

UNDERSTANDING THE AFFECTIVE DIMENSION OF OCCUPATIONAL
PARTICIPATION AMONG ADOLESCENTS WITH AUTISM SPECTRUM DISORDER:
AN ECOLOGICAL MOMENTARY ASSESSMENT STUDY

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ABSTRACT

Aaron Ray Dallman: Understanding the Affective Dimension of Occupational Participation Among Adolescents with Autism Spectrum Disorder: An Ecological Momentary Assessment Study
(Under the direction of Antoine Bailliard)

Individuals with autism spectrum disorder (ASD) often experience problems in occupational participation that are secondary to co-occurring mental health conditions such as depression or anxiety. The purpose of this project was to enhance understanding of factors that influence depressive symptomatology and subjective experiences of occupational participation for adolescents with ASD. Three specific aims were addressed, each drawing from data obtained from a larger study. The study, Temporal Evaluation of eMotion, Place, and Occupation (TEMPO), included 17 adolescents with autism spectrum disorder (ASD), ages 11-17 years, and their caregivers. First, participants completed an in-person visit during which they completed self-reported and parent-reported measures of depression, a measure of intelligence quotient, and questionnaires on other demographic information. Second, participants completed an ecological momentary assessment (EMA) of depressive symptoms and occupational experiences. Adolescents were signaled to complete the EMA protocol six times per day for seven consecutive days. In Chapter Three, fidelity results from the TEMPO study are presented. In this chapter, evidence that EMA is a helpful tool for clinical occupational therapy practice and occupational therapy and occupational science research is also presented. In Chapter Four, the findings that the social dimension of occupation was a significant predictor of momentary affect and depressive symptomatology

are presented. For children at earlier pubertal stages, increased quantity of social interaction was related to momentary positive affect (PA); for children at later pubertal stages, increased quality of social interaction was related to momentary PA. I also found that affective instability was related to parent-reported depressive symptomatology. In Chapter Five, I further explored the relationships between affective and subjective experiences during occupational participation. I evaluated the relationship between temporal patterns of occupational participation and subjective experiences. Four themes are discussed including: (1) adolescents with ASD participate in a range of occupations, most commonly screen-time occupations; (2) adolescents with ASD spend significant time spent in enjoyable occupations with others; (3) adolescents with ASD report more PA than negative affect; and (4) high variability characterizes the subjective experiences of adolescents with ASD. Findings across the three aims led to the identification of key factors that influence the affective dimension of occupation.

To my father, Barry, who always encouraged me to pursue my passions (musical, academic, clinical, or otherwise), lead in whatever I do, and who, though unable to witness me reach this milestone, would be incredibly excited to see me reach this step in life.

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LIST OF ABBREVIATIONS

AASP	Adolescent/Adult Sensory Profile
ABIQ	Abbreviated intelligence quotient
AIC	Akaike information criterion
ADOS	Autism Diagnostics Observation Schedule.
AOTA	American Occupational Therapy Association
ASD	Autism spectrum disorder
ADHD	Attention deficit hyperactivity disorder
BRIEF	Behavior Rating Inventory of Executive Function, second edition
CAOT	Canadian Association of Occupational Therapists
CDI 2: PR	Child Depression Inventory Second Edition: Parent Report
CDI 2: SR	Child Depression Inventory Second Edition: Self Report
CFS-APQ	Chronic Fatigue Syndrome – Activities and Participation Questionnaire
DF	Degrees of freedom
DSM-IV	Diagnostic and Statistical Manual of Mental Disorders, fourth edition
DSM-V	Diagnostic and Statistical Manual of Mental Disorders, fifth edition
EMA	Ecological momentary assessment
F	F-statistic
HIV	Human immunodeficiency virus
ID/DD	Intellectual Disabilities and Developmental Disabilities
IQ	Intelligence quotient
M	Mean
MSSD	Mean square successive difference
NA	Negative affect
PA	Positive affect
RRB	Restricted and repetitive behaviors
SD	Standard deviation
SB-5	Stanford-Binet Intelligence Test, Fifth Edition

OEP	Occupational Experiences Profile
PANAS-C-SF	Positive Affect and Negative Affect Scale, Child Version, Short Form
PDD	Pervasive developmental disorder
PDD-NOS	Pervasive developmental disorder – not otherwise specified
PDS	Pubertal Development Scale
TEMPO	Temporal Evaluation of eMotion, Place, and Occupation
USPSTF	United States Preventative Services Task Force

CHAPTER 1: BACKGROUND AND LITERATURE REVIEW

1.1 Introduction

Researchers and clinicians alike are gradually beginning to recognize the role of mental health, especially mental health problems such as in the case of depression, towards well-being among individuals with autism spectrum disorder (ASD). Characterized by features such as an increase in obsessions and rituals, loss of former interests, agitation, increased stereotypical behaviors, increased self-injury, decreased adaptive functioning, and sleep disturbances (DeFilippis, 2018), depression is a particularly problematic mental health comorbidity linked to suicide. However, researchers and practitioners generally know little about who, with ASD, is at risk for co-occurring depression.

Why should occupational therapists and occupational scientists be involved in assessing and treating psychiatric disorders in autism? The answer lies in the fact that mental health conditions directly impact well-being and participation in occupations. Indeed, occupational scientists have long recognized the consequences of occupational participation on emotional well-being, suggesting that psychiatric concerns are essential for both occupational therapists and occupational scientists. Given this critical link, the current project explored factors that relate to mental health outcomes in this population by addressing three primary aims:

Aim 1. Evaluate the practicability of ecological momentary assessment to evaluate personal factors (e.g., emotions) and occupational participation in both research and therapeutic contexts, with a particular focus on adolescents with autism spectrum disorder (See Chapter 3).

Aim 2. Test the hypothesis that individuals with ASD and increased parental reported depressive symptomatology also demonstrate increased child-reported emotional instability and emotional inertia (See Chapter 4).

Aim 3. To understand in which occupations individuals with ASD report participating during the summer months, and to understand to what degree and in what profile affective experiences (e.g., bodily feelings and emotions) are reported during participation in occupation.

The aims were addressed using different methodological and analytical approaches, and I describe each in a single manuscript-style chapter (Chapters 3-5). This chapter provides a general overview of the diagnosis of ASD, mental health and depression in ASD, and emotion and occupation to lay the groundwork for the project.

1.2 Autism Spectrum Disorder

The ASD Phenotype. ASD is a lifelong neurodevelopmental disorder characterized by deficits in social communication and social interaction across multiple contexts, atypical sensory processing, along with restricted, repetitive patterns of behavior (RRB), interests or activities. While these prodromal symptoms are expected to be present in early childhood, they continue throughout development, and thus ASD is considered a lifelong disability. First described by Leo Kanner in 1943 (Kanner, 1943), there is increasing recognition amongst scientists that ASD is a heterogeneous spectrum of unique deficits related to social communication and the presence of RRBs and, importantly, the profile of these deficits is expected to change across the lifespan (Seltzer, Shattuck, Abbeduto, & Greenberg, 2004). Altered sensory processing is another core feature of ASD (see Baum, Stevenson, & Wallace, 2015 for a review). Atypical sensory processing patterns are present across all age groups, including adolescents (Leekam, Nieto, Libby, Wing, & Gould, 2007). There is little consensus on how to categorize sensory processing

patterns in this group (Marco, Hinkley, Hill, & Nagarajan, 2011). However, sensory processing patterns in this population are often divided into three main patterns: sensory hyper-sensitivity (strong negative reactions to low-level sensory stimuli), sensory hypo-sensitivity (diminished responses to sensory stimuli), and sensory seeking (strong desire for certain kinds of sensory experiences) (Baranek, David, Poe, Stone, & Watson, 2006). Atypical sensory processing impacts family participation in work, family, and leisure activities (Schaaf et al. 2011) and has been implicated in increasing mental illness symptoms of typically developing adults (Engel-Yeger & Dunn, 2011). One factor that impacts the autism spectrum trajectory is verbal ability as those who demonstrate better language ability also demonstrate better adaptive functioning and greater magnitude of symptom improvement over the lifespan (Howlin, Goode, Hutton, & Rutter, 2004); however, during adolescence, greater verbal ability can be problematic as it may predict onset of mental illness, particularly the onset of depression (Shattuck et al., 2007). Together, this research suggests that the ASD phenotype may look different both between individuals and within the same individual across developmental stages.

Given the diagnostic fuzziness and variability of this behavioral profile, a diagnosis of ASD typically requires a multi-pronged approach composed of gold-standard measures like the Autism Diagnostics Observation Scale, second edition (ADOS-2; Lord et al., 2012), a historical interview, and discussion about the child's performance in other contexts. Previously, under the DSM-IV (Association, 2000), ASD has been known as autism, pervasive developmental disorder (PDD), pervasive developmental disorder not otherwise specified (PDD-NOS), or Asperger's syndrome.

