The Self-Awareness of Adolescents with FASD: A Secondary Analysis Study

by

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Abstract

Fetal Alcohol Spectrum Disorder (FASD) describes a range of cognitive, behavioural, and social difficulties that can occur due to prenatal alcohol exposure. It is estimated that 1% to 4% of Canadians are affected by FASD. Individuals with FASD frequently demonstrate difficulties in their executive functions (EF), which are high-level cognitive processes required in goal-directed behaviours, such as working memory, inhibition, and attention shifting. EF is related to self-regulation, which is the ability to regulate their thoughts, feelings, and behaviours. Individuals with FASD frequently demonstrate difficulties related to self-regulation, which may be a hallmark of the disorder. An important first step in the regulatory process is taking note of one's internal states to regulate one's behaviours, referred to as self-awareness. To date, no researchers explored the self-awareness of individuals with FASD. This study explored the self-awareness of 27 adolescents with FASD who had completed a clinical intervention study. Difference scores were calculated to compare adolescent self-ratings of their internal arousal states with similar ratings from the interventionists trained to evaluate participants' arousal states. Repeated measures ANOVAs of the difference scores were not statistically significant. There was a significant interaction effect between participants' sex and difference scores ($F(2,36) = 6.171$, $p=0.05$). Correlations between participants' and interventionists' ratings were significant at all time points ($p=0.01$). These findings indicate that the online awareness of adolescents with FASD was consistent. Further study is needed to explore individuals' online awareness within FASD populations and examine whether online awareness is a potential area of strength for adolescents with FASD.

Preface

This thesis is an original work by Vannesa Joly. The research project, of which this thesis is a part, received research ethics approval from the University of Alberta Research Ethics Board, No. Pro00064830, October 23, 2017.

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Introduction

Fetal alcohol spectrum disorder (FASD) is a neurodevelopmental disorder that occurs in individuals who were exposed to alcohol prenatally. Individuals with FASD experience a range of physical, cognitive, and psychological difficulties, and often require individualized support throughout their lives as a result (Gill & Thompson-Hodgetts, 2018). To improve the intervention outcomes and day to day functioning of individuals with FASD, we must first understand their unique abilities and needs.

The prevalence of FASD has been difficult to accurately establish due to the stigma associated, a lack of knowledge of FASD, and variations in the presentation of physical and cognitive symptoms (Boseck et al., 2015). Regardless, several estimates place the rate of FASD between 1% to 4% of the population in North America (Nash et al., 2015; Popova et al., 2016; Soh et al., 2015). Canadian researchers have recently estimated rates of FASD to range from approximately 2% to 3% of the overall population, while some "…*high-risk communities*…" have rates of FASD as high as one in five births (Brenna et al., 2018, pp 219; Popova et al., 2018). It is essential to note that FASD impacts individuals and their families from all socioeconomic and ethnic backgrounds (Popova et al., 2016). The cost of caring for each Canadian child with FASD is estimated to be as much as one million dollars (Popova et al., 2011). FASD is one of the most common identifiable causes of developmental delays in school-age children (Williams et al., 2015).

Individuals with FASD form a diverse population with many areas of strength and difficulty and are often unique in their presentation of and experiences related to FASD (Popova et al., 2016). Common characteristics frequently associated with FASD include hyperactivity,

difficulties with attention, impulsive behaviours, and deficits related to intellectual abilities, social cognition, and executive functions (Gill & Hodgetts, 2018). Executive functions (EF), in particular, are a marked area of impairment in children and adolescents with FASD that likely persists throughout the lifespan (Best & Miller, 2010; Soh et al., 2015). EF are interrelated, higher-level cognitive processes that direct behaviours related to goal attainment, such as working memory, inhibition, and organization (Best & Miller, 2010; Hofmann et al., 2012). The practical application of EF requires robust regulatory control, referred to as self-regulation (Blair, 2016).

Difficulties related to self-regulation are also a prominent issue experienced by individuals with FASD (Gill & Thompson-Hodgetts, 2018), including challenges maintaining focus, controlling impulses, and regulating emotions (Soh et al., 2015). Researchers have noted that the difficulties with regulation experienced by individuals with FASD increase with age, which may be reflected by a growing gap in self-regulation abilities throughout adolescence (Khoury et al., 2015). Targeted interventions improve the self-regulation of children with FASD (Nash et al., 2015; Soh et al., 2015), although more research is needed to determine the effects of such interventions for adolescents with FASD (Skorka et al., 2020). One of the first steps in initiating self-regulation is taking note of and identifying our cognitive and emotional states (Jain et al., 2013; Morin, 2011). This process, known as self-awareness, has not been carefully examined within individuals with FASD. Gaining knowledge about adolescents with FASD's self-awareness will help inform the emerging evidence regarding the use of intervention to target these domains within adolescents with FASD (Paley & O'Connor, 2011; Skorka et al., 2020). This knowledge will also provide information that may inform the continual improvement of such interventions for this population (Gill & Thompson-Hodgetts, 2018).

Cognitive Processes Involved in Regulatory Control

Regulatory behaviours are influenced by multiple cognitive processes, including self-awareness, self-regulation, and EF (Hofmann et al., 2012). EF, self-regulation, and self-awareness combine and interact to influence behaviours; self-awareness influences self-regulation, which impacts consistent access to executive functions and ultimately leads to regulatory behaviours (Blair, 2016; Hofmann et al., 2012; Verhoeven et al., 2013). This study explored the self-awareness of adolescents with FASD to understand these EF domains better, believing that we may contribute to improved regulatory control for individuals with FASD. The following review presents EF, self-regulation, and self-awareness within a mental hierarchy that contributes to regulatory control.

Executive Functions

Executive functions (EF) is a term used to describe a wide range of high-level mental processes related to goal-oriented behaviours across cognitive, emotional, and social domains (Hutchison, 2011). EF has been described as cognitive functions that can facilitate a person's self-regulation and self-control abilities (Blair, 2016). As such, they are necessary for day-to-day functioning, academic performance, and socially appropriate behaviours (Kingdon et al., 2016). There is an emerging consensus among researchers regarding the organization of the domains included within the umbrella of EF (Kingdon et al., 2016).

Several researchers have proposed a "unity and diversity" approach to EF to describe the domains included in EF as distinct yet interrelated (Best & Miller, 2010; Blair, 2016). Researchers agree that EF includes impulse control, emotion processing, working memory, mental flexibility, and problem-solving strategies (Blair, 2016; Nash et al., 2015). Others have also proposed the inclusion of inhibitory control, or the ability to activate specific information,

inhibit non-optimal information, and cognitive flexibility, which can shift one's focus, as components of executive functions (Blair, 2016). These EF domains work in concert, rely on similar brain mechanisms, and are described as distinct yet correlated aspects of EF (Best & Miller, 2010; Blair, 2016). From a developmental perspective, the degree to which the EF domains are related or independent likely fluctuates throughout the lifespan, with children and adolescents demonstrating swift changes in different domains at specific stages (Best & Miller, 2010). The successful application of EF is related to active self-regulation abilities (Soh et al., 2015).

Self-Regulation

Generally, self-regulation is the ability to regulate one's thoughts, feelings, and behaviours to behave per environmental demands (MacCobb et al., 2014; Williams & Shellenberger, 1996). Self-regulation can be defined by the context in which it is being explored (Martini et al., 2016). Since self-regulation has been explored in various settings, including clinical, educational, and psychological contexts, many definitions exist (Martini et al., 2016). For example, in school settings, self-regulation refers to the ability to maintain attention to complete learning tasks (MacCobb et al., 2014; Martini et al., 2016). In social psychology, self-regulation describes the ability to infer information from one's physical environment (MacCobb et al., 2014; Martini et al., 2016). Self-regulation is often used interchangeably with terms such as self-control or behavioural regulation (Gill & Thompson-Hodgetts, 2018). Several researchers have also used self-regulation findings to extrapolate EF findings (e.g., Soh et al., 2015). These inconsistencies sometimes create difficulties in interprofessional understanding of how self-regulation is constructed and thus targeted through intervention (Gill & Thompson-Hodgetts,

2018). Regardless, researchers observe self-regulation through many domains, including physiological, attentional, emotional, behavioural, and cognitive (Reid et al., 2019).

The substantial amount of research exploring self-regulation across various settings and populations indicates its perceived importance. Gill and Thompson-Hodgetts (2018) reviewed existing literature regarding self-regulation and individuals with FASD and noted five defining attributes most consistently identified for self-dysregulation. These include impulsivity, defined as conceding to the impulse to seek immediate gratification; lack of inhibition, which includes overriding automatic behaviours to instead engage in goal-directed behaviour; distractibility; hyperactivity; and emotional dysregulation (Gill & Thompson-Hodgetts, 2018). The definition of self-regulation used in the current study will be in keeping of that used by the creators of the Alert Program®. Self-regulation is the ability to maintain focus, control impulses, and regulate one's behaviours and emotions to respond appropriately to the environment (Williams & Shellenberger, 1996).

Integrating EF and Self-Regulation

There are several different approaches to studying EF and self-regulation (Hofmann et al., 2012). EF has been studied as an outcome, as a predictor, as outcome and predictor, as the mediator, or as the moderator related to self-regulation (Hofmann et al., 2012). A bidirectional developmental model of executive functions exists that views the relationship between executive functions and self-regulation as reciprocal (Blair, 2016). The bidirectional model states that high-level EF occurs due to self-regulation, while executive functions also facilitate self-regulation (Blair, 2016). EF direct attention and organize problem-solving strategies such that they play a role in facilitating self-regulation. Given the reciprocal nature of executive functions and self-

regulation, the inverse of that is also true; for executive functions to be carried out effectively, its related domains are also reliant on effective self-regulation (Blair, 2016).

In this way, executive functions and self-regulation abilities exist within an adaptive feedback loop that occurs in response to environmental cues (Blair, 2016). The development of adolescents' self-regulation results from its relationship with executive functions based on their lived experiences (Blair, 2016). In short, executive functions interact with an individual's arousal level and previous experiences to guide behaviours (Blair, 2016).

