoL. The present findings suggest a possibility that to improve coping and QoL among youth with ADHD, these two illness beliefs might be possible targets for intervention. For instance, clinicians may help adolescents perceive less impact and strengthen their belief in their personal control by providing some cognitive-behavioral interventions. Having said that, the finding on the relationship between perceived control and QoL has to be interpreted with great caution because the perception of personal control was a significant predictor only after an outlier was removed from the analysis.

4.5. Coherence

Our data are the first to demonstrate that sense of understanding of

³ According to the literature on coping with chronic illnesses in children and adolescents, acceptance and cognitive restructuring include a factor related to accommodative or secondary control coping, which represents coping efforts to adapt to stress; wishful thinking includes a factor that reflects passive, avoidant, or disengagement coping, which represents a cognitive avoidance of the source of stress [31, 32].

ADHD is related to coping strategies. Interestingly, adolescents who have a stronger sense of coherence of ADHD are more likely to adapt to the stress of having the disorder. In contrast, those who have little coherent understanding of the disorder are more likely to disengage. These findings support Emilsson et al. [8] who found that lower coherence was associated with reduced treatment adherence. Taken together, these findings seem highlight the importance of coherence among youth with ADHD, which has received sparse research attention to date.

Since most existing psycho-education efforts tend to focus on educating parents [e.g., 37,38], the current study underscore the importance of psycho-education for the diagnosed adolescents, as coherent understanding of the disorder go together with better coping and treatment adherence. It implies that future psycho-education given to adolescents should not solely focus on the objective knowledge of ADHD, but also on strengthening their appraisal of their understanding of the disorder.

4.6. Cause

Surprisingly, our study failed to find evidence supporting that etiological beliefs are related to coping strategies. Accounting for relevant variables, perceived causes did not predict such strategies, suggesting that etiological beliefs' role in coping may not be as central as some of the literature may suggest. That said, stronger belief in biological causes was correlated with longer perceived course of ADHD, indicating that endorsing genes and brain abnormalities as important causes is related to being pessimistic on the course of the disorder. These findings are in line with the theories of and findings on prognostic pessimism in health psychology [e.g., 39, 40, 41, 42].

Focusing on less common etiologies, beliefs in psychological and environmental causes seem to be related to experience of QoL. Specifically, adolescents who attribute less importance to psychological and environmental causes enjoy better QoL. Although most participants in the current study did not strongly endorse these causes, a minority of them seem to have particularly strong beliefs in these causes. Our findings thus suggest clinicians might need to be cognizant of the etiological beliefs of ADHD among some adolescents and their potential detrimental associations with inferior QoL.

4.7. Timeline

Longer perceived duration seems to be associated with active rather than passive coping; a surprising finding to theories and findings in prognostic pessimism literature [e.g., 39, 40, 42]. This finding suggests that being pessimistic about the prognosis of ADHD does not seem to be detrimental to coping in this instance. Those who expected a long duration of ADHD seem to be more adapt to the stress of having the disorder instead of disengaging; a tendency that was more common among those who perceived a shorter course.

Importantly, such discrepant findings between the present study and previous research on elements related to prognostic pessimism imply that pessimistic expectation are multifaceted and may play a different role in youth with developmental disorder than individuals with mental and physical illnesses. Longer perceived duration may hold hidden coping benefits among adolescents with ADHD whereas it seems detrimental among people with mental and physical illnesses. Further evidence supporting the distinctive role of long perceived course in ADHD is that it was not related to lower QoL in the adolescents in this sample, unlike the case of people with psychosis [43, 44, 45]. Since ADHD is a chronic disorder that well over a half of the diagnosed adolescents continue to struggle with into adulthood [46, 47, 48], these findings seem to suggest that adolescents who perceive the duration of ADHD more realistically are more likely to cope with the disorder actively.

Table 3
Correlation analysis of adolescents' illness representations.