ASD Across the Lifespan. While it is true that the DSM categorizes ASD as a disorder present in early development, manifestations of autism persist throughout the lifespan, including

adolescence. Indeed, the DSM-V notes that social skills may mask ASD symptoms until a later developmental period, such as adolescence, when demands exceed the individual's capacities (American Psychiatric Association, 2013a). Problematically, though, there is relatively little research examining the impact of ASD amongst adolescents and adults (see Seltzer et al., 2004 for a review). The heterogeneity of the autism spectrum may limit our understanding of this developmental period. Similar to the variability observed in symptom manifestations in early childhood, the clinical course of ASD also demonstrates great heterogeneity during other developmental stages. Clinical and research accounts suggest that some individuals with ASD lose skills over time, others plateau in adolescence, and others continue to gain skills throughout their lifespan (Seltzer et al., 2004). Specific to adolescence, parents report concerns related to their child's behavior (i.e., increased aggression) (Mazurek, Kanne, & Wodka, 2013), sexuality and intimacy (Holmes, Himle, & Strassberg, 2016), family participation (i.e., restricted opportunities for families to engage in the community) (Bagatell, 2016), sleep (Goldman, Richdale, Clemons, & Malow, 2012), peer friendship and relationships, (Orsmond, Krauss, & Seltzer, 2004), and access to healthcare services (Zuckerman, Lindly, & Sinche, 2015).

It is important to note that there is disagreement between the research priorities of researchers who adopt a medical model of disability and the research priorities of individuals on the spectrum themselves. The vast majority of research in the field, including the literature previously reviewed, has focused on deficits regardless of whether the dependent variables are meaningful to those on the spectrum. Researchers and stake-holders who self-identify as having ASD have called for research that targets factors that influence the well-being of those on the spectrum (Chown et al., 2017; Pellicano, Dinsmore, & Charman, 2014). Specifically, individuals on the autism spectrum have called for research into understanding their daily life (Pellicano,

Dinsmore, & Charman, 2014). For example, individuals with ASD often demonstrate altered social processing (see Laugeson, Frankel, Gantman, Dillon, & Mogil, 2012, for a review) and try to put on a façade of pretending to be normal in social situations (Pellicano, Dinsmore, & Charman, 2014). Over time, persistent attempts of hiding one's features of ASD may lead individuals with ASD to feel isolated and have reduced well-being (Shattuck, Wagner, Narendorf, Sterzing, & Hensley, 2011). Social experiences have also been implicated in depression in this group (Bellini, 2006), further signifying social experiences play a role in the well-being of this population. Ultimately, this area of research when considered within the picture of the priorities of individuals with ASD suggests that research examining subjective and social experiences among adolescents with ASD remains an important next step.

Social communication and social motivation in ASD. An altered social communication profile is a core feature of ASD that may be particularly problematic during adolescent occupations and consequentially make individuals with ASD vulnerable to emotional comorbidities and reduced well-being (Bellini, 2006). Accordingly, this research forefronts the social dimension of occupation by examining how social experiences impact affective experiences with the view that social experiences have an important role in well-being. Previous research has found that individuals with ASD who have higher rates of self-perceived social deficits also have increased depression (Gotham, Bishop, Brunwasser, & Lord, 2014). This relationship has traditionally been measured where perception of social deficits is conceptualized as a long-term trait, but it may be that state momentary social experiences also impact well-being. Ultimately, this would suggest that social interactions viewed positively may decrease one's rate of self-perceived deficits, while self-perceived negative social interactions may heighten the rate of perceived deficits and lead to consequential depressive symptomatology.

This hypothesis is supported by emerging research, which has found that both adolescents and adults with ASD report feeling withdrawn in social settings (McDougall et al., 2018). This area of inquiry is in line with the voices of those on the spectrum who emphasize that research should move beyond identifying deficits and instead focus on issues that impact well-being without following normative assumptions of what constitutes well-being (Milton & Bracher, 2013).

While a prominent theory of ASD has largely focused on deficits in social motivation (Chevallier et al., 2015; Chevallier, Kohls, Troiani, Brodtkin, & Schultz, 2012), a growing body of work adopting a neurodiversity approach indicates those on the ASD spectrum have different, but not reduced, social motivation (Chevallier, Grèzes, Molesworth, Berthoz, & Happé, 2012). Differing patterns of social motivation may explain why youth with ASD indicate they have more friendships than their parents report for them (Kuo, Orsmond, Cohn, & Coster, 2013). For example, youth with ASD often have virtual friendships (Stendal & Balandin, 2015), but parents may fail to count these virtual relationships as friends. Also, individuals with ASD have a reduced social network size compared to their typically developing peers, which often includes others on the spectrum (Locke, Ishijima, Kasari, & London, 2010). These smaller networks offer the same protective benefits as their typically developing peers who have larger social networks (Locke, Ishijima, Kasari, & London, 2010). In a qualitative study, adults with ASD indicated that they often struggle to fit into social norms and instead prefer friendships in which the demands to adapt or ‘fit-in’ are reduced (Sosnowy, Silverman, Shattuck, & Garfield, 2018). This is unsurprising as most individuals, with autism or not, seek friendships and social situations in which they are accepted. Reduced social network size does not necessarily imply that individuals with ASD have reduced social motivation. Instead, it provides further evidence that adolescents with ASD have different patterns of social motivation driven largely by their subjective

experiences. Identification of situations, both social and not, in which individuals with ASD feel accepted and appreciated may play a key role in their expression of social motivation and in their affective experiences. Given the prominent relationship between well-being and social experiences in those with ASD, research that forefronts subjective experiences will lead to important insights with clinical implications. When negative social experiences occur, negative feelings may then develop and continue to persist despite changes in situations and occupations and may lead to maladaptive decreased well-being and increasing risk for mental health comorbidities.

Mental Health in Individuals with ASD. Depression is a commonly reported mental health comorbidity in ASD (Mazefsky, Kao, & Oswald, 2011). Estimates of depression in the ASD population range from 2% (Ghaziuddin, Tsai, & Ghaziuddin, 1992) to 44% (Strang et al., 2012). Additionally, self-reported depression in individuals with ASD has shown drastically different incidence rates than typically developing peers. For example, estimates of self-reported depression using the Child Depression Inventory Second Edition: Self Report (CDI 2: SR) range from 0% (Mazefsky et al., 2011) to 9% (Solomon, Miller, Taylor, Hinshaw, & Carter, 2012). Although clinicians and researchers often prefer to measure depression using self-reports, these discrepancies in prevalence have led scholars to argue that levels of self-reported depression in ASD are unreliable (e.g., Mazefsky, Kao, & Oswald, 2011; Solomon, Miller, Taylor, Hinshaw, & Carter, 2012). While there is no consensus regarding the incidence of depression, the studies mentioned above suggest that individuals with ASD are at high risk for depression, especially compared to their typically developing peers (who have a prevalence of 7.5%) (Avenevoli, Swendsen, He, Burstein, & Merikangas, 2015).

The variance in observed prevalence can be explained in part because it is challenging to differentiate prototypical ASD symptoms from comorbid depression due to overlapping symptomatology. DeFilippis (2018) noted that common features such as an increase in obsessive and ritualistic thinking, agitation, self-injury, sleep disturbances, and a decrease in former interests and adaptive functioning are part of the behavioral phenotypes of depression in this population and overlap with core features of ASD. This overlapping symptomatology may be particularly problematic during adolescence as explained by the two-hit model of ASD, a model that posits ASD status and adolescence can increase the risk for mental health comorbidities.

Two-hit model of ASD. Adolescence may be a particularly vulnerable time for mental health comorbidities in individuals with ASD (Picci & Scherf, 2015). Adolescence is characterized by increased social demands, pubertal hormonal changes, and increased academic demands. For both individuals with and without disabilities, adolescence can be a challenging time physically, socially, and academically. According to the two-hit model of mental health risk in ASD (Picci & Scherf, 2015), individuals with ASD experience the first *hit* with biological, genetic variations that predispose them to the typical challenges experienced by individuals with ASD. These challenges are evident in the DSM-V criteria for ASD, namely deficits in social-emotional reciprocity, nonverbal communication, and in developing, maintaining, and understanding relationships (American Psychiatric Association, 2013b). Additionally, the unique sensory processing patterns of individuals with ASD may increase their susceptibility to depression symptomatology (Serafini et al., 2017). These initial vulnerabilities pose unique social challenges for children as they are developing. The second *hit* occurs when children transition into the period of adolescence during which initial vulnerabilities worsen with the onset of the hormonal, social, and academic challenges typical of adolescence. The two-hit

model is thus a useful perspective for this dissertation as it considers why adolescence may be a particularly vulnerable time for depressive symptomatology in individuals with ASD. Further, this perspective highlights how varying social situations may impact depressive symptomatology.

The Relationship Between Mental Health and Mental Illness in those with ASD.