The bidirectional nature of EF and self-regulation may be due to the brain regions that underlie EF reciprocally interacting with brain regions responsible for self-regulation (Blair, 2016; Heatherton & Wagner, 2011). The brain region primarily involved in executive functions is the prefrontal cortex (Blair, 2016; Soh et al., 2015). Similarly, brain regions believed to be involved in self-regulation include the subcortical frontal cortex, the frontal-striatal network, the right cingulate gyrus, and areas related to the limbic systems (Blair, 2016; Soh et al., 2015). Individuals who are aware of their inner emotional states and behaviours are more likely to reflect and report on instances of dysregulation (Gill & Thompson-Hodgetts, 2018). Thus, self-regulation is related to self-awareness.

Self-Awareness

Self-awareness is a cognitive process that involves identifying, processing, and storing information about the self (Morin, 2011). Self-awareness is developed over time through various social experiences and environments (Duval & Wicklund, 1972). Self-awareness is commonly thought to be an essential first step in regulatory control and adjusting our behaviours (Verhoeven et al., 2012). Self-awareness triggers a realization that a change in behaviours may be needed. (Verhoeven et al., 2012). Since it is a complex process, self-awareness is impacted by

the involvement of multiple facets of awareness and relationships to other cognitive processes, including EF (Morin, 2011; Demetriou & Bakracevic, 2008). Thus, there are discrepancies in the definitions of and measures used to examine self-awareness across contexts (Morin, 2011). The discrepancies are reflected by the use of many different terms combined with the term self-awareness to specify further or define it, such as objective, primary, conscious, automatic, and peripheral (Billon, 2016; Duval & Wicklund, 1972; Heotis, 2018; Morin, 2011). The variety of applications for self-awareness and its apparent pertinence across fields is indicative of its relevance in day-to-day functioning (Deya & Julius, 2014). These variations have resulted in somewhat mixed findings on the effectiveness of self-awareness in interventions and on therapeutic outcomes when self-awareness has been assessed across various settings using different methods (Robertson & Schmitter-Edgecombe, 2015). Despite some inconsistencies within the existing literature, researchers continue to investigate self-awareness and its role in intervention.

Many theories exist that attempt to explain the complex and multi-dimensional nature of self-awareness. One such theory is a multi-dimensional self-awareness model, the Pyramid Model (Crosson et al., 1989). This model includes three interdependent hierarchical levels, beginning with anticipatory awareness, followed by emergent awareness in the middle, and intellectual awareness at the base (Robertson & Schmitter-Edgecombe, 2015). This model's hierarchical nature requires that intellectual and emergent awareness are prerequisites to anticipatory awareness. Anticipatory awareness is the knowledge that a deficit is likely to cause a problem or delay on specific tasks before engaging in them (Robertson & Schmitter-Edgecombe, 2015). Developing an awareness of personal strengths and deficits may be essential for individuals to build on their strengths and circumvent challenges (Burnside & Fuchs, 2013).

O'Keefe and colleagues (2007) conducted a study of individuals with traumatic brain injury and found that they demonstrated impaired anticipatory awareness compared with the control group.

A separate model of multi-dimensional self-awareness that does not use a hierarchical structure is the Dynamic Comprehensive Model of Awareness (DCMA), which focuses on the relationships between metacognition and awareness (Robertson & Schmitter-Edgecombe, 2015). DCMA distinguishes between online and offline awareness. Online awareness exists before completing a task, while offline awareness, also known as metacognitive awareness, only exists during and immediately after completing a task (Robertson & Schmitte-Edgecombe, 2015). Online awareness is further separated into two interacting components: the task's conceptualization and appraisal and the altering of beliefs or perceptions about a task following its completion. This latter aspect of online awareness is self-monitoring, which includes error-monitoring or the ability to recognize errors, and self-regulation, which is the ability to adjust performance based on task requirements (Robertson & Schmitte-Edgecombe, 2015). Per DCMA, self-regulation is closely linked to self-monitoring, and the interplay of this relationship has implications for interventions targeting each of these constructs (Robertson & Schmitte-Edgecombe, 2015).

In adolescence, self-awareness describes adolescents' knowledge of their physical, emotional, and cognitive states (Hoerold et al., 2008; John et al., 2017). Self-awareness is an essential process that involves "*...reconciling multiple conceptions of the self...*" (Deya & Julius, 2014, pp 1091). This definition is relatively simple given that self-awareness has been explored across multiple research contexts, including fields related to philosophy, medicine, and psychology, and often has a unique meaning in each (e.g., John et al., 2017; Billon, 2016; Lewis

& Wahesh, 2012; Morin, 2011; Hoerold et al., 2008). As Billon (2016, pp 732) stated, “[t]here are many ways to be aware of oneself.”

Just as there are several models describing self-awareness, there are also various methods and measures designed to induce and capture it (Morin, 2011). These include mirrors, voice recordings, audiences' presence, and self-report measures that researchers have used to direct attention inwards (Morin, 2011). According to Hoerold and colleagues (2008), one of the most common methods of assessing self-awareness across the literature is to compare the difference between questionnaire responses obtained from study participants and those from a clinician or a caregiver. This difference measure can capture information about participant perceptions of a particular behaviour or deficit, which, when compared with another's, allows for identification of their self-awareness (Hoerold et al., 2008).

Toglia and colleagues (2010) used this method to evaluate four adults' self-awareness with traumatic brain injury before and following the completion of an intervention targeting their self-regulation and awareness. These researchers used the Awareness Questionnaire to capture participant's self-awareness, with one form completed by the participant and another by a clinician familiar with the participant (Toglia et al., 2010). Toglia and colleagues (2010) calculated a difference score between participants' and clinicians' ratings to ascertain whether the participant over- or under-estimated their functioning level. No meaningful overall trend was evident, although specific individuals demonstrated greater awareness as indicated through their difference scores (Toglia et al., 2010). The individual differences noted between participants suggest that self-awareness abilities are multifaceted. These authors also stated that explicit instruction could support self-awareness in individuals with cognitive deficits (Toglia et al., 2010).

In another self-awareness study, researchers used self-report questionnaires to compare individuals with traumatic brain injuries with age-matched controls. Individuals with traumatic brain injuries who accurately evaluated their performance or the difficulty of a task demonstrated an increase in the number of strategies used to complete said task (Robertson & Schmitter-Edgecombe, 2015). Specifically, Robertson and Schmitter-Edgecombe (2015) compared the error-monitoring of individuals with a moderate to severe traumatic brain injury compared with an age-matched control group. Robertson and Schmitter-Edgecombe (2015) reported that participants with a traumatic brain injury demonstrated significantly lower levels of error monitoring at baseline and follow-up than the control group.

Within an intervention context, higher self-awareness levels are associated with motivation, participation, and better functional outcomes (Toglia et al., 2010; Verhoeven et al., 2012). These findings demonstrate the need for self-awareness to be targeted within intervention settings to support functional outcomes and successful engagement within interventions (Demetriou & Bakracevic, 2008; Toglia et al., 2010). Researchers and clinicians who would like to encourage participants' engagement in interventions and help participants achieve the intervention's functional outcomes should also target their self-awareness.

Fetal Alcohol Spectrum Disorder (FASD)

Individuals exposed to alcohol prenatally can experience a broad spectrum of cognitive, behavioural, and social difficulties. In particular, EF problems and self-regulation have been tied to adverse outcomes for adolescents with FASD (Kingdon et al., 2016; Paley & O'Connor, 2011). These outcomes have been well documented and can include disrupted school experiences, difficulties maintaining employment and housing, involvement in the criminal justice system, and increased risk of drug abuse (Gill & Thompson-Hodgetts, 2018; Nash et al.,

2015; Paley & O'Connor, 2011; Soh et al., 2015). That said, adolescence can also be a period of opportunity. Adolescence, defined by the World Health Organization as people aged 10 to 19 years, is a time of rapid biological, social, and cognitive development that can impact lifelong habits (Jain et al., 2013). Adolescence is a critical period to provide interventions and support, particularly for individuals with FASD (Coriale et al., 2013; Jain et al., 2013; Paley & O'Connor, 2011).

With appropriate support and interventions, individuals with FASD can and do experience long-term positive outcomes (Brown et al., 2017). Interventions targeting EF have demonstrated improvements in individuals with FASD to regulate their emotions that can otherwise result in rapid shifts in mood (Nash et al., 2015). Without such appropriate interventions, individuals with FASD can experience impulsive and sometimes aggressive behaviours (Coriale et al., 2013). Improving the EF of individuals with FASD can curtail some of the adverse life outcomes associated with FASD (Gill & Thompson-Hodgetts, 2018; Nash et al., 2015; Paley & O'Connor, 2011; Soh et al., 2015).

Executive Functions in FASD

Researchers have described the deficits in EF demonstrated by individuals with FASD as a hallmark of the disorder (Green et al., 2009; Nash et al., 2015); Soh and colleagues (2015) remarked that the severity of impairments to executive functions demonstrated by individuals with FASD are "…*most striking*…" (pp 2). The specific aspects of executive functions most impacted by FASD are beginning to be identified by researchers (Kingdon et al., 2016; Soh et al., 2015). Examining the impacts of FASD on EF has been difficult due to methodological challenges that arise when testing EF with different age groups, the number of domains that comprise executive functions, and individual variation within FASD populations (Best & Miller,

2010; Khoury et al., 2015). Developing an understanding of the impacts of FASD on the EF of individuals with FASD is essential for diagnostic and treatment purposes (Rasmussen et al., 2007). Thus, researchers continue to explore specific domains within executive functions better to understand the interactions between executive functions and FASD.

Several researchers have found deficits in the EF of children with FASD compared with other children their age. In their review of behavioural and neuropsychological effects of FASD, Coriale and colleagues (2020) noted areas of EF that are impacted for individuals with FASD include problem-solving, abstract thinking, automatic behaviour inhibition, and working memory domains of executive functions. These findings are in keeping with Rasmussen and colleagues (2007) findings, who examined parents' ratings on the Behaviour Rating Inventory of Executive Function (BRIEF). Rasmussen and colleagues (2007) found that children with FASD displayed "profound deficits" in their executive functions as rated by their parents across all BRIEF scales. Moreover, even compared to children with other neurodevelopmental disorders, children with FASD still demonstrated more severe deficits in the BRIEF (Rasmussen et al., 2007). In another study, Green and colleagues (2009) found that children with FASD demonstrated deficits related to attention, planning, strategy use, and working memory when completing four computerized neuropsychological tasks. These researchers have described particular difficulties with EF domains related to attention, inhibition, and memory experienced by children with FASD. These domains were described by Best & Miller (2010) as foundational aspects of EF.