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	
1. Consequence																							
2. Timeline	.28*																						
3. Personal con.	-.14	.10																					
4. Med. control	-.11	-.08	.19																				
5. Beha. control	.13	-.05	-.05	.23																			
6. Identity	.47**	.17	-.40**	-.20	.04																		
7. Concern	.38**	.15	-.03	-.09	-.11	.32*																	
8. Coherence	.07	.10	.13	.06	.10	-.10	-.06																
9. Emo. Rep.	.39**	.11	-.30*	-.04	-.11	.34**	.46**	-.26*															
10. Parenting	-.11	.09	.14	-.04	-.20	.10	.14	-.18	.05														
11. Genes	.37**	.26*	-.09	.06	-.03	.18	.03	-.07	.06	-.10													
12. Brain	.31*	.02	-.11	.06	.21	.36**	.20	-.17	.25	-.11	.12												
13. Learning	.16	-.02	-.00	-.09	-.14	.12	.11	-.24	.25*	.30*	.05	.19											
14. Schoolwork	-.11	.02	.24	.04	.02	-.10	-.08	-.31*	-.03	.10	-.19	-.04	.27*										
15. Efforts	-.18	-.04	.10	-.26*	.05	-.09	.05	-.10	.07	.39**	-.12	-.11	.36**	.24									
16. God	-.08	.29*	-.04	-.21	-.02	-.02	.01	-.11	.37**	.16	-.02	.07	.17	.09	.09								
17. QoL	-.26*	-.19	.25	.21	.21	-.38**	-.40**	.35**	-.32*	-.25	.04	-.00	-.26*	-.07	-.31*	-.00							
18. Acceptance	-.15	.06	.49**	.23	-.02	-.35**	-.34**	.56**	-.47**	-.21	.02	-.16	-.22	-.17	-.25	-.21	.56**						
19. Distance	-.09	.23	.32*	.02	.14	-.31*	-.26*	.33*	-.18	.06	.01	-.31*	-.10	-.20	.13	-.02	.24	.53**					
20. Emo. Reac.	.10	.16	.00	-.06	-.05	.41**	.56**	-.35**	.39**	.17	.03	.36**	.14	.24	.13	.15	-.30*	-.51**	-.38**				
21. Wish. Think.	-.03	-.08	.01	.05	-.03	.20	.33**	-.25*	.14	.13	.13	.13	.11	.19	.27*	.02	-.21	-.28*	-.19	.59**			
22. Ad. to med.	-.01	-.33*	-.11	.18	.05	.04	-.07	-.08	-.03	-.17	-.09	.06	-.18	-.03	-.19	-.16	.05	-.03	-.18	.06	.02		
23. Ad to beha.	.17	-.06	-.40*	-.02	-.19	.11	.20	-.24	.48**	.10	-.07	.02	-.10	.06	.06	-.04	-.05	-.42*	-.47*	.18	-.05	.49*	

Note. Personal con. is personal control; Med. control is medication control.
Beha. control is Behavioural therapy control; Emo. Rep. is emotional representations.
Emo. Reac. is "Emotion-Reaction" coping; Wish. Think. Is "Wishful-Thinking" coping.
Ad. to med. is adherence to medication; Ad to beha. is adherence to behavioural therapy; QoL is quality of life.
*Correlation is significant at the 0.05 level (2-tailed), **. Correlation is significant at the 0.01 level (2-tailed).

7

4.8. Treatment control

The present study demonstrates that adolescents' faith in treatment effectiveness is related to their QoL. Adolescents who have greater faith in behavioral treatment seem to enjoy better QoL, which has not been reported previously. Given that previous studies [e.g., 16, 39] have suggested that youth with ADHD show mixed feelings about medications (i.e., acknowledging their effectiveness yet are apprehensive of their side effects), stronger faith in a non-pharmacological treatment may be viewed as beneficial to their QoL. That being said, this finding has to be interpreted with caution as this belief was a significant predictor only after removal of an outlier.

4.9. Gender differences

Male adolescents in this sample perceived less impact of ADHD, engaged in more active coping, and enjoyed better QoL than their female counterparts. These findings suggest that female adolescents with ADHD might experience more difficulties in their management of the disorder than their male counterparts, and their perception of ADHD may hence deserve more attention. Such findings can be potentially explained by societal overt or tacit acceptance of impulsivity and hyperactivity of boys [49].

4.10. Relationships between perception of ADHD and treatment adherence

Surprisingly, we did not find evidence in support of any of the predictions related to treatment adherence, which is inconsistent with previous findings among adolescents with ADHD [8] and people with mental illnesses [e.g., 33,45]. Such discrepancies may be due to the different measures of treatment adherence. In Emilsson et al.'s study, adolescents self-reported their treatment adherence on a 5-item measure, whereas a single item, a parent-report measure, was used in the current study. Another possible explanation is that most of the controlled for additional pertinent variables, whereas the previous studies did not. Acknowledging these inconsistencies, future research using a more sensitive measure of treatment adherence is required before drawing a strong conclusion.

4.11. Limitations

The findings of the present study have to be interpreted in the context of a number of limitations. First, the present study had a small sample size and limited power, diminishing the ability to identify weak effects. The limited power may have also contributed to failing to find corroborating evidence to some of the previous research. Second, there was no independent sample validating the newly developed Brief ADHD Perception

Table 4
Hierarchical regression of adolescents' perceived causes of ADHD predicting their coping and QoL.