Primary constructs of interest in this dissertation include mental health and mental illness, particularly in relation to depressive symptomatology. A theoretical framework for this project's conceptualization of the mental health continuum is based on Caspi et al. (2014) and Lahey et al. (2015) who conceptualize mental health along one continuum. According to this hierarchical framework, psychopathology is conceptualized by one general psychology dimension, coined the *p* factor, and other more specific dimensions (e.g., internalizing and externalizing dimensions). The *p* factor represents a singular continuum of general psychological functioning, much like how intelligence quotient (IQ) is believed to be a measure of general intelligence that is comprised of other subdomains (Meier & Meier 2018). According to this model, low functioning is indicated by a variety of patterns, including high affective instability, long periods of sadness, and aggression which are all risk factors for mental illness; high functioning is indicated by subtle emotional fluctuations in response to daily life, agreeableness, conscientiousness and is protective against mental illness. General psychological functioning is viewed on a continuous, normally distributed scale from low to high comprised of multiple related subdomains of mental health and well-being. This includes but is not limited to psychosis (Caspi et al. 2014), response inhibition (Wright et al. 2014), patterns of affect (Caspi et al., 2014; Ward et al., 2017), and affective regulation (Shields et al. 2019). A higher score on the *p* factor indicates increased psychopathological severity and risk of mental illness, while a lower *p* factor indicates a lower

risk for mental illness (Conway et al., 2019). This framework suggests that decreasing psychological functioning is associated with worsening severity and longer duration of mental illness. In accordance with this framework, I view psychological functioning as a continuous indicator in which decreased functioning (as manifest by emotional instability) relates to increasing mental illness. While I recognize that emotional instability is just one component of the *p* factor, a significant body of research has implicated emotional instability in depression (e.g., Houben, Van Den Noortgate, & Kuppens, 2015; Thompson et al., 2012; Thompson, Berenbaum, & Bredemeier, 2011). Quantitative research often seeks to identify the most important variables in explaining variance of a particular variable. I propose that emotional instability may be a central component of the parsimonious model of depression risk.

The *p* factor has high predictive validity in mental illness and explains why adults with decreased general psychological functioning have much higher rates of mental illness (Kim & Eaton, 2015). Individuals with decreased psychological functioning, as indicated by the *p*-factor, have increased risk of depression (Waldman, Poore, van Hulle, Rathouz, & Lahey, 2016) and anxiety (Castellanos-Ryan et al., 2016). The *p* factor has also been implicated in suicidality among adolescents (Deutz, Geeraerts, van Baar, Deković, & Prinzie, 2015). One component of the *p* factor is emotional instability (Siegel, 2015; Ward et al., 2017; Conway et al., 2015), which has been linked to depression (Koval, Sütterlin, & Kuppens, 2015).

This theoretical perspective is also consistent with approaches to mental illness that categorize mental illness dimensionally, such as the Research Domain Criteria project (Cuthbert & Insel, 2010), and identify transdiagnostic risk factors for mental illness. The Research Domain Criteria project defines six domains of human functioning which center around contemporary knowledge of major systems of emotion, cognition, motivation and social behavior. These

domains are used to classify mental illness based on dimensions, and not categories, of observable behaviors and neurobiological measures. The project promotes the identification of transdiagnostic symptoms, symptoms present across varying mental illnesses, to better characterize the various dimensions of mental illness. The p factor is conceptualized as a dimensional indicator of functioning (Caspi et al., 2014) and thus an individual's psychological functioning is expected to change in response to new developmental periods or environmental contexts (Carver, Johnson, & Timpano, 2017). Because psychological functioning is variable and dimensional, an individual can have initial periods of decreased psychological functioning that gradually worsen over time into longer, more severe periods ultimately leading to mental illness. The important point here is that as psychological functioning decreases (and risk for mental illness increases) overall functioning is also impacted. According to this perspective, it is expected that an individual with decreased psychological functioning may have negative impacts to their daily occupations (e.g., an individual with high degrees of emotional instability may struggle to complete a homework assignment after hearing a negative comment from a peer). The developmental progression of a mental illness indicates that an individual with a depressive disorder would likely present with periods of milder depression at earlier developmental stages (see O'Sullivan 2004). This approach also suggests that identification and treatment of transdiagnostic symptoms (e.g., affective instability) will have important clinical implications, because improving functioning in areas related to transdiagnostic symptoms is likely to prevent or treat a number of potential mental illnesses. It also suggests that increased psychological functioning will improve other areas of daily functioning, such as completing homework in the case of an individual who struggles to concentrate due to emotional instability. Transdiagnostic

treatment approaches (i.e., those targeting a transdiagnostic symptom) have already proven fruitful for improving anxiety, depression, and quality of life (Newby et al. 2015; Norton 2012).

I view this mental health framework within the two-hit model to propose that adolescence may be a challenging time in which, for some, psychological functioning is decreased thereby increasing risk for mental illness, particularly depression. Identification of individuals with decreased psychological functioning, as operationalized as affective instability, is thus important towards identification of those who may be at risk for mental illness.

1.3 Emotion and Occupation

A central belief for this research is that “the basis of experience is emotional” (Whitehead, 1961, p. 178) and that affective experiences impregnate all occupations. From its foundation in 1990, occupational scientists have recognized the inherent connection between context, occupation, and emotion (Yerxa, 1990). Before providing a brief review of the literature on how occupational science researchers have characterized the affective dimension of occupation, I will first define terms for clarity. For this dissertation, I define two core components of the affective experience to distinguish between emotions and affectus. Affectus is the incipient state of emotion that emerges, persists, and shifts in the context of an occupation (Dallman & Triplett, 2019., p. 1). Embodied experiences such as unease in the gut when approaching a meeting with one’s boss, or tightness in the hands when waiting on hold with a cable company, are examples of affectus by this definition. These embodied experiences are not easily described by traditional emotional words nor are they experiences that are assumed static (i.e., I do not assume that tightness in the gut is just one experience, but instead is characterized by a host of growing and changing bodily experiences), yet many can agree these affectus experiences are ubiquitous. I have also chosen Spinoza’s term affectus to follow my previous

work published in occupational science literature (Dallman & Triplett, 2019) and to avoid confusion with psychology's tradition of using affect and emotion interchangeably. In Chapter 5, I explore the phenomenon of affectus through examination of emotions and co-occurring bodily feelings. For ease in translation of these findings, I cast these experiences as co-occurring bodily feelings, thereby limiting the use of jargon; however, the concept of affectus served as a fundamental guide for that research area. In contrast to affectus, I define emotions as the psychological constructs which are labeled forms of affectus. Emotions, such as angry or happy, are limited by the lexicon of culture and informed by folk psychology (Barrett, 2006; Hoemann & Barrett, 2018). This definition draws from the work of post-structuralist philosophers Massumi and Deleuze. As Massumi notes:

An emotion is a subjective content, the socio-linguistic fixing of the quality of an experience which is from that point onward defined as personal. Emotion is qualified intensity, the conventional, consensual point of intersection of intensity into semantically and semiotically formed progressions, into narrativizable action reaction circuits, into function and meaning. (Massumi, 1995, p. 88)

I use the instrument the Positive and Negative Affect Schedule (PANAS) (Sanmartín et al., 2018) to capture 10 emotions which are placed into two domains, positive and negative affect. Positive affect (PA) reflects the degree a person may feel enthusiastic, active, and alert. Negative affect (NA) reflects the degree a person feels aversive mood states such as anger, contempt, disgust, and nervousness (Watson, Clark, & Tellegen, 1988). Adopting this definition of affect rests in contrast to some psychologists who draw further distinction between emotion and affect (Barrett, 2017; Barrett, Mesquita, & Gendron, 2011; Hoemann, Gendron, & Barrett, 2017); these researchers consider affect

broadly as any state that represents how an object or situation impacts a person, which includes changes to one's body (Duncan & Barrett, 2007). To help clarify our meaning, I adopt the term *affectus* to refer to similar experiences referenced by Barrett as *affect*, which brings to light the many different ways situations impact a person (e.g., bodily feelings in response to changing situations). Importantly, the process of ascribing language to *affectus* obfuscates the richness and heterogeneity of the experience by subsuming it under a label with normative assumptions of experience. *Affectus* then is purposively defined broadly to encompass and capture the full range of experiences captured under the affective domain during occupational participation. By taking a broad perspective on *affectus*, I recognize that emotional labels are “crude tools for describing and interpreting the whole range of human emotions” (Wierzbicka, 2009, p. 3).

Consequently, affective experiences that are not easily captured by emotion labels are difficult to describe. This difficulty is problematic because research participants may experience complex vacillating emotions as they engage in occupational performance that neither fit into traditional definitions of emotions nor are captured in most measures of emotional experience (Sullivan & Strongman, 2003). For adolescents with ASD, this suggests that assessment methods that employ traditional emotional language (e.g., happy or sad) would be insufficient for understanding their affective experiences. This dissertation includes a combination of quantitative and qualitative methods that will aim to capture the breadth of experiences described within the affective domain, thereby accounting for the lexical challenge inherent in affective experiences. I combine assessments that evaluate experiences using both traditional emotion words (such as “happy) and bodily experiences that may accompany emotions to capture both of these

affective dimensions. Given that this dissertation forefronts the affective dimension of occupation, it is important to consider how occupational scientists have conceptualized the connection between emotion and affectus.

Occupations as a mechanism for changing emotions. Occupational scientists have frequently studied how engagement in occupation changes one's emotional experiences. Graham (2002), for example, found that dancing with others results in participants sharing in the process of learning how particular cultures express emotions. According to research in this area, engaging in an occupation, such as dance, with others results in a shared emotional experience best understood as an outcome of shared occupational participation (Pierce, 2009). Other research in this area by Sakuae and Reid (2012) has shown how women participating in a tea ceremony experience shared emotion. Through co-occupation, participants' emotional experiences can be modulated, suggesting that the social dimension of occupation may be important when considering issues about emotion. As a whole, this body of scholarship suggests that occupations can lead to changes in emotional states.