Khoury and colleagues (2015) further examined these EF domains through a review of 46 existing studies comparing children and adolescents with FASD to their same-age peers without FASD across domains related to executive functions. Khoury and colleagues (2015) examined working memory, which is the ability to monitor, apply, and update incoming information;

response inhibition, defined as the ability to deliberately inhibit automatic responses; set-shifting, which refers to switching back and forth between tasks (Khoury et al., 2015). Khoury and colleagues (2015) found medium effect sizes of inhibitory control and working memory and a large effect size for set-shifting of children and adolescents with FASD, with the difference in effect size between set-shifting and inhibitory control approaching significance. Khoury and colleagues (2015) noted that this difference might be due to task complexity since tasks requiring set-shifting frequently rely on more EF.

Green and colleagues (2009) evaluated the reaction time, decision making latencies, and problem-solving in children between the ages of eight to 15. Green and colleagues (2009) found that children with FASD demonstrated longer reaction times, fewer problems solved, and increased errors made compared with the control group. These authors noted that individuals with FASD demonstrated similar difficulties related to executive functions as individuals with frontal lobe lesions, including tasks that depend on the frontal lobe, such as difficulties with complex adaptive behaviours that require the integration of multiple domains (Green et al., 2009). Fryer and colleagues (2007) noted reduced functioning in the frontal-striatal network of the frontal cortex in children with FASD, which impacts executive functions, and smaller orbitofrontal regions, which are implicated in impulse control. Together these studies highlight the effects of FASD on EF, particularly as they relate to attention, inhibition, and memory. These abilities can be hindered by how individuals can control their thoughts, feelings, and behaviours, referred to as self-regulation (Blair, 2016).

Self-Regulation in FASD

Within the FASD literature, self-regulation is an area of frequent study (Gill & Thompson-Hodgetts, 2018). Researchers have established that FASD affects brain regions that

support self-regulation (Soh et al., 2015). Deficits in self-regulation predict the behavioural disturbances and the delayed social skills demonstrated by children with FASD (Nash et al., 2014). Recent intervention studies have demonstrated that self-regulation and executive functions can be targeted and improved for individuals with FASD (Kable et al., 2016).

Reid and colleagues (2019) examined children with FASD's physiological self-regulation before and after completing a mindfulness breathing exercise. Children with FASD demonstrated lower levels of physiological indicators of self-regulation at baseline, which improved to the point that their physiological indicators of self-regulation were in keeping with their same-age peers after completing the mindfulness exercise (Reid et al., 2019). The GoFAR program is another 10-week intervention that targets self-regulation and teaches adaptive life skills to children with FASD (Kable et al., 2016). Through computer games, homework assignments, and training for their parents, children five to ten years were taught to control impulsive and destructive behaviours. Kable and colleagues (2016) found that children who participated in the GoFAR program demonstrated decreases in destructive behaviours, such as temper tantrums, as reported by parents.

Similarly, Mandryk and colleagues (2013) developed a computer-based biofeedback training system targeting the self-regulation of children ages eight to 17 years with FASD. In this system, players chose the physiological system they wished to train. The game graphics were altered based on the user's physiological state as gathered by a sensing system. Results suggested that players demonstrated more significant improvements in altering their physiological state in later sessions than beginning sessions (Mandryk et al., 2013). These authors demonstrate that the self-regulation of children and adolescents can be targeted and improved through various approaches.

Another program that has established effectiveness in improving children's self-regulation with FASD is the Alert Program®. Soh and colleagues (2015) reported increases in the frontal gray matter of children with FASD who underwent a 14-week Alert Program® intervention that targeted their self-regulation. Another analysis by Nash and colleagues (2015) found that after completing a 14-week Alert Program® intervention, parents of children with FASD reported decreases in their child's externalizing behaviours and improvements in their emotional and behavioural regulation. These studies support the use of intervention to improve the self-regulation and executive functions of children with FASD.

Though there has been an increase in the number of studies evaluating the impacts of FASD on executive functions and self-regulation of children and adolescents, there continues to be a need for further study, since much of the existing research focuses on elementary-age children (Nash et al., 2015; Soh et al., 2015; Paley & O'Connor, 2011). Through interventions targeting such domains, several of the adverse outcomes associated with FASD may be mitigated by improvements to executive functions (Nash et al., 2015).

Self-Awareness in FASD

Despite the range of literature regarding the development and implications of self-awareness, little is known about self-awareness in adolescents with developmental disabilities, particularly FASD (Abbatte, Boca, & Gendolla, 2016; Hoerold et al., 2008; Paley & O'Connor, 2011). A few studies regarding lived experiences of individuals with FASD have mentioned participant self-awareness related to their FASD diagnosis or as a call for future study (e.g., Burnside & Fuchs, 2013; Paley & O'Connor, 2011). For example, one case study examined the school experiences of a young adult male with FASD. The participant highlighted an understanding of his abilities and how he adapted these strengths during his time at school

(Brenna et al., 2017). Another group of researchers gathered lived experiences of youth with FASD as they transitioned from child welfare care to independent living in a Canadian context. They demonstrated different levels of understanding of their FASD diagnosis (Burnside & Fuchs, 2013). Burnside and Fuchs (2013, pp 55) further described the self-awareness of adolescents and young adults with FASD transitioning to independent living and demonstrating a "*…clear progression of insight that developed as youth matured…*" youth achieving self-awareness years after reaching the age of majority. These researchers highlight the need for concrete education and support around self-awareness throughout childhood, adolescence, and young adulthood to ensure that individuals with FASD develop necessary self-awareness levels to support their day-to-day functioning (Brenna, 2017; Burnside & Fuchs, 2013).

Despite these findings, no studies exist that have specifically explored self-awareness for individuals with FASD, particularly within an intervention. The unique circumstances of individuals with FASD and the complexity of self-awareness make this a salient area of study.

Current Study

This quantitative study investigates the impacts of engaging in an adapted version of the Alert Program® on the self-awareness of adolescents with FASD. The Alert Program® is a 12-week manualized program designed to improve self-regulation and has demonstrated improvements in elementary-age children (Soh et al., 2015; Nash et al., 2015; Paley & O'Connor, 2011). It has also shown to improve the self-regulation of children with FASD, conduct disorder, and emotional disturbances (Nash et al., 2015; Soh et al., 2015; Paley & O'Connor, 2011). Although the Alert Program® does not explicitly focus on the development of self-awareness, participant's self-ratings of their Alert Levels were tracked at multiple points throughout each session before and following the completion of every activity.

Participants' self-ratings of their Alert Levels are indicators of their ability to reflect on and describe their perception regarding their emotional arousal at a given point in time, a necessary first step outlined within the Alert Program® intervention. Interventionists also completed ratings of what they perceived the participants' Alert Levels to be, to provide an objective benchmark of arousal level. Several researchers have used this method to access self-awareness in various populations, including Hoerold and colleagues (2008), Robertson and Schmitter-Edgecombe (2015), Steward and colleagues (2014), and Toglia and colleagues (2010). A comparison of the participants' self-rating with the interventionist's rating of the participant's Alert Levels, provides an indicator of whether participants are over- or under-estimating their Alert Level. In essence, this allows for objective consideration of how well the youth's self-awareness matches that which is observed by a trained outsider. By acknowledging their regulation level, participants will be better able to alter it using the intervention strategies.

Research Questions and Hypotheses

Research Question 1.

Does the self-awareness of adolescents with FASD improve throughout a 12-week intervention targeting their self-regulation? In what ways do participants' age and sex impact their self-awareness throughout the intervention?

Research Hypothesis 1: I expect that there would be a decrease in the difference between participants' Alert Level self-ratings and the interventionists' ratings of the participants' Alert Levels throughout the intervention. In other words, I hypothesize that the difference between participants' and interventionists' ratings of the participants' Alert Levels will be more significant at the beginning of the intervention and smaller at the end of the intervention. I also expect to

find that older adolescents between the ages of 14 and 17 demonstrate greater self-awareness than adolescents between the ages of 11 and 13 years.

Research Question 2.

Do the participants' Alert Levels impact their self-awareness? Do participants with more extreme Alert Levels demonstrate decreased levels of self-awareness?

Research Hypothesis 2: I expect to find participants' self-awareness to vary based on their level of alertness. Specifically, that there will be a greater difference between participants' and interventionists' ratings of the participants' Alert Levels when the participants' self-rating of their Alert Levels falls within the Too Low range compared with self-ratings of Just Right or Too High.

Methods

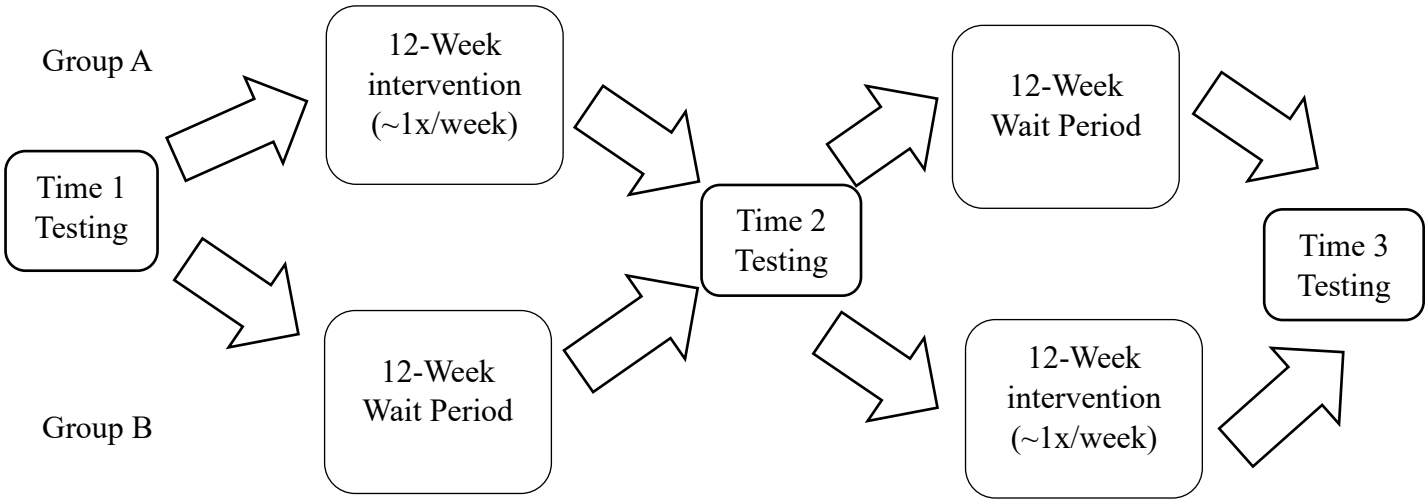
In this quantitative study, the impacts of a 12-week intervention study on the self-awareness of adolescents with FASD are explored. Although not directly targeted within the intervention, self-awareness is linked with self-regulation (Silvia & Phillips, 2013). Due to the limited literature on self-awareness for individuals with FASD, this study is one of the more significant of its kind.