	Minimization (R ² = .401**) ¹			Quality of Life (R ² = .347**) ¹		
	β	ΔR ²	Δp	β	ΔR ²	Δp
<i>Step 1</i>		.17	.014*	.18	.012*	
Genes	-.02			-.05		
Brain	-.26*			.02		
Psy. & env. causes	-.32*			-.43**		
<i>Step 2</i>		.23	.001*	.17	.008*	
Genes	.07			.08		
Brain	-.20			.13		
Psy. & env. causes	-.27*			-.42**		
Age	-.04			-.27*		
Gender	-.29*			-.26*		
Severity	-.39**			-.29*		

Note. Psy. & env. causes is psychological and environmental causes.

*p < 0.05, **p < 0.01.

¹ Indicates the final model variance explained.

Table 5
Hierarchical regression of adolescents' perception of ADHD predicting their coping and quality of life.

Predictor	"Reactive-Wishful" Coping			Quality of Life (With an outlier)			Quality of Life (Without an outlier)		
	Step 1 (R ² = .293**)²	Step 2 (R ² = .311**)²	Step 3 (R ² = .630**)²	Step 1 (R ² = .361**)²	Step 2 (R ² = .474**)²	Step 3 (R ² = .497**)²	Step 1 (R ² = .388**)²	Step 2 (R ² = .532**)²	Step 3 (R ² = .603**)²
Timeline									
Personal control	.17	.25*	.25*	-.12	-.17	-.15	-.13	-.20	-.16
Medicine control	.35**	.25*	.11	.13	.21	.18	.19	.29*	.25*
Beha. ther. control	-.00	.04	.06	-.07	.01	.06	.10	-.04	.11
Coherence	.06	.10	-.06	.16	.16	.16	.20	.20*	.22*
Impact of ADHD	.39‡	.27*	-.32*	.28*	.13	.08	.22	.05	-.09
Psy. & env. causes	-.32**	-.29*	.50**	-.35**	-.32**	-.25**	-.34**	-.30**	-.18
Age	-.19*	-.13	-.	-.	-.38**	-.39**	-.43‡	-.43‡	-.47‡
Gender	.10	-.15	-.10	-.15	-.09	-.09	-.17	-.17	-.22
Severity of ADHD	-.23*	-.00	-.10	-.13	-.13	-.13	-.22	-.22	-.24*
	-.21	-.21	-.21	-.10	-.10	-.10	-.24*	-.24*	-.24*

Note. Beha. ther. is behavioral therapy.
Psy. & env. causes is psychological and environmental causes.
² Indicates the final model variance explained.
*p < 0.05, **p < 0.01, ‡p < 0.10.

Questionnaire, which may limit the validity of the current findings. Third, the low reliability of the compound variables (e.g., beliefs in the psychological and environmental causes of ADHD) may also limit the validity of adolescents' perception of ADHD presented in the current study. Fourth, the cross-sectional design of the present study prohibits the examination of the causal relationships between perceptions and the outcomes. A longitudinal study is required to provide greater insight into how perception of ADHD may change as age, the duration of diagnosis, and the duration of treatment grow and the causal links those shifts bring about in coping and QoL. Lastly, the majority of participants in the present study were recruited from an educational consultancy; future research that involves more youth from clinics/hospitals is needed to examine whether there are differences in the perception of ADHD between recipients of different treatments.

4.12. Conclusions

The present study demonstrated that a number of illness beliefs of ADHD among diagnosed adolescents are related to important outcomes. Two illness beliefs that were found to be of particular relevance to coping are perceived impact and sense of coherence. Reduced perceived impact and greater coherence seem to be associated with active coping, whereas greater perceived impact and weaker coherence seem to be associated with passive coping. Moreover, two other illness beliefs, stronger faith in personal control and longer expected duration of ADHD, also seem to go together with active coping. Weaker attribution to psychological and environmental causes seems to be beneficial to ADHD-diagnosed youth's QoL. Other illness beliefs, such as stronger faith in behavioral treatment and personal control, may also be beneficial to their QoL. Taken together, these findings indicate the potential utility of CSM in understanding coping and QoL among diagnosed adolescents. Furthermore, the findings suggest that female adolescents diagnosed with ADHD might in need of more attention and assistance in their management of the disorder.

Declarations

Author contribution statement

I.Y.T Wong: Conceived and designed the experiments; Performed the experiments; Analyzed and interpreted the data; Contributed reagents, materials, analysis tools or data; Wrote the paper.

I. Dar-Nimrod: Conceived and designed the experiments; Analyzed and interpreted the data; Contributed reagents, materials, analysis tools or data; Wrote the paper.

D.J Hawes: Conceived and designed the experiments; Wrote the paper.

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Competing interest statement

The authors declare no conflict of interest.

Additional information

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