Emotions as isolated domains. Occupational science researchers frequently represent emotions as isolated domains of experience (see Dallman & Triplett, 2019 for a review). Scholars in this area assume that individuals who report feeling an emotion, such as angry, are reporting the same experience as another individual who reports feeling angry. These static emotion terms assume distinct boundaries between emotion states, as well as a subset of shared basic emotions (Kagan, 2010). Importantly, the lexicon of the individual's culture further limits the breadth of experiences captured by emotion words. "This is problematic because words such as 'happy,' 'sad,' and 'exhausted' are understood to be universal" (Dallman & Triplett, 2019, p. 1), but in most cases, these emotions do not "look alike, feel alike, or have the same

neurophysiological signature” (Barrett, Lindquist, & Gendron, 2007, p. 4). Rather, emotions are “culturally and symbolically produced, expressed, and felt” (Leavitt, 1996, p. 532) by both researchers and participants. With these challenges in mind, this dissertation examines both affectus and emotion to avoid normative expectations associated with emotional labels and explore the unfolding of affective experiences.

Emotion, ASD, and Occupational Science. The majority of occupational science research on emotions among those on the autism spectrum has focused on parent perspectives of emotion (Boyd, McCarty, & Sethi, 2014) and has seldom directly investigated the emotional experiences of individuals with ASD in the context of occupation. However, a few occupational science scholars have used ethnographic methods to explore occupational engagement from the perspective of individuals with ASD (Bagatell, 2007). In a secondary data analysis, Bagatell (2012) noted that the emotional prompts of a classmate with ASD facilitated engagement of an individual with ASD, which provides early evidence that emotional experiences mediate engagement in occupation. Additionally, Spitzer (2003) ethnographic study of children with ASD provides evidence that occupations are the means through which children with ASD experience pleasure. This dissertation research leverages that finding to examine how positive occupational experiences may impact subsequent occupational participation.

Given the dearth of literature directly examining the affective dimension of occupations in individuals with ASD, research that explicitly investigates this relationship will have a significant contribution to the occupational science literature. Knowledge in this area is important because it will provide insight into the process through which emotions change for this population, which has treatment implications for depression in adolescents with ASD.

1.4 Defining Occupation

A central premise in this research is that affective experiences arise through occupation and, accordingly, it is important to consider how occupational scientists have defined occupation to understand when and how I expect affective experiences to emerge. Because occupational scientists have begun and sustained a tradition of debate and dialogue regarding the term occupation, there is no shortage of definitions of occupation in occupational science. I define occupations as the individualized, one-time engagement in a particular activity that is situated in physical, social, environmental, and embodied contexts (Pierce, 2001). While patterns of action formulated through habit development comprise occupational performance, I side with Pierce (2001) in arguing that occupational participation is a doing in a certain and specific context (temporal, geographical, and social). This definition thus differentiates activities, which are the general set of doings that people conceptualize, from occupations, which are the specific non-repeatable event of someone doing within a specific context. This definition rests in contrast to other occupational scientists who have situated occupations within the bounds of a particular culture. For example, Yerxa et al. (1990) defined occupation as “chunks of culturally and personally meaningful activity” that can be “named in the lexicon of our culture” (Yerxa, 1990, p. 301). Given that I define occupations as the one-time, non-repeatable experience, it is important to consider how to categorize occupations to allow for comparisons of occupational participation.

Some definitions of occupations have suggested that occupations can be categorized. Kielhofner (2002) defines occupation as the “doing of work, play, or activities of daily living within a temporal, physical, and sociocultural context that characterizes much of human life” (p. 5). However, Jonsson (2008) has critiqued the use of such categorizations of occupation and

suggested that individuals do not experience occupations as fitting neatly into these three categories. Instead, Jonsson argues for the categorization of occupations based on how people experience their occupational engagement. Hammell (2009) echoes this sentiment by calling for client-driven categorizations of occupations. She argues that current categorizations reflect an ableist and Western idea of doing. In this study, I categorize occupations dimensionally by examining how the participants report their level of enjoyment during their occupational participation. By adopting a fluid conceptualization of occupation that avoids research-led categories, I allow for heterogeneity in the experience of occupational engagement.

1.5 Gaps in the Literature

While a growing body of literature suggests that individuals with ASD experience increased rates of clinical depression and depressive symptomatology, the transactions of depressive symptomatology and occupations in this population remains unclear. This dearth in the literature is surprising given that emotional experiences, and by extension depressive symptomatology, and environments and situations have been linked in other populations, suggesting that transactions in this area may have major clinical significance. Given that adolescents with ASD are particularly vulnerable to co-occurring mental health conditions such as depression, a clear understanding of these transactions in the adolescent ASD population is a serious concern for occupational therapy and occupational science research and practice. Further, the development of research methods that are uniquely able to assess these transactions in a variety of real-world settings will provide occupational therapists and occupational scientists working across a number of different populations a new tool for assessing and evaluating the relationship between occupation and other client factors. Ecological momentary assessment has shown to be a promising approach in other disciplines such as psychology but has had limited

application in occupational therapy research and practice. The EMA method is uniquely able to assess transactions in real-world contexts. Perhaps, one reason that occupational therapists have not widely implemented this method is an absence of methodological guidance on how to implement EMA in occupational therapy and occupational science research and practice.

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CHAPTER 2. THEORETICAL AND PHILOSOPHICAL PERSPECTIVES INFORMING THE PROJECT

2.1 Perspectives of Transaction

Occupational scientists have critiqued theoretical frameworks which portray the person as separate from and contained within the environment (Dickie, Cutchin, & Humphry, 2006). The transactional perspective, based on the philosophy of John Dewey, argues that the individual and the environment are co-constitutive and co-defining facets of a situational whole. The analytic focus of this perspective is not on the individual or the environment, but on the relationship between the two.

The transactional perspective and Dewey's philosophy emphasized the importance of habits to occupational performance (Cutchin, Aldrich, Bailliard, & Coppola, 2008). Through habits, individual and environment are brought together into functional coordination. Functional coordination is the active process through which a person and context co-constitute one another to the end of achieving optimal functioning and harmony (Aldrich & Cutchin, 2013).

We think of [habits] as passive tools waiting to be called into action from within... It makes us do things we are ashamed of, things which we tell ourselves we prefer not to do. It overrides our formal resolutions, our conscious decisions. When we are honest with ourselves we acknowledge that a habit has this power because it is so intimately a part of ourselves. It has a hold upon us because we are the habit. (Dewey, 2005, p. 24)

The lived being is a conglomerate of these predisposed, relational, and necessary habits (Kestenbaum, 1978). According to Dewey, when habits do not functionally coordinate, these configurations then require modification, because they are incompatible to the present situation. Although few scholars have fully explored Dewey's perspective on emotion, Angier (1927) provided one analysis of Dewey's corpus of emotion scholarship. Angier argued that habits are akin to attitudes, which are residual reactive patterns formed through past experiences. When these configurations do not functionally coordinate, they then create conflicts that give rise to emotions (Angier, 1927). Although Angier does not situate these conflicts within the context of an activity, I argue that these conflicts occur within an occupation. Recent theory from occupational scientists (Bailliard, 2015) and psychologists (Barrett, 2017) suggest that anticipated consequences of action, based on sedimented habits from past experiences, guide expectations of experience and when those expectations are not met a new constellation of predictions and emotions arise (Hoemann, Gendron, & Barrett, 2017).

The transactional perspective was highly influential in the design of this dissertation's methods. In this project, I aim to account for and examine the transaction between context, emotion/affectus, and occupation by assessing emotions and affectus in a variety of contexts. Additionally, I include the social dimension of occupation in order to acknowledge that occupational participation does not rest within the individual, but instead rests in the relationship between individuals, those they are around, and the occupation itself.

2.2 Phenomenology of the Embodied Organism

The transactional perspective is synergistic with Merleau-Ponty's phenomenological perspective and suggests that all information is processed and experienced through our corporeal bodies (Bailliard, Carroll, & Dallman, 2018). Sensory habits guide the body's performance

through the world (Bailliard, 2013) and orient a person to potential directions of action (Bailliard et al., 2018). Additionally, perceptual couplings with the social and physical world become the basis for learning, shared experiences (Bailliard et al., 2018), and emotions (Krueger, 2013). This perspective highlights that emotions are an emergent and relational phenomenon that rises through couplings with the sensorial and social world (Game, 1997). Indeed, from a Merleau-Pontian phenomenological perspective, emotions are entangled with our sensory experiences (Jones, 2012).

For Merleau-Ponty, emotions (and their expression) are not symbolic references to internal states, but “appear as experienced events of being movingly touched in relation to (one-) selves, others and worlds” (Küpers, 2014, p. 152) and occupations. To have and experience an emotion “is to process, realize, or to enact a moving relation to the phenomenal world” (Küpers et al., 2014, p. 159). As this relation develops, habits of perception and orientation become guiding forces for occupational performances (Bailliard et al., 2018) and emotional experiences (Barrett, Quigley, & Hamilton, 2016). Thus, emotion and affectus are an emergent indeterminate potentiality, implicated in occupational engagement that arises through the real-virtual. To speak of occupational engagement is to speak of actions laden with emotional and affective meanings. This transaction is an important point for this study because it suggests that emotions are not fixed states, but instead will continually change as situations change. Additionally, this theory suggests that relying purely on cognitivistic or linguistic accounts of emotion is insufficient for describing affectus. Thus, exploring these dimensions of experience requires multimodal approaches. Methods of assessment that use both emotion words and embodied physical accounts of sensations will be advantageous in elucidating these complex phenomena.