Procedure

Study recruitment began in January 2016 and continued until November 2018. The intervention took place in hospital settings located in Edmonton, AB and Vancouver, BC. Enrollment was continuous to allow participants to begin at a time that worked best for them. A waitlist intervention design was used, which ensured that all participants received the intervention while still allowing comparisons between those who received the intervention and those who have not by alternating when participants received the intervention (Fig. 1).

Participants were assigned to the intervention (group A) or waitlist (group B) groups to control for age and sex. Participants in both groups underwent three testing points and the order in which the testing and intervention sessions were delivered varied by group (Fig. 1).

Figure 1.
Intervention Timeline



Participants in both groups completed the first testing time point, then participants in group A received the intervention for 12-weeks immediately after, while participants in group B waited. Once the 12-week intervention and the waiting period was complete, participants in both groups completed the second testing time point, after which participants in group B completed the 12-week intervention while participants in group A waited. After the 12-week intervention and waiting period, participants in both groups then underwent a third and final testing time point. At each testing point, participants and their parents completed a series of tests and self-report questionnaires that measured IQ, behavioural difficulties, and participants' mindset. Participants were provided with a small gift card after completing each testing point.

Participants

Adolescents were recruited through purposive sampling, using invitations distributed by the Glenrose Rehabilitation Hospital FASD Clinical Services, Sunnyhill Health Centre, and other community partners, including the Canada FASD Research Institute's social media. Interested caregivers contacted the research team for further information and then scheduled a testing session. Participants were included in the study if they had a formal diagnosis of FASD, were between 11 and 17 years and lived in the greater Edmonton, AB or Vancouver, BC areas. Adolescents were removed from the study if they had other genetic or neurodevelopmental disorders.

The Adapted Alert Program®

The Alert Program® was initially designed for children between the ages of eight to 12 years by occupational therapists Williams and Shellenberger (1996). Williams and Shellenberger (1996) designed the Alert Program® using eight key concepts, including sensory integration and arousal theory. Sensory integration was first proposed by Ayres (1979) and is defined as the organization of sensory information regarding the physical environment and bodily conditions to move, learn, and act appropriately in a given context. Arousal theory requires that individuals attain a level of arousal that allows them to attend to, concentrate on, and perform tasks to suit the context. The Alert Program® classified arousal in three states: Too High, Too Low, and Just Right. Five sensory domains described the different self-regulation strategies available to participants; mouth, move, look, listen, and touch.

The Alert Program® was broken into three distinct phases, each with unique goals. The first stage, identifying engine speeds, included the first four sessions and required students to learn about the Alert Levels and label theirs and others' alert states in and out of the intervention setting. The second stage included sessions five through eight and involved experimenting with

different sensory strategies to practice changing the participants' engine speeds. These sessions included experimenting with various self-regulation strategies that alter arousal levels to help them choose which strategies work best for them. The final stage, regulating engine speeds, includes sessions nine through 12. These sessions required participants to independently select and implement self-regulation strategies outside of the intervention setting and navigate different contexts where strategy options might be limited (Williams & Shellenberger, 1996).

The adaptations made to the Alert Program® for this study were to adjust the program to be suitable for adolescents. Throughout 12-sessions, adolescents completed the three phases of the Alert Program®, with some of the activities altered to meet the hospital environment's needs and the adolescent population. For example, an obstacle course activity was an option for the beginning of each session in the original Alert Program®. For the adapted version, that activity was replaced with several other activity options for the participant to select from, including yoga or other stretching exercises, colouring, or playing a card game. Each session included an introductory activity chosen by the participant, followed by two to three other activities based on the session's theme. The amount of parental involvement was adapted from the original version of the Alert Program® for the adolescent population; aside from the first session, parents were not required to complete any readings or other educational materials.

Measure

The Interventionist Record Form (IRF)

The IRF was completed by the interventionist throughout each session with input from the participant. The IRF collected qualitative and quantitative information regarding the strategies participants used in the session, whether the strategies participants used changed between settings, and participants' self-ratings and interventionists' ratings of the participants' Alert

Levels throughout the intervention. To review the complete IRF refer to Appendix A. For this study's purposes, the participant and interventionist ratings of the participant's self-regulation level, referred to as their Alert Levels, will be examined.

Participants and interventionist ratings of participants' self-regulation levels were collected using a seven-point Likert scale that ranked participants' self-regulation from one (Extremely Low) to seven (Extremely High). The goal of each activity was to get the participant to a Just Right level, or a four on the Likert scale. Participant and interventionist ratings of participant's self-regulation were collected before and after completing each activity throughout most sessions, except for the first two sessions. This was in keeping with the Alert Program's® goals and schedule, which did not require participants to begin identifying their arousal levels until session three. Participant self-ratings of their Alert Levels reflects their ability to note, track, and describe their emotional regulation. By comparing their ratings with those of the interventionist, we can determine their ratings' accuracy compared with an objective third party, the trained interventionist.

Analysis

All raw data that was collected from the IRF was entered into an SPSS database for analysis.

Research Question 1

Self-awareness was measured through difference scores that compared participants' Alert Level self-ratings with the interventionists' ratings. As previously described, there is precedence within the literature for measuring self-awareness using difference scores (e.g., Hoerold et al., 2008; Toglia et al., 2010). This method allowed for comparisons of participant and interventionist ratings throughout the intervention. The difference score was calculated for each

participant in each session by subtracting the interventionist's Alert Level rating from the participants' self-rating at every time point.

A rating was collected from the participant and interventionist before and after completing each activity in all 12 sessions, up to a maximum of four activities in each session. Thus, to reduce the number of ratings for the repeated measures analysis, each participant's average difference score was calculated in each session. A one-way within-subjects repeated-measures ANOVA was conducted using average difference scores for sessions three through 12. The assumptions for this analysis were not met. Thus, the ten average difference scores were reduced to three time points; the first time point included sessions three and four, the middle time point included sessions five through eight, and the final time point included sessions nine through 12. These groupings were selected based on the goals of the adapted Alert Program®. The assumptions were met using the three average difference scores. Thus, a one-way within-subjects repeated measures ANOVA determined whether participants' difference scores significantly changed.

Participants' sex was added to the repeated measures ANOVA as a between-subjects factor. After a significant interaction effect was found between sex and difference scores, repeated measures ANOVA simple effects analysis was conducted to further compare males to females. The data file was split between males and females, then the repeated measures ANOVA was conducted again without sex added as a between-subjects factor.

Participants' self-ratings and interventionist ratings of participants' Alert Levels were compared through bivariate correlations. Average participant and interventionist rating scores for each session were used to compare participants' average self-ratings with the interventionist's

average rating of the participants' Alert Levels across all ten sessions. Paired samples t-tests compared the means of participant and interventionist ratings throughout the intervention.

Finally, individual-level frequency analysis compared the size of the Alert Level rating difference between participants and interventionists at each time point in every session. Percentages were calculated of participants whose Alert Level rating fell within one, two, or three points of the interventionists' ratings. The individual-level analysis allowed for insight into the nuance of individual-change over the intervention course.

Research Question 2

The link between the participants' Alert Level and the size of the difference scores between the participants' and the interventionists' ratings of the participants' Alert Level was examined. A one-way repeated measures ANOVA was conducted to determine whether a Too Low Alert Level impacted the size of the difference between participants' and interventionists' ratings of the participants' Alert Level. First, participants' average ratings for each session were dichotomously coded as either Too Low if the participants' rating was one of the first two numbers on the seven-point Alert Level Likert scale. Participants whose scores fell outside this range on the seven-point Alert Level Likert scale were coded as zero to indicate not Too Low. At each session, these variables were then grouped into three time points throughout the intervention and then added as a covariate to a repeated-measures analysis of the difference scores throughout the intervention.

Assumptions

A one-way repeated measures ANOVA assumes that sphericity, homogeneity of variance, and normality are met. The assumption of sphericity was tested using Mauchly's test of sphericity for all repeated measures analysis; first, the average difference scores across all

sessions indicated that the assumption of sphericity had not been met $\chi 2(44) = 92.992$, $p = 0.000$. Thus, to meet the sphericity assumption, average difference scores were then calculated at three-time points during the intervention, as was previously described. The first time point included the average difference scores for sessions three and four. The second time point included average difference scores for sessions five through eight. The final time point included the average difference scores of sessions nine through 12. Mauchly's test of sphericity indicates that the assumption of sphericity was met for the three average difference scores, $\chi 2(2) = .398$, $p = .535$, and participants were split by gender to compare the difference scores of males and females. Sphericity was met for the repeated measures ANOVA to answer research question two using the three-time points, $\chi 2(2) = .560$, $p = .756$. Homogeneity of variance was tested using a covariance matrix scatterplot for the interventionist and participant ratings. The normality of the participants' and interventionists' ratings were assessed using histograms of the participants' self-ratings of their Alert Level compared with the interventionists' ratings, all of which fell within a normal curve. A scatterplot of the average participants and interventionist ratings demonstrated linearity between these ratings.

Results

Demographics

Twenty-seven adolescents met the inclusion criteria enrolled in the study (BC site n=10; AB site n=17). Four participants are not included in the final analysis due to dropping out before completing all 12 intervention sessions. The total number of participants included in the study was 23, with the total number of female participants n=13, and males n=10. The average age of participants was 13.74 years, with n=12 participants between ages 14 to 17 years, and n=11

between 11 and 13 years. The average IQ of participants was 94.52 (range of 66-121) measured at baseline.