2.3 Philosophical Position

I hold a pragmatist philosophical position that guided the research aims and research direction for this current project. Pragmatism is concerned with answering questions about epistemology and ontology through an examination of the things people actually, or might do. This view rests in stark contrast to other postmodernist thinkers, namely Lyotard (Lyotard, Bennington, & Massumi, 1984), Foucault (2013), and Nietzsche (Gemes, 1992), who resist the existence of certain knowledge in favor of a constant indeterminate knowledge. The pragmatist tradition, however, acknowledges that while there is no true knowledge, everyday people practically deal with everyday tasks. That is, by the nature of being human, we must make decisions throughout our day. When this philosophy is extended to research, it suggests that practitioners and clinicians must produce trustworthy knowledge that is applicable to practice and the lives of people (Dewey, 1958a). In this study, I evaluate occupational participation through ecological momentary assessment. This methodology evaluates what people do while they are actually engaging in that activity, thereby bringing the participants engagement in real activities to the forefront. Additionally, the pragmatist tradition considers seemingly mental objects, such as emotions and depressive symptomatology (a central focus in the present study) as situated within a system of interdependent components and a social praxis (Guyon et al., 2018, p. 152). Accordingly, mental objects “should be seen as resulting from a process integrated into a system of interacting and interdependent components. In such systems, the activity of every process is interdependent with others...” (Guyon et al., 2018, p. 152). In this project, I examine mental attributes *in vivo*, and thus, I evaluate them within the participant’s contexts.

Recently, researchers have questioned the role of quantitative research in the pragmatist tradition. Zyphur and Pierides (2017) question whether traditional quantitative research methods

are ethical and can solve human social problems, a necessary condition of pragmatist research. However, I agree with Powell (2019) in arguing that “the choice is not between ethical and unethical quantitative research, but among a range of imperfect quantitative methods, each invite its own human error” (p. 5). Thus, quantitative research is not perfect, but neither is qualitative research; instead, I propose that pragmatic research should be evaluated in the way it impacts the lives of everyday people. Further, I agree with Jayanti (2011), who argued that pragmatic research should be evaluated based on a set of criteria in order to “judge the quality of a particular piece of research” (p. 443) from a particular epistemological standpoint. This project addresses four of the seven proposed criteria for pragmatic research, and these criteria include: (1) examines interconnections between units, (2), integrates theory-generation and theory-testing, (3) produces outputs which take the form of patterns, and (4) uses a dual focus on both the means and ends. I address the first criteria by assessing the connection between emotions, environments, and occupational participation. I address the second criteria by testing theory developed for the typically developing population while simultaneously generating theory for individuals with ASD. This dissertation research addresses the third criteria by analytically examining patterns of emotions. Lastly, I address the fourth criteria by focusing this research on both *means*, momentary affective experiences, as well as the *ends*, depressive symptomatology. Naturally, evaluating the pragmatic contribution of research *a priori* is impossible. However, by keeping the research aims in line with the everyday problems of individuals with ASD, I align this dissertation research with the practical need areas of those with ASD.

The pragmatist tradition also brings to light how I, as a researcher, have habits of thinking which serve as “an acquired predisposition to ways or modes of response” (p. 42) within my research. These habits guide my research aims and suggest particular modes of research.

However, Dewey's scholarship also emphasizes how, through a democratic process of education, one experiences challenges and subsequent growth, thereby inviting different modes of thinking. Accordingly, my team of dissertation advisors and consultants includes individuals from a variety of stakeholder and expertise positions; by including experts in special education, developmental psychology, clinical psychology, mental health, and autism, this research project has been challenged by multiple individuals. Together, these advisors form a research community with shared responsibility in the growth and development of the dissertation project. They have also enabled my own research habits to be challenged while simultaneously giving this research project, "the power to grow" (Dewey, 1923, p. 62).

In addition to the previously mentioned criterion for evaluating pragmatic research, I maintained a pragmatist perspective in general by using three primary strategies. (1) I incorporated multiple perspectives on depressive symptomatology (both parent and child), thereby decentralizing research from either parent or child perspectives. I also (2) evaluated emotions as emerging properties developed through and embedded in intersubjective interactions during everyday occupational participation. (3) I also evaluate emotions using a multi-morphic scale. I incorporated multiple perspectives (both the parent and the child himself) and multiple types of assessment (retrospective reports and *in vivo* EMA).

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CHAPTER 3. METHODOLOGICAL CONSIDERATIONS AND PRACTICALITY OF ECOLOGICAL MOMENTARY ASSESSMENT OF OCCUPATIONAL PARTICIPATION WITH ADOLESCENTS WITH AUTISM SPECTRUM DISORDER

3.1 Background

Occupational therapists view transactions between clients, environments, and occupational participation as a central concern in the promotion of health and well-being. For decades, occupational therapy practitioners and researchers have called for a thorough understanding of the environment-person relationship to facilitate the development of targeted interventions that meet real-world needs in context (see Yerxa, 1980; Fisher, 1998). As aptly stated by the Canadian Association of Occupational Therapists (CAOT), through skilled occupational therapy intervention, “the client is encouraged to discover new ways of viewing occupational performance problems, implement accurate methods to assess present capacities, and consider suggestions for use of person and environmental resources” (CAOT, 1999, p. 2) that vary with the occupation of interest. As this statement implies, to ensure the translation of evidence-based practices into a client’s real-life, both occupational therapists and researchers need a thorough understanding of a client’s natural contexts in order to understand how person and environment merge to generate performance for occupational therapists to purposefully leverage an individual’s unique environmental resources in the intervention (AOTA, 2014). Moreover, in doing so, occupational therapists produce research and practice that maintains ecological validity and provides an understanding of real-world engagement. Ecological validity is the degree an assessment or treatment represents an individuals’ interactions and performances with their situations (Wallisch, Little, Dean, & Dunn, 2018). Indeed, “providing opportunities for

all members of society to engage in health-promoting occupations through flexibility in the analysis of the environment and context in which clients thrive is essential” (AOTA, 2015, p. 6913410050p5).

Ultimately, both occupational therapists and occupational therapy researchers share a set of values that are concerned with how occupation impacts and is impacted by a person’s natural contexts (Canadian Association of Occupational Therapists, 2002). Both the Canadian Framework for Ethical Occupational Therapy Practice (Brockett, Dick, & Canadian Association of Occupational Therapists, 2006) and the American Occupational Therapy Code of Ethics (AOTA, 2015) implicate understanding the environment and how skills taught in therapy translate into the environment as essential for ethical practice, suggesting that understanding a client’s natural context is not only best practice, but also a necessary component of ethical occupational therapy practice. Therefore, it is important to consider the ecological validity of occupational therapy assessments.

Ecological Validity in Occupational Therapy Assessments and Research. Established through either the veridical approach, defined as a proven statistical relationship with real-world performance, or verisimilitude approach, defined as the ability of an assessment to closely resemble performance in the real-world, ecological validity is important for occupational therapy assessment as it ensures skills assessed relate to performance in an individual’s daily life. Understanding how occupational performance looks and feels for an individual in the moment is of great importance when considering factors that are difficult to capture via retrospective reports such as pain, fatigue, emotions, or frequency counts of other phenomena. For example, consider the example of assessing how pain impacts activities of daily living. When measures that have poor ecological validity, such as those that rely on retrospective report (i.e., “how painful has

doing the laundry been for you over the past two weeks?”), are employed, participants often underreport their degree of pain (Schwarz, 2007). In such a scenario, a hand therapist using a retrospective measure might underestimate the impact carpal tunnel syndrome is having on a client’s activities of daily living.

Assessments used in both occupational therapy practice and research with established veridicality are tests such as the Adolescent/Adult Sensory Profile (AASP; Engel-Yeger, 2012). The AASP has been shown to be related to the development of close relationships in adulthood (Jerome & Liss, 2005), depression (Pfeiffer, Kinnealey, Reed, & Herzberg, 2005), and food selectivity (Kuschner et al., 2015) which provides evidence that the measure has statistical relationships to real-world performance. By using assessments with established validity through the veridical approach, researchers and practitioners ensure that the assessed areas are important for a client’s daily life and impact other areas of functioning.

A second approach to establish ecological validity is verisimilitude. The Behavior Rating Inventory of Executive Function (BRIEF; Gioia, Isquith, Guy, & Kenworthy, 2000), for example, has validity established through the verisimilitude approach and provides insight into a client’s executive functioning performance in everyday occupational participation by examining behaviors that occur in a child’s normal day to day life, such as: remaining seated during tasks, transitioning between activities, and accepting changes to the normal routine. Assessments with ecological validity established through the verisimilitude approach offer the advantage of providing a picture of performance in relevant environments.

Methodological Issues Beyond Ecological Validity during Measurement in Research and Practice. When an assessment approach has established ecological validity, it remains important to consider the advantages and limitations of the type of assessment, as monolithic

assessment approaches risk misclassification of behaviors and experiences (Hom, Joiner, & Bernert, 2016). For example, therapists and researchers often use observation of occupational performances (AOTA, 2014; Mulligan, 2003), but time demands placed on practitioners often limit the length of occupational evaluations and opportunities for observations (Jongbloed & Wendland, 2002). When possible, observational methodologies are advantageous as they allow for the trained eye of the occupational therapist and researcher to observe and assess real-world performances in a context that has high ecological relevance to the client's real-world context. However, research is beginning to converge to show that additional persons present during an assessment (e.g., a therapist or researcher) can impact performance (Constantinou, Ashendorf, & McCaffrey, 2005; McCaffrey, Lynch, & Yantz, 2005). The presence of a researcher may also impact how participants respond to questionnaires, leading participants to respond with more socially desirable responses (Tracey, 2016), which, when used in isolation, can result in the misclassification of performances. For example, a client or research participant who normally walks around their house without a prescribed adaptive walking device may be more careful to use the device when an occupational therapist or researcher is present or report that they do so when asked by a therapist during an in-person occupational profile interview.