Research Question 1

A one-way repeated measures ANOVA was conducted using average difference scores for three-time points; that is, the first average difference score included sessions three and four; the second includes sessions five through eight; the third includes sessions nine through 12. No significant within-subjects effect for the average difference scores (p=.564). Post hoc analysis findings indicated no significant effect between the average difference scores (p=.822). Between subjects' factors of sex and age were included in the one-way repeated measures ANOVA. The analysis revealed no significant effect of age on difference scores at all three time points (p=.177), although a significant interaction effect between sex and the difference scores was noted ($F(2, 36) = 6.171$, $p = .005$). Based on the pairwise comparison, average difference scores at all three time points were not significantly different (T1 & T2 p=.697*,* T1 & T3 p=.474, T2 & T3 p=.262*)*. The repeated measures ANOVA simple effect analysis revealed significant within-subjects effect for female average difference scores ($F(2, 24) = 3.433$, $p = .049$), but not males ($p = .103$). Table 1 summarizes the mean difference scores by gender at all three time points.

Table 1.
Mean difference scores by sex at the three time points.

Sex		**Mean difference scores (SD)**
Male	Mean difference score for sessions three and four	.0763 (.27184)
	Mean difference score for sessions five through eight	-.1499 (.33639)
	Mean difference score for sessions nine through 12	.0958 (.20474)
Female	Mean difference scores in sessions three and four	-.0352 (.26097)
	Mean difference score for sessions five through eight	.1286 (.22091)
	Mean difference score for sessions nine through 12	.0174 (.21635)

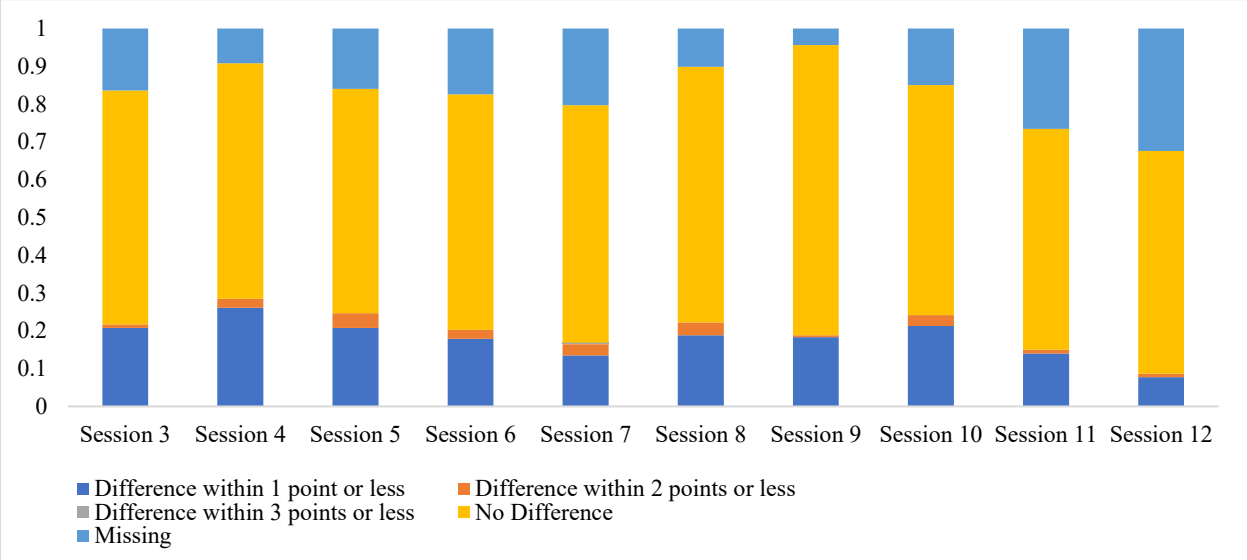
Bivariate correlation analysis comparing participants' average Alert Level self-ratings and interventionist's rating were significant at all sessions. The size of the correlation is largest in sessions three (r=89.1%) and eight (r=89.6%). The smallest correlation sizes were noted in sessions four (r=60.4%), seven (r=68.8%), and twelve (r=68.6%), which are still indicative of a moderate relationship. Table 2 is a complete list of the correlations between participant self-ratings and interventionist ratings of the participants' Alert Level.

A paired samples t-test compared the means of participant self-ratings with interventionist ratings of the participants' Alert Levels for each intervention. The differences between participant and interventionist ratings were significant at sessions eight ($t(22)=2.358$, $p=.028$) and 10 ($t(21)=2.114$, $p=0.047$). Otherwise, no other significant differences exist between the mean ratings of participants and interventionists.

Individual-level frequency analysis determined the number of participants whose scores fell within one, two, three points of the interventionists' ratings, and the number of participants whose scores did not differ from the interventionists' (Fig. 2 & Table 2). In session three, 61.84% of participants' ratings did not differ from the interventionists' ratings, while in session 12, 58.94% of participants' ratings did not differ from the interventionists' ratings. In session seven, .48% of participants demonstrated a three-point difference in their ratings compared to the interventionists', which is the only session in which a difference of this size was noted. Otherwise, most participants' scores fell within 1 point or did not differ from the interventionists' ratings across all sessions. Graphs (Figures 3 to 25) were created that track each participants' mean ratings in each session compared with the interventionists' ratings.

Figure 2

Size of the difference scores in each session



Frequency analysis examined the percentage of participants whose ratings fell within one, two, or three points of or did not differ from the interventionists' ratings.

Table 2

Bivariate Correlations & Size of Difference Scores

Session	Pearson Correlation (mean participant and interventionist ratings)	Participants whose rating did not differ from the interventionists'	Participants whose rating was within 1 point or less of the interventionists'	Participants whose rating was within 2 points or less of the interventionists'	Participants whose rating was within 3 points or less of the interventionists'
3	.891*	61.84%	20.77%	9.66%	0%

4	.604*	62.32%	26.09%	2.41%	0%
5	.780*	59.42%	17.87%	3.87%	0%
6	.844*	62.32%	13.53%	2.41%	0%
7	.688*	63.80%	18.84%	2.90%	0.48%
8	.896*	67.63%	18.36%	3.38%	0%
9	.859*	76.81%	21.26%	0.48%	0%
10	.724*	60.87%	14.01%	2.90%	0%
11	.809*	58.45%	14.01%	0.96%	0%
12	.686*	58.94%	7.73%	0.96%	0%

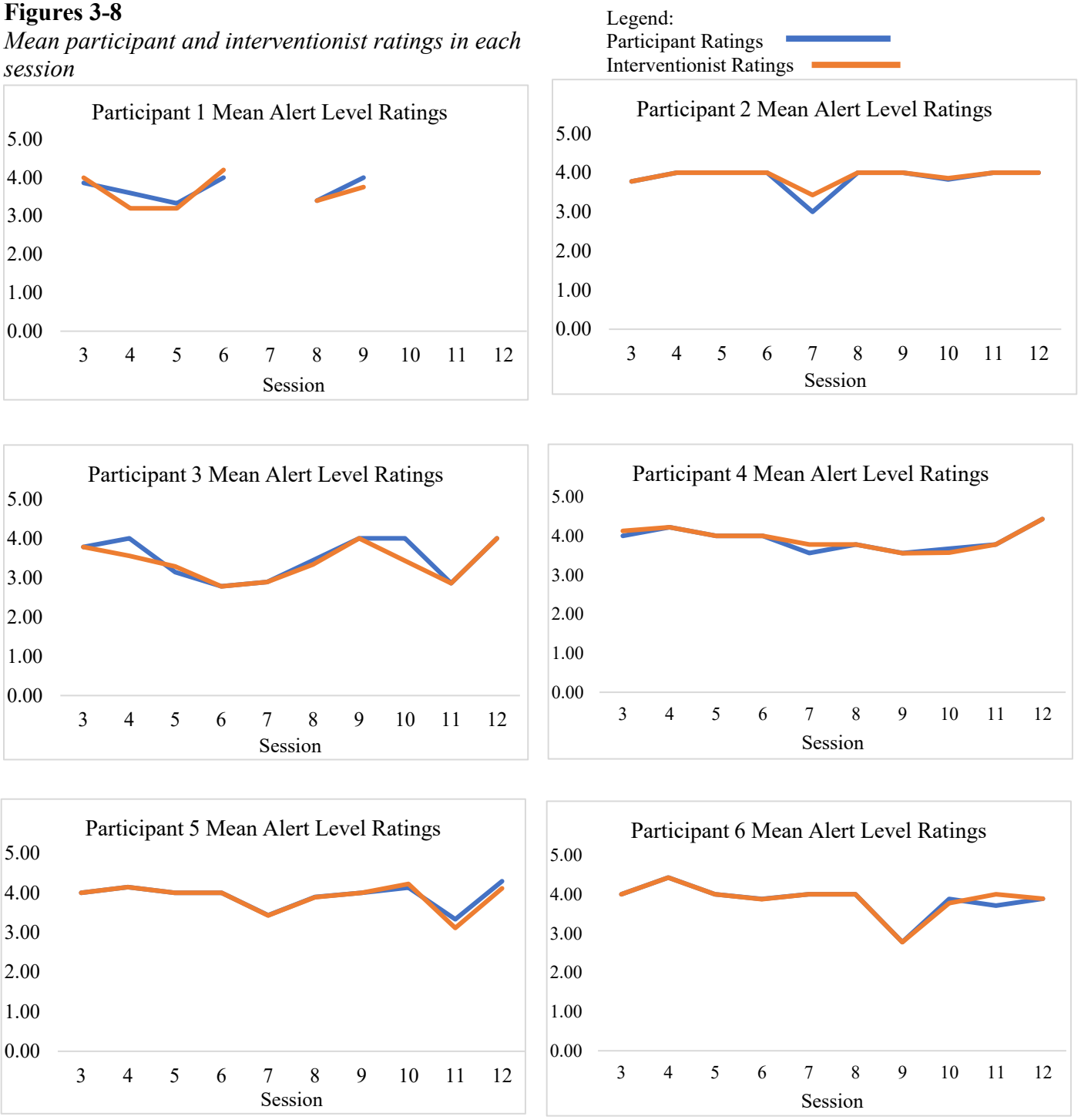
*Correlation is significant at the p=0.01 level

Research Question 2

A one-way repeated measures ANOVA was conducted to determine whether a Too Low Alert Level impacted the difference scores. Average difference scores and Too Low scores at the three time points during the intervention compared the participants' Alert Levels to the average difference score. No significant within-subjects effect of average difference scores with the added covariate Too Low was found; at time one (p=.597), time two (p=.658), or time three (p=.713). Pairwise analysis findings indicated no significant effect was found between the average difference scores and the Too Low rating between any of the sessions. Based on the pairwise comparison, average difference scores with the Too Low covariate did not significantly differ between the three time points.

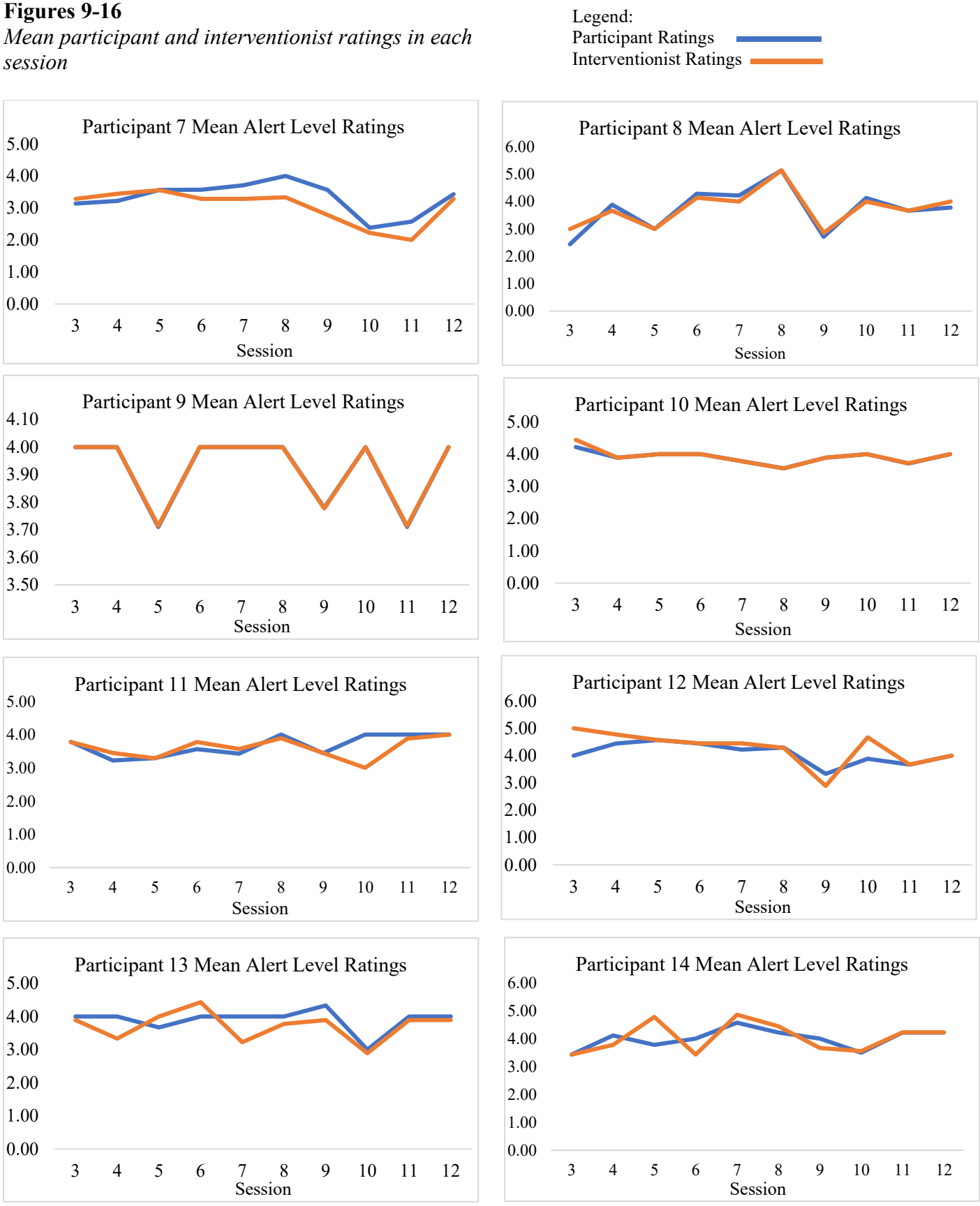
Figures 3-8

Mean participant and interventionist ratings in each session



Figures 9-16

Mean participant and interventionist ratings in each session



Figures 17-24

Mean participant and interventionist ratings in each session

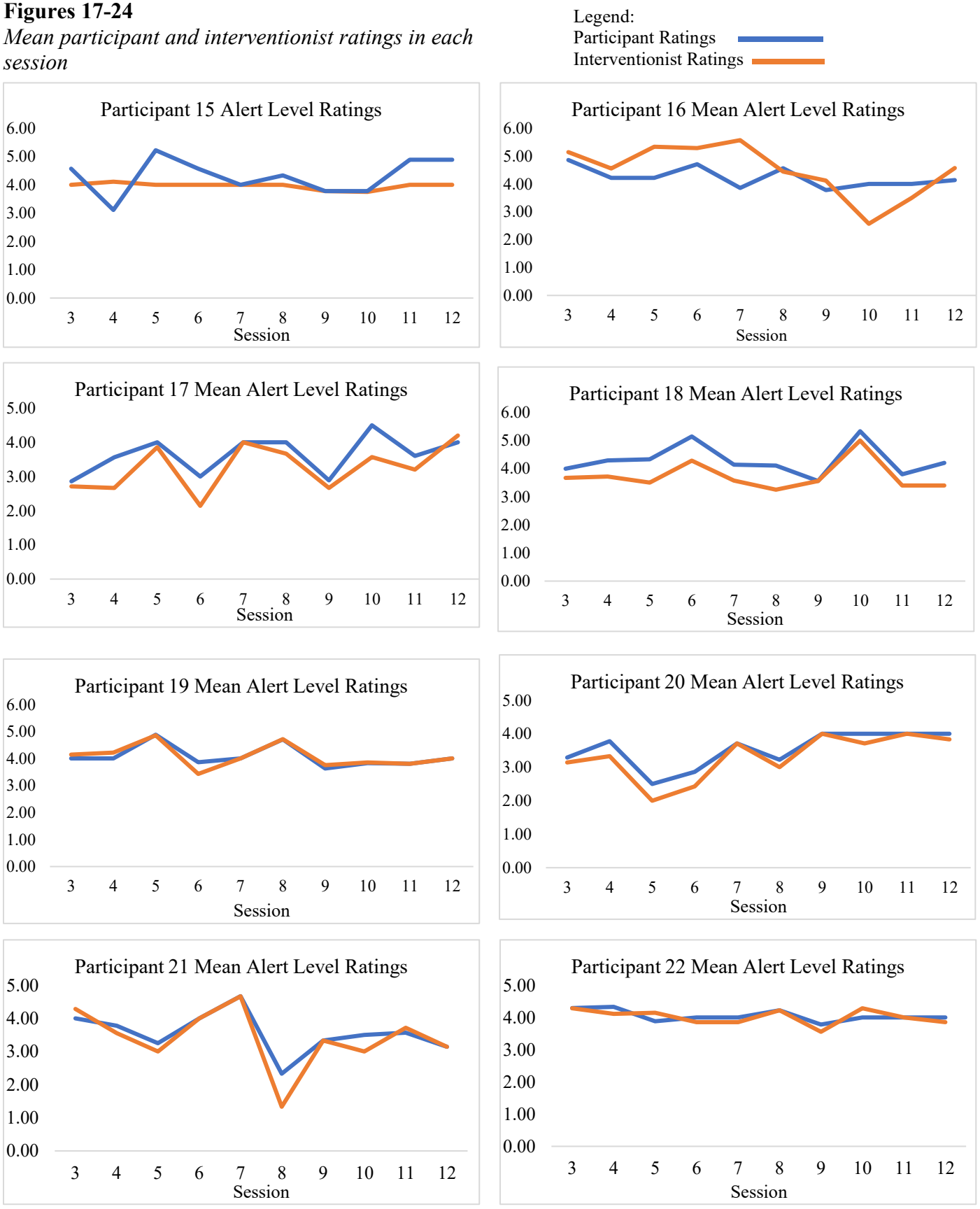
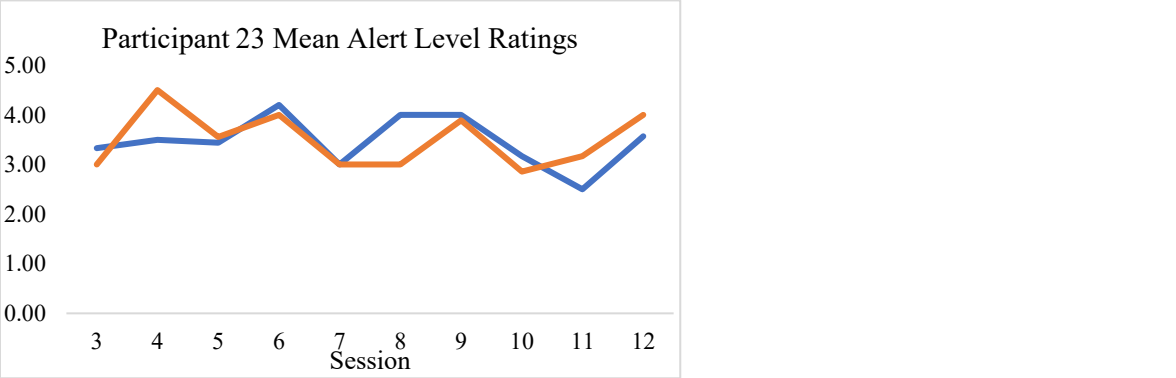


Figure 25

Mean participant and interventionist ratings in each session



Discussion

This study sought insight into the self-awareness of adolescents with FASD. Self-awareness was measured by comparing study participants' self-ratings with interventionists' ratings of the participants' Alert Levels.

Regarding the first hypothesis, group-level analyses of the difference scores did not significantly change throughout the intervention. Correlation analysis comparing interventionist and participants' ratings of the participants' Alert Levels was significant at all time points. Stronger correlations between the interventionist and participant ratings in earlier sessions compared with later sessions. Similarly, individual-level analyses demonstrated that most participants had similar ratings to the interventionist throughout the intervention. These findings demonstrate that participants could reflect on and describe their internal arousal states accurately from the intervention's beginning.