When observation of occupational performance in a client's natural context is not possible, therapists often use retrospective accounts from clients or caregivers. While performance-based observations and retrospective accounts have shown moderate similarity in some studies (Nielsen & Wæhrens, 2015), other studies have shown discordance between retrospective-reports and observations of instrumental activities of daily living (Hilton, Fricke, & Unsworth, 2001) bringing into question the veracity of such reports. Affective experiences, such as life satisfaction, are particularly prone to retrospective bias (Walker, Skowronski, &

Thompson, 2003). Individuals' current experiences tend to influence how they report past experiences (i.e., if they are happier now, they will report generally being happier in the past despite actually feeling sad) (Walker, Skowronski, & Thompson, 2003). Additionally, individuals tend to remember only the salient moments, the peaks and ends of events, and not the duration, suggesting that some of the minor fluctuations in elements of occupational performance will be lost by reflective accounts (Smallwood & O'Connor, 2011).

While retrospective accounts are prone to bias, it is important to acknowledge their utility. Retrospective reports provide insight into how a client remembers past events. When participants reflect on their lives and tell their stories, they account for the salient meaning of these events. Without meaning, occupational therapy interventions and research can quickly become prescriptive and not client centered. Reflective accounts provide perspective on the why behind what people do. Additionally, retrospective accounts enable researchers to understand how past events have been brought forth into an individual's identity (McAdams 2018). If, however, it is important to avoid retrospective bias for the research or clinical question at hand, methods that assess occupational performance during occupational engagement will reduce the time between an occupational experience and reporting, leading to reduced opportunities for a new experience to reframe past experiences. There are many examples of when occupational therapists may be motivated to reduce retrospective bias. For example, a therapist may be interested in examining the intensity of pain while completing activities of daily living. Reports of pain are highly influenced by retrospective bias (Teirlinck et al. 2019) and would therefore fail to capture the real-world frequency of pain and its impact on participation. To fully understand the impact of pain on moments of occupational participation, a therapist would benefit from capturing data in the moment the phenomena are experienced. A therapist may also be interested

in understanding the degree of fatigue experienced throughout a day. The nuances of degrees of fatigue are also subject to retrospective bias (Schneider, Stone, Schwartz, & Broderick, 2011) and would be better captured by assessment methods that measure fatigue as it occurs. In these examples, and in the many others when retrospective bias may be problematic, it is advantageous to use assessment tools with greater ecological validity, such as ecological momentary assessment.

Ecological Momentary Assessment as an Ecologically Valid Assessment of Occupational Performance. Ecological momentary assessment (EMA) includes a variety of ecologically valid assessment types that share three broad qualities, they: 1) capture the variation of an individual's momentary experiences over time, 2) assess the relationship between contextual factors and individual experiences, and 3) examine variations of a phenomena of interest over time (Stone & Shiffman, 1994). The vast majority of EMA research has been conducted by psychologists interested in understanding problematic behaviors (i.e., smoking) (Shiffman et al., 2002). Ironically, while EMA is often praised for its ecological validity, most researchers ignore critical ecological variables (such as activity performance) in their analyses of EMA data (Ram, Brinberg, Pincus, & Conroy, 2017).

Prior to the explosion of mobile technology, EMA methods were limited to more rudimentary forms of data collection, such as daily diaries completed by participants on paper and pencil and at the end of the day (Intille, Stone, & Shiffman, 2007). However, with the ever-growing availability and affordability of mobile technology, EMA is increasingly easier to implement using applications available in a client's mobile device (such as timers), email messages, or text messages. EMA is one ecologically valid assessment method (Shiffman & Stone, 1998) that may be beneficial for occupational therapists and researchers in the creation of

occupational profiles and in the ongoing assessment of an individual's occupational performance. While these platforms allow for a more intense or nuanced sampling scheme, the repeated sampling methodology is invasive, and thus, researchers and clinicians must exercise caution in the design and implementation of EMA. To reduce invasiveness, occupational therapists must carefully consider how often and under what circumstances a phenomenon should be assessed to provide a comprehensive understanding while avoiding undue client burden.

Study Purpose

With these interests in mind, the aim of this paper is to evaluate the utility of EMA of occupational participation in occupational therapy practice and research. We begin by presenting a study using EMA to explore the affective dimensions of occupation among adolescents on the autism spectrum. We simultaneously review key considerations in the design of EMA studies, fore fronting both clinical and research issues.

3.2 Demonstrating the utility of EMA

EMA is a rich assessment method for both occupational therapy clinicians and researchers as it provides a nuanced and detailed perspective about occupational participation. In this paper, we present methods and results from the Temporal Evaluation of eMotion, Place, and Occupation study (TEMPO) to demonstrate the utility of EMA for occupational therapy research. We also extend these findings to argue that EMA could be advantageous in occupational practice. TEMPO focuses on the use of EMA as a self-report tool of occupational participation and client factors (i.e., emotions) among adolescents with autism spectrum disorder (ASD). Ecological momentary assessment is advantageous to examine this research area because emotions are expected to vary in response to occupational participation throughout the day. We

were particularly interested in the emotional experiences of adolescents with ASD because these individuals are at increased risk for co-occurring mental health conditions, particularly depression, (Mazefsky, Kao, & Oswald, 2011) and occupational participation has been linked to emotions (Dallman & Triplett, 2019; Graham, 2002; Martin, Sadlo, & Stew, 2012; Wright, Wright, Sadlo, & Stew, 2014), suggesting that occupations may play a key role in the experience of depressive symptomatology in this population.

Researchers in occupational therapy frequently rely on parent reports of emotional patterns among those on the autism spectrum (e.g., Boyd et al., 2014), and few have investigated the emotional experiences of individuals with ASD in the context of occupation (e.g., Bagatell, 2007). However, we were aware of no studies examining emotional and occupational experiences in this population using self-report by the individual with ASD himself. While there remains a gap in understanding subjective occupational experiences in this population, a growing body of literature has emphasized the importance of using self-reports from those on the autism spectrum to understand their subjective experiences (Chen, Bundy, Cordier, Chien, & Einfeld, 2015; Jaswal & Akhtar, 2019; Kapp, Goldknopf, Brooks, Kofner, & Hossain, 2019; Kenny et al., 2016; Vincent et al., 2017), suggesting that self-report to understand occupational and emotional experiences will continue to be an important area for future research. Self-report is preferred in emotion-based research as emotions are believed to be, at least in part, personal (Barrett, Mesquita, Ochsner, & Gross, 2007). Investigating the relationship between affective experiences and occupational participation is particularly important due to the high prevalence of depression in this population (Mazefsky, Pelphrey, & Dahl, 2012) as affective variability is believed to be a transdiagnostic symptom linked to mental illness and depression (Barrett, Quigley, & Hamilton, 2016; Marwaha et al., 2018). Given the dearth of literature directly examining the affective

dimension of occupations in individuals with ASD and the lack of assessments targeted to the affective dimension of occupational participation in a variety of contexts, we investigated the relationship between occupational participation and affective instability, a transdiagnostic symptom related to mental illness (Jahng, Wood, & Trull, 2008). In this paper, we forefront the decision-making processes used through the TEMPO research study in the hope that the description of this process may be useful to clinicians and researchers aiming to employ EMA in clinical and research settings.

Study Description

The TEMPO study used semi-random sampling EMA, discussed later. Participants were 17 male adolescents with ASD aged 11-18 years ($M=14$ years, $SD=2$ years). Sample characteristics are presented in Table 3.1, stratified by the percentage of study completion. We stratify participants by degree of study completion to demonstrate that no variables explained who, among our participants, was most likely to complete the study. This finding is discussed later, but provides evidence for the utility of EMA in the ASD population. Participants resided in Central and Eastern North Carolina and were required to have a composite abbreviated intelligence quotient greater than 85, speak fluent English, and have regular access to a mobile phone. Ethical approval for this study was granted by the Institutional Review Board of the University of North Carolina at Chapel Hill. Parents were informed about the study through an ASD research registry, flyers posted on social media, and a central database of university-affiliated employees/students. Parents interested in the study contacted the research team via email, postcard, or phone call. Interested parents were then contacted and invited for participation by the first author. All participants were evaluated by the first author and a research assistant.

During the initial screening visit, participants completed the Stanford-Binet Intelligence Test, fifth edition (Roid, 2003) and a set of demographic questionnaires. Caregivers also completed a set of demographic questionnaires about themselves and their child. Adolescents with ASD engaged in EMA procedures during which they were signaled six times a day, semi-randomly for seven consecutive days to complete a questionnaire through Qualtrics (Qualtrics, 2019). Each participant’s initial prompt was sent semi-randomly within two hours of their parent-reported waketime. Subsequent prompts were sent two hours after the initial message.