Concerning the second hypothesis, participants' arousal state did not demonstrate an effect on the difference scores. This finding is likely due to most average scores falling within the Just Right range (numbers three through five on the Likert scale). The lack of apparent dysregulation noted by participants and interventionists likely limited this analysis. Differences

in individual presentation of participants could also have influenced how the interventionist perceived their Alert Levels. Williams and Shellenberger (1996) explained in Alert Program® training: Children and adolescents who appear in either of the extremes, Too Low or Too High, may fall in the opposite range. That is, adolescents who are Too Low can appear to be Too High when they attempt to self-regulate (Williams & Shellenberger, 1996).

Given this study's goals and design, it is unclear whether the difference between interventionist and participants ratings had a relationship with participants' self-regulation ability. Further research is needed regarding the differences in self-awareness for males and females with FASD. Two themes identified from these research findings were leveraging strengths and sex differences in self-awareness.

Leveraging Strengths

Participants demonstrated consistent self-awareness abilities throughout the entire intervention. More specifically, adolescents with FASD demonstrated the ability to recognize their internal states within the intervention setting. Considering the setting and limitations of the measure, adolescents demonstrated situation-specific, in-the-moment, awareness of their internal bodily states instead of more global definitions of self-awareness. Given the consistency demonstrated by participants throughout the intervention, in-the-moment bodily awareness may be a potential strength for adolescents with FASD.

Group-level trends demonstrated similar ratings between participants and the interventionists in the intervention's early and middle portions. Greater self-awareness at the beginning of intervention is related to increases in social functioning at one-year follow-up post-intervention (Verhoeven et al., 2011). The increased divergence between the participants' and the interventionists' ratings in later sessions could be due to changes to the intervention's goals. Later

sessions encourage participants to implement and identify their regulatory states outside of the intervention. This finding may highlight changes to the goals of the Alert Program® in the final four sessions, which include increased independence and self-advocacy. The divergence in ratings could reflect the participants' overestimation of the frequency with which their arousal state is in the Just Right range. Steward and colleagues (2014) noted a similar pattern with adolescents with ADHD who had completed the BRIEF compared with their parents' ratings on the same measured. By calculating difference scores, Steward and colleagues (2014) noted that adolescents reported experiencing fewer EF difficulties than their parents, and endorsed more potent EF abilities related to working memory, inhibition, and self-monitoring than their parents' ratings.

The ability to perceive internal bodily signals is vital to emotional awareness (Herbert et al., 2011). This type of self-awareness is related to interoceptive awareness (Herbert et al., 2011) and online awareness (Hoerold et al., 2008). Compared with metacognitive awareness, online awareness changes more frequently because it takes place immediately before, during, and after completing a task (Hoerold et al., 2013). Improvements to online awareness can result in increased behavioural regulation (Hoerold et al., 2013; Roberts & Schmitter-Edgecombe, 2015). Metacognitive awareness is viewed as an overall awareness of one's strengths and abilities, whereas online awareness includes abilities to recognize errors and anticipate challenges as they occur in-the-moment (Hoerold et al., 2013). Whether these aspects of self-awareness exist within a hierarchy is unclear, but online and metacognitive awareness are distinct yet closely related (Hoerold et al., 2013). The consistency demonstrated by adolescents with FASD in this study to accurately note and describe their level of internal arousal in-the-moment is in keeping with descriptions of online awareness, which may be an area of relative strength for this sample.

Sex Differences in Self-Awareness

Sex differences in the development of self-awareness have not been previously explored concerning adolescents with FASD. In this study, participant sex was the only between-subject factor to affect the difference scores of adolescents with FASD significantly. Males demonstrated smaller changes to their difference scores over the intervention course, with a peak in their difference scores at the beginning and end of the intervention. In contrast, females demonstrated the most substantial difference scores in the middle of the intervention. Female adolescents with FASD were able to access their online awareness within an intervention setting when session goals did not focus on trying new and different strategies, as was done in sessions three through eight. In contrast, the online awareness of male adolescents with FASD demonstrated more consistency in the difference scores in the sessions that involved the use of such strategies.

One aspect that could cause the sex differences in the self-awareness in adolescents with FASD was the type of information collected; physiological arousal states as defined by the Alert Program®. Silvia and Phillips (2013) compared conscious and subliminal prompts to target self-awareness in adults engaged in a computer-based task. Silvia & Phillips (2013) found that physical and subliminal prompts equally promoted participants' online awareness and improved their regulatory behaviours. The current study applied descriptions of internal arousal states' that were concrete and clearly defined by the Alert Program®. Participants were prompted by the interventionists to represent their arousal states using props immediately before and after completing in-session activities. The use of concrete and physical prompts may have been beneficial for accessing male awareness, which is in keeping with findings from Herbert and colleagues (2011). Herbert and colleagues (2011) examined the interoceptive awareness and

emotional experiences of healthy adults. These researchers found that males whose awareness was directed externally from themselves also struggled to note their internal emotional states (Herbert et al., 2011). The type of descriptions used within the Alert Program(r) may have been easier for male than female adolescents to apply to their internal states.

Another explanation for the differences in self-awareness between males and females with FASD could reflect the differences between self-awareness types. Steward and colleagues (2014) investigated the self-awareness of EF abilities in adolescents with Attention Deficit Hyperactivity Disorder (ADHD). These researchers created difference scores using self-report responses from adolescents with ADHD and parents' responses to the BRIEF (Steward et al., 2014). In contrast to the findings from the current study, Steward and colleagues (2014) found that male adolescents with ADHD were more likely than females to overestimate their EF abilities. The differences in findings between our study and that of Steward and colleagues (2014) may reflect the differences between online and metacognitive awareness. Specifically, males may be more proficient with online awareness. At the same time, males struggle with abstract aspects of self-awareness, such as describing their EF, while the opposite may be true for females (Steward et al., 2014). There may be differences in how males and females with FASD access different aspects of self-awareness.

Implications & Next Steps

As has been previously described, adolescents with FASD demonstrated consistent online awareness throughout a clinical intervention study. Thus, online awareness is something that could be leveraged in interventions with this population. That is, asking youth with FASD what they are experiencing in-the-moment could benefit their engagement and the intervention outcomes. This is in line with Toglia and colleagues (2010), who noted that self-monitoring

improvements facilitated positive intervention outcomes. Hoerold and colleagues also examined online awareness in non-neurological populations and noted that online awareness is related to increased memory and decreased anxiety (Hoerold et al., 2008). In FASD populations, metacognitive awareness strategies have demonstrated success. Makela and colleagues (2019, pp 123) taught children with FASD "*...how to think about thinking...*". They found that children with FASD required less prompting to engage in strategies to support task completion. Similarly, the GoFAR intervention designed to target self-regulation through metacognitive strategy training has demonstrated success in improving regulatory behaviours in children with FASD (Kable et al., 2016). These authors' findings suggest that interventions for children and adolescents with FASD should directly target their self-awareness to support intervention outcomes.

Despite these researchers' findings, no previous researchers have explored the online awareness of adolescents with FASD directly. In the current study, online awareness was accessed through concrete language and physical tools to support participants as they described their internal arousal states. In this way, the online awareness of adolescents with FASD may be more effectively targeted using such concrete strategies and focusing on physiological states. Further research is needed to understand the online awareness of individuals with FASD, including the impacts of concrete language. Regardless, the findings from the current study present opportunities for the use of online awareness to support engagement in and successful outcomes through interventions for adolescents with FASD.

Another implication from the study is the impact of sex on the online awareness of adolescents with FASD. This is surprising when compared with other studies, wherein males more frequently demonstrate higher discrepancy scores and are presumed to experience more

difficulty with self-awareness (Steward et al., 2014; Weil et al., 2013; Wright et al., 2017). Given the current study findings, male adolescents with FASD can more accurately reflect on and describe their internal arousal states than females. Future interventions designed for males with FASD could strive to access self-awareness using more concrete, in the moment language similar to online awareness. In contrast, females may require more supports to access online awareness. This presents a potential difference in how researchers and clinicians help adolescents with FASD access their online awareness. Male and female adolescents with FASD may require different scaffolding of supports when accessing online self-awareness. Weil and colleagues (2013) noted that female participants demonstrated stronger metacognitive abilities related to evaluating their performance after completing a computer-based task. It could be that females are more adept at metacognitive awareness, such as identifying internal emotional states, as has been noted by researchers such as Jain and colleagues (2013), Weil and colleagues (2013) and Wright and colleagues (2017). Female adolescents with FASD may not be as adept as males regarding tasks that require online awareness and may require scaffolding of their online awareness through metacognitive awareness.

Overall, self-awareness should continue to be studied within FASD populations. The findings from the current study indicate that online awareness may present a domain that can be leveraged and targeted directly to support regulatory behaviours. Adjustments to intervention support and program planning present more tangible and concrete language to access online awareness. Individuals with FASD would likely benefit from interventions that directly target self-awareness as a functional outcome. Best and Miller (2010) stated that researchers should continue to identify the mechanisms through which self-awareness develops to determine better strategies and interventions that can be implemented within each developmental period to foster

self-awareness across the lifespan. Future researchers should explore how apparent arousal states impact adolescents' self-awareness to gain further insight into this population's self-awareness.

Limitations

This study was not without its limitations. First, the measure used was not designed to target self-awareness and is likely not the most precise measure of this construct. In particular, participant self-ratings were not collected in the first two sessions, limiting the impacts of the repeated measures analysis. Despite that, the measure collected information from participants and interventionists, which is in keeping with methods used by other researchers examining self-awareness (e.g., Steward et al., 2014). Though it may be a broad measure of self-awareness, the IRF was still used to provide preliminary insight into the self-awareness of adolescents with FASD, which is an area of limited study at the time of this analysis.

Second, there were some inconsistencies regarding how the ratings were recorded using the IRF. For example, some participants did not complete all four activities in each session, which impacted the number of ratings collected in each session for each participant. There may be some gaps in the data as a result. However, participant and interventionist ratings were collected in tandem in sessions three through 12; whenever a participants' Alert Level rating was recorded, so too was the interventionists'. Thus, difference scores could be calculated in most sessions for all participants who completed the intervention.

Finally, the small sample size limits the generalizability and thus the ability to say that self-awareness is an area of relative strength for adolescents with FASD. However, in consideration of the population, the length of the study, and the setting in which the interventions took place, the sample size is in keeping with other studies of this population (e.g., Makela et al., 2019; Nash et al., 2015; Soh et al., 2015). Thus, in consideration of the population and study

context, the sample is reasonable. Though perhaps lacking in some generalizability, these results reveal some interesting trends in the self-awareness of adolescents with FASD that prompt further examination of this construct within the FASD population.

Despite these limitations, this study provides some fascinating insight and a beginning step in developing our understanding of the development of self-awareness of adolescents with FASD. Though there are still questions and future study of self-awareness within this population, it will be essential to further our understanding and better support, which could likely be an area of strength for individuals within this population.

Conclusion

Throughout a 12-week clinical intervention, adolescents engaged in psychoeducational activities and discussions to improve their self-regulation abilities. Self-regulation is the adolescents' ability to regulate their thoughts, feelings, and behaviours in relation to environmental demands. Effective self-regulation is reliant on self-awareness, though little is known regarding the effects of FASD on self-awareness. Self-awareness was explored by creating difference scores that allowed for comparison between participant and interventionist ratings of the participants' arousal level. In this way, participants' ratings reflected their ability to reflect and describe their internal arousal states. In contrast, the interventionist ratings provided an objective baseline from a professional trained to identify arousal states.

The group-level analysis and individual level frequency analyses determined no significant changes in participants' self-awareness. The group-level analyses revealed no significant effects of the intervention on participant self-awareness, though sex significantly affected self-awareness. Correlation analysis compared participant ratings with interventionists' ratings and found significant correlations at all time points. The findings of the current study

point to self-awareness as a potential domain that could be leveraged to support the consistent access to the EF abilities of adolescents with FASD, and should continue to be studied to determine how to leverage this strength within clinical and educational settings.

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Appendix A

Interventionist Record Form

A1) **Today's session is program session** _____ (of 12).

A2) **Which session outline in the manual are you following?**

_____

A3) **Has this session outline already been attempted/completed previously?** ☐ Yes ☐ No ☐ N/A *(1st session)*

A4) <u>If yes</u>, how many times have you previously taught this session outline?

_____

A5) **Participant's self-reported Alert level prior to starting the session:***(N/A for sessions 1 & 2)*

Extremely Low	Low	Low-Just Right	Just Right	Just Right-High	High	Extremely High
1	2	3	4	5	6	7

A6) **Interventionist's perception of the participant's Alert level prior to starting the session**:

Extremely Low	Low	Low-Just Right	Just Right	Just Right-High	High	Extremely High
1	2	3	4	5	6	7

Between Sessions (N/A if Session 1)

B1) **Did the participant or caregiver report use of the participant's strategies/Alert concepts after the last session?** ☐ Yes ☐ No

B2) **<u>If yes,</u> how and where were the strategies used? Were they successful? – how do they know? Were there any challenges? (describe)**

_____

_____

_____

_____

_____

_____

B3) **Did the participant complete last session's practice component at home?**

☐ Yes ☐ No ☐ Partially ☐ N/A

B4) **Did the caregiver report assisting with the "Practice" component at home after last session?**

☐ Yes, all of it ☐ Yes, some of it ☐ No ☐ Not Applicable

B5) **How much time did the caregiver report helping with the practice component?**
_____mins *(write 0 if none)*

B3) **Description of caregiver's participation at home between last session and current session:**

Caregiver Involvement

C1) **Did the caregiver participate in the parent component during this session (Reading Take 5! or handouts)?**

☐ All ☐ Some ☐ None ☐ Not Applicable

C2) **How much time did the caregiver report spending on the parent component today?**
_____mins*(write 0 if none)*

C3) **Description of caregiver's participation during current session:**

Review of Last Session

C1) **Was the participant able to recall information from the last session <u>without</u> prompting?**

☐ Yes ☐ No ☐ Partial Information

C2) **<u>If yes or partial</u>, briefly state concepts remembered by the participant:**

_____

_____

_____

_____

_____

_____

_____

C3) **Was the participant able to recall information from the last session <u>with</u> prompting?**

☐ Yes ☐ No ☐ Partial Information

C4) **Which concepts needed to be reviewed or prompted?**

_____

_____

_____

_____

_____

C5) **Did you complete last session's practice component at the beginning of today's session?**

☐ Yes ☐ No ☐ Partially ☐ N/A (was completed at home/no practice component)

Activity #1:

D1) **Activity options offered by the interventionist:**

_____

_____

_____

D2) **Activity option chosen by participant:**

_____

D3) **Participant's self-reported Alert level <u>prior to</u> the activity:** *(N/A for session outlines 1 & 2)*

Extremely Low	Low	Low-Just Right	Just Right	Just Right-High	High	Extremely High
1	2	3	4	5	6	7

D4) **Interventionist's perception of the participant's Alert level <u>prior to</u> the activity**:

Extremely Low	Low	Low-Just Right	Just Right	Just Right-High	High	Extremely High
1	2	3	4	5	6	7

D5) **How engaged was the participant in the activity?**

Not engaged	Somewhat engaged	Mostly engaged	Engaged	Highly engaged
1	2	3	4	5

D6) How could the activity be adapted to increase of participant engagement?

_____

_____

_____

_____

D7) **Participant's self-reported Alert level <u>after</u> the activity:***(N/A for session outlines 1 & 2)*

Extremely Low	Low	Low-Just Right	Just Right	Just Right-High	High	Extremely High
1	2	3	4	5	6	7

D8) **Interventionist's perception of the participant's Alert level <u>after</u> the activity**:

Extremely Low	Low	Low-Just Right	Just Right	Just Right-High	High	Extremely High
1	2	3	4	5	6	7

Activity #2:

E1) **Activity options offered by the interventionist:**

_____

_____

_____

E2) **Activity option chosen by participant:**

_____

E3) **Participant's self-reported Alert level <u>prior to</u> the activity:** *(N/A for session outlines 1 & 2)*

Extremely Low	Low	Low-Just Right	Just Right	Just Right-High	High	Extremely High
1	2	3	4	5	6	7

E4) **Interventionist's perception of the participant's Alert level <u>prior to</u> the activity**:

Extremely Low	Low	Low-Just Right	Just Right	Just Right-High	High	Extremely High
1	2	3	4	5	6	7

E5) **How engaged was the participant in the activity?**

Not engaged	Somewhat engaged	Mostly engaged	Engaged	Highly engaged
1	2	3	4	5

E6) How could the activity be adapted to increase of participant engagement?

_____

_____

_____

E7) **Participant's self-reported Alert level <u>after</u> the activity:***(N/A for session outlines 1 & 2)*

Extremely Low	Low	Low-Just Right	Just Right	Just Right-High	High	Extremely High
1	2	3	4	5	6	7

E8) **Interventionist's perception of the participant's Alert level <u>after</u> the activity**:

Extremely Low	Low	Low-Just Right	Just Right	Just Right-High	High	Extremely High
1	2	3	4	5	6	7

Activity #3:

F1) **Activity options offered by the interventionist:**

_____

_____

_____

F2) **Activity option chosen by participant:**_____

F3) **Participant's self-reported Alert level <u>prior to</u> the activity:** *(N/A for session outlines 1 & 2)*

Extremely Low	Low	Low-Just Right	Just Right	Just Right-High	High	Extremely High
1	2	3	4	5	6	7

F4) **Interventionist's perception of the participant's Alert level <u>prior to</u> the activity**:

Extremely Low	Low	Low-Just Right	Just Right	Just Right-High	High	Extremely High
1	2	3	4	5	6	7

F5) **How engaged was the participant in the activity?**

Not engaged	Somewhat engaged	Mostly engaged	Engaged	Highly engaged
1	2	3	4	5

F6) How could the activity be adapted to increase of participant engagement?

_____

_____

_____

F7) **Participant's self-reported Alert level <u>after</u> the activity:** *(N/A for session outlines 1 & 2)*

Extremely Low	Low	Low-Just Right	Just Right	Just Right-High	High	Extremely High

1	2	3	4	5	6	7

F8) **Interventionist's perception of the participant's Alert level <u>after</u> the activity**:

Extremely Low	Low	Low-Just Right	Just Right	Just Right-High	High	Extremely High
1	2	3	4	5	6	7

Activity #4:

G1) **Activity options offered by the interventionist:**

_____

_____

_____

G2) **Activity option chosen by participant:**_____

G3) **Participant's self-reported Alert level <u>prior to</u> the activity:** *(N/A for session outlines 1 & 2)*

Extremely Low	Low	Low-Just Right	Just Right	Just Right-High	High	Extremely High
1	2	3	4	5	6	7

G4) **Interventionist's perception of the participant's Alert level <u>prior to</u> the activity**:

Extremely Low	Low	Low-Just Right	Just Right	Just Right-High	High	Extremely High
1	2	3	4	5	6	7

G5) **How engaged was the participant in the activity?**

Not engaged	Somewhat engaged	Mostly engaged	Engaged	Highly engaged
1	2	3	4	5

G6) How could the activity be adapted to increase of participant engagement?

_____

_____

_____

G7) **Participant's self-reported Alert level <u>after</u> the activity:***(N/A for session outlines 1 & 2)*

Extremely Low	Low	Low-Just Right	Just Right	Just Right-High	High	Extremely High
1	2	3	4	5	6	7

G8) **Interventionist's perception of the participant's Alert level <u>after</u> the activity**:

Extremely Low	Low	Low-Just Right	Just Right	Just Right-High	High	Extremely High

Additional Strategies

H1) **Were any additional strategies used to maintain the participants Alert Level during the session?**

☐ Yes ☐ No

H2) **If yes, what strategies were used and when were they used in the session?**

_____

_____

_____

_____

H3) **Which strategies were most successful? Why?**

_____

_____

_____

H4) **Which strategies were most unsuccessful? Why?**

_____

_____

_____

Session Information Sheet (SIS)

I1**) Was the SIS Completed?** ☐ Yes ☐ No ☐ Partially

I2) **Was the SIS Provided to the Caregiver?** ☐ Yes ☐ No ☐ Not Applicable

I3) **Did you make a copy of the SIS for your file?** ☐ Yes ☐ No ☐ Not Applicable

Planning for Next Session:

J1) **Should certain concepts/components of the session outline be reviewed next session?**
☐ Yes ☐ No

J2) **<u>If yes</u>, which concepts/components should be reviewed:**

_____

_____

_____

_____

_____

J3) **Should the entire session outline be re-administered the following session?**
☐ Yes ☐ No

J4) **If yes, why should the session be re-administered?**

_____

_____

_____

_____

_____

_____

J5) **How long was this week's session?** _____ minutes