Table 3.1: Demographics of responders vs. non-responders

	<u>> 60% response rate (n=12)</u>	<u><60% Response Rate (n=5)</u>
Child Age	14(2.47)	14 (1.58)
Overall % Completion	84(15)	55(29)
ABIQ	108(16.10)	102(11)
CDI 2: SR Total	14.17(9.76)	9(4.53)
CDI 2: PR Total	61.67(10.82)	60(4.10)
Child Race	White (n=11) Black (n=1) Mixed-race(n=1)	White (n=3) Other (n=1)
Child Educational Placement	Regular public school (n=8) Regular private school (n=2) Special class in regular school (n=1) Special school for children with disabilities (n=1) Home-schooled (n=1)	Regular school (n=3) Home-schooled (n=1)

ABIQ=Abbreviated Intelligence Quotient, CDI 2: SR =Child Depression Inventory Second Edition: Self Report, CDI 2: PR=Child Depression Inventory Second Edition: Parent Report

The results of the study are presented in Chapter 4. However, here we present the key methodological challenges we encountered along with the ways we addressed these issues.

Methodological Challenges and Considerations in EMA Research

EMA studies should be carefully designed in order to strike a balance between assessment sensitivity, participant burden, potential contributions to understanding a research area, and potential contributions to understanding a client's particular needs. First, we present three general classes of EMA and highlight the clinical and research considerations for each approach. We then present specific considerations when conducting EMA research.

Daily Diary Approach to EMA. In the daily diary approach, participants complete a questionnaire, usually at the same time of every day (e.g., every morning, every evening, etc.). Often times, researchers and clinicians employ the daily diary approach under the assumption that the phenomenon of interest does not meaningfully vary throughout the day or assume that retrospection can summarize any variations experienced during the day (Stone, Shiffman, Atienza, & Nebeling, 2007). The daily diary approach asks participants to answer questions about a set period (i.e., the past 24 hours, the workday, or the past week). The utility of daily-diary approaches for occupational therapy practice is vast as the approach is strongly advantageous to understanding patterns of occupational engagement. Occupations that are likely to occur throughout the day (e.g., toileting, reading) can be assessed at the end of the day, enabling the clinician or researcher to see an individual's broad occupational experiences that day. Indeed, daily diary approaches have already been incorporated into occupational therapy scholarship. For example, Atler (2014) used a daily diary approach to developing the Occupational Experiences Profile (OEP). The OEP is a client-centered time-use diary that captures three dimensions of occupational participation: pleasure, productivity, restoration, and social connection during a 24-hour period (Atler & Berg, 2018). Although daily diary approaches are clearly advantageous for questions about human participation, daily diaries either

(1) rely on retrospective reports and consequentially are subject to retrospective bias and lapses in memory or (2) ask participants to complete them throughout the day, which is subject to absentmindedness. Additionally, it is important to note the systematic application of daily diary approaches of EMA is uncommon in both clinical and research practice, perhaps due to the burden on both the administrator and on the participant.

Event Sampling Approach to EMA. In some cases, it may be appropriate to assess moments when a particular occupation is occurring. In these cases, event-sampling is preferred (Shiffman et al., 2002). In the event-sampling approach, individuals complete a questionnaire or assessment during specific events or occupations. Methods akin to the event sampling approach have been applied to a limited degree in occupational therapy research and practice in the forms of paper/pencil questionnaire (Sanford & Butterfield, 2005). However, the growing availability of technology allows both clinicians and researchers to apply more advanced forms of the event-sampling approach (Shiffman, Stone, & Hufford, 2008). While event-related assessment does not provide a full picture of a client's day, it offers the advantage of assessing occupational performance during the client's engagement in a particular occupation of interest as it occurs in the real-world. Event-based sampling can include measurement of the frequency of an event (e.g., how many times an individual with cancer is unable to complete activities of daily living due to pain in a given week?, how often an older adult falls in their home?, or the number of times a person with autism experiences sensory overload?). Additionally, event-based sampling can be used to understand more detailed information associated with occupational performance, such as factors that relate to the person, environment, and occupation. For example, to better understand the occupation of shopping, a participant could complete a questionnaire regarding

their personal experiences (i.e., sensory experiences while shopping), the environment (i.e., number of people around), and the occupation (i.e., length of the shopping trip).

Given the potential ambiguity of events and their frequency, a limitation to event-based sampling is that there is no clear way of determining compliance, the extent to which a participant completed the questionnaire during all expected periods. If there is a systematic reason why participants are not completing questionnaires (i.e., participants fail to complete the questionnaire when they are very tired), then the conclusions that can be drawn from the research are limited (Little & Rubin, 2002). Additionally, event-based reports are subject to falsification, the intentional departure from the prescribed research process (Shiffman, Stone, & Hufford, 2008) (i.e., completing food diaries for a week on the final day of the week instead of each day throughout the week) suggesting that researchers should be cautious in drawing conclusions from event-based approaches.

Semi-Random Sampling Approach to EMA. Semi-random sampling procedures signal participants throughout the day to complete an assessment or questionnaire using mobile technologies such as email, text, beeper, or other one-way or two-way devices. Typically, these semi-random windows are established for each participant individually and based on a participants' sleep/wake cycles in order to avoid disrupting natural sleep patterns. Shiffman, Stone, and Hufford (2008) argue that random sampling is the most effective way to a true picture of a participants' daily activities, because it ensures that every occupation has the same chance of making its way into the sample. Random sampling may be advantageous when assessing chronic client factors that impact occupational participation throughout the day. For example, to assess chronic fatigue, one client factor that impacts occupational performance (AOTA, 2014; Youngstrom, 2002) and varies throughout the day, an occupational therapist may consider an

adaptation of the chronic fatigue syndrome-activities and participation questionnaire (CFS-APQ) to measure activity limitations and participant restrictions over the course of a day. In the TEMPO study, we chose the semi-random sampling approach because we believe that emotions would vary throughout the day and thus a more intensive sampling procedure was needed than could be provided by event-based sampling. We chose to not employ the daily diary approach due to concerns of low ecological validity, reporting bias, and the potential for memory lapses. Additionally, we were interested in the connection between occupation and emotion, thus we wanted to ensure that every emotional experience had an equal chance of being included in the study to avoid systematic bias that may be present in other approaches.

Questionnaire Design. The most important issue in the design of a research or clinical EMA study is the design of the questionnaire or survey instrument. EMA researchers often use a combination of standardized measures and non-standardized measures. In the TEMPO study, we used one standardized measure, the Positive and Negative Affect Schedule-Children's Version, short form (PANAS-C-SF) (Sanmartín et al., 2018). Researchers have frequently used varieties of the PANAS-C-SF in EMA research (Kovac, Mosner, Miller, Hanna, & Dichter, 2016), suggesting that it would likely be useful for our study of emotional patterns. We supplemented this measure with a non-standardized occupational questionnaire. Details about the occupational questionnaire and rationale for each question are presented in Table 2.

In both clinical and research settings, it may be important after data collection has begun to evaluate participants' responses for veracity and assess issues of questionnaire design. If issues of understanding are identified early in the research process, it may be possible to modify the questions to improve understanding or to contact participants directly to provide further explanation about problematic questions. We recommend ongoing monitoring of the data to

evaluate and address any potential misunderstandings with questions. For example, in the TEMPO study, we evaluated the responses to the open ended question “what were you doing the moment you were beeped?”. During the training procedures, we discussed potential answers to this question, discussed problematic responses (such as indicating that they are taking the survey), and asked participants to model a response as if they were signaled one hour ago. We examined each participant’s open-ended responses qualitatively. It was expected that participants would report a variety of activities throughout their day. Thus, if participants reported completing the same activity for more than two signals (i.e., longer than four hours) the data were further examined for veracity and other measurement issues. Only two participants reported engaging in the same activity in two subsequent signals. One participant reported playing video games with friends. The second participant reported “doing homework” and “STILL [*sic*] doing homework.” Overall, participants in the TEMPO study reported a variety of activities such as academic activities (e.g., completing homework), social activities (e.g., hanging out with friends), and family activities (e.g., having dinner with family).

Length of Assessment. In general, when designing an EMA questionnaire, it is important to consider the length of the assessment and typical completion times. In particular, it may be important to note how individual client factors may impact the length of completion time for assessment methods. For example, some participants may be more willing to complete lengthy questionnaires on the computer where they can type more easily than on mobile phones. For others, the hassle of accessing and using an internet browser may significantly increase completion time, preferring instead for paper and pencil forms. Once again, in clinical settings we recommend working in close partnership with the client to decide the most appropriate and

easily accessible method. In research, carefully identifying the subject pool and involving stakeholders to identify their respective preferences will be an important step.

When using more intensive sampling schemes, such as random sampling, shorter assessment lengths are preferred to reduce participant burden. In our study, the median length of the EMA questionnaire was 48 seconds. Six cases were identified as outliers (mean completion time of outlier cases was 251 minutes). Given the extraordinarily long completion time of these cases, it is likely that the participant completed the survey (as none of these cases had missing values), but forgot to press the submit button. After the removal of these extreme cases, the mean EMA survey completion time was 59 seconds ($sd=42$ seconds).

Sampling Frequency and Duration of Assessment. A simultaneous concern when implementing EMA across all settings is the balance between questionnaire design and sampling frequency. In the TEMPO study, participants were sampled during waking hours using a semi-random sampling scheme and received a total of 42 messages (six messages per day for seven days). We chose six messages per day because we were interested in understanding the variability of emotions throughout the day, which has been related to depression (Marwaha et al., 2018; Solhan, Trull, Jahng, & Wood, 2009). In semi-random sampling EMA, it is ideal if a phenomenon can be assessed at two continuous time points to capture appropriate levels of phenomena stability and variability. We believed that two hours between each message was a short enough period in which an emotion could occur for two continuous messages. However, we also wanted to ensure we did not message participants too much resulting in increased burden and fatigue.

We also chose to randomize only the initial start time (and not subsequent EMA signals) in order to avoid signals coming too close to each other. Ideally, when using this approach,

participants should not know when messages are going to occur as this may lead to changing behaviors. By randomly changing when participants received their first message, we believed that participants were unlikely to expect signals at a particular time.

Table 3.2 : Mobile assessment questionnaire and rationale

<u>Question</u>	<u>Response Type</u>	<u>Rationale</u>
PANAS-C-SF (10 questions like <i>How happy are you?</i>)	Likert-type (1-5) with visual anchors (visuals adapted from Kovac, Mosner, Miller, Hanna, & Dichter, 2016)	A brief measure of current emotional states, enabling us to examine associations of occupational participation with PA and NA.
What are you doing right now?	Open-ended	A brief indicator allowing participants to self-describe their current occupations.
How many people are around you right now?	Ordinal (four levels: (1) no one, I am alone, (2) 2-5 people, (3) 6-10 people, or (4) more than 10	Previous literature has characterized social participation as social/non-social (Kovac et al., 2016). We use an ordinal scale to better characterize the nuances of social interaction.
How much are you enjoying your current level of social interaction (the people you are around)?	Likert-type (1-10)	A measure of hedonic experience associated with social interactions in order to capture the variability associated with social interactions.
How much are you enjoying your current activity?	Likert-type (1-10)	A measure of hedonic experience in occupational participation.
How does your body feel right now?	Choose all that apply	A concrete way of identifying the relationship between emotion and body experiences, enabling us to create an embodied understanding of emotions.

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PANAS-C-SF=Positive Affect and Negative Affect Schedule, Children’s Version, short form, PA= positive affect, NA= negative affect

To further reduce the chances of participants changing behavior, we also instructed participants to complete the mobile assessment as soon as possible after receiving the message. In cases when participants felt uncomfortable completing the questionnaire, such as during a church service, it was acceptable to complete it after the activity had finished.

Ethics. Whenever information is exchanged between researcher/therapist and clients, it is important that adequate protections against data breach are in place. In our study, adolescents were sent a text message with a link to complete an electronic questionnaire. While many platforms exist specifically for EMA research, we found that the majority of these EMA platforms were highly expensive and unlikely to be feasible for clinicians or smaller research studies. Instead, we found that online survey platforms are widely available for free and were easy to deploy in an EMA study. While there is always the option of paper and pencil surveys, requiring participants to carry surveys with them throughout the day heightens the risk for the information to be lost due to participants forgetting to complete the diaries, becoming fatigued with bringing diaries with them throughout the day, and misplacing paper forms resulting in a breach of confidentiality. Online surveys, however, are only available to the study team once completed and data is locked behind password protection. Also, online surveys can be administered via mobile phones, which are generally available to participants at all times. In our text messages to participants, we included only a brief greeting and a link to the survey. This method protects participants' privacy by not including any identifiable information in any non-secure communication. As an additional layer of protection, we also did not include any private health information (such as names) in the surveys themselves. Mobile phones are well-integrated into the daily occupations of society; in many cases, periodically pulling out a mobile phone will likely draw less attention than pulling out a paper booklet. We propose that the

overall integration of mobile technology in society will aid in the effort to increase fidelity, decrease opportunities for lost data, and improve overall acceptability of the assessment procedures.

Who Might Be Able to Complete an EMA? A challenging issue for clinicians and researchers alike is deciding who may be a good candidate for EMA given the intensive sampling nature of this approach. In our experience, a brief screen of participants' willingness to comply with procedures can provide important insight into whether EMA is appropriate for a participant. In general, researchers will establish a threshold completion rate in order to establish the minimal amount of acceptable missing data. For clinicians, completion thresholds may be less important, but likely could be set in conjunction with the client in order to develop the therapeutic partnership. In our study, we established a completion threshold *a priori*, at 60% (responding to 25 of possible 42 messages). This threshold was chosen based on previous completion rates observed in EMA studies among individuals with ASD (Khor, Gray, Reid, & Melvin, 2014). We choose this threshold in order to identify whether endogenous or exogenous factors predict who may be more willing or able to complete an EMA.

In our study, the majority of participants ($n=12$, 71%) completed at least 60% of the EMA procedures (See Table 2). Five participants were below the 60% threshold with the lowest response rate was only seven times (i.e., once per day). These individuals did not differ from the overall sample with regard to age, child-reported depressive symptomatology or parent-reported depressive symptomatology ($p>.05$). While missing data were associated with the number of days in the study ($B=-5.93$, $p<.01$), the relatively small effect size suggests that potential fatigue effects were likely to be minor. Post hoc linear regression analyses showed that participation in

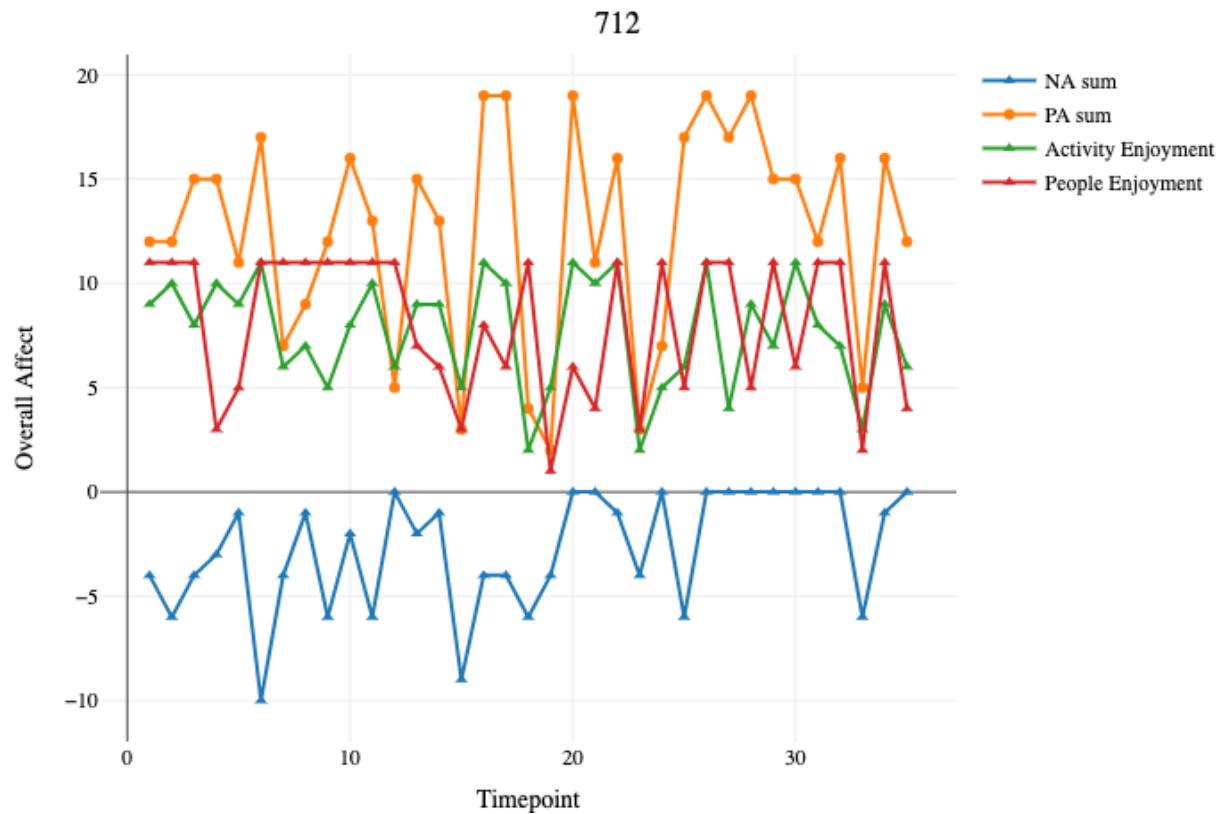
days six (52 responses) and seven (56 responses) was reduced when compared to day four (75 responses).

Encouraging Ongoing Participation as Required by Intensive Sampling. Given that a universal trait of EMA research is the administration of repeated assessments, it is important to consider factors that may encourage continued participation. One factor that may have been instrumental towards participants' continued participation was parental involvement. We leveraged parent involvement in the research process by involving parents in the EMA training procedures. We found that, by including parents in the EMA training procedures during the initial assessment, parents and caregivers often independently discussed with their child the importance of completing the questionnaire. This is unsurprising given that parents may serve as important mediators in adolescent involvement in research (Rossi, Reynolds, & Nelson, 2003). Other strategies that we used that may encourage continued participation included: providing participation-contingent compensation (i.e., compensation based on the number of responses), emphasizing the importance of continued participation throughout the training and consent process, and calling participants midway through the assessment to reengage their interest. Additionally, using a less intensive sampling scheme (fewer prompts per day), may lead to better overall response rates. However, fewer prompts provide less nuance and risks missing important variations in the phenomenon (i.e., short periods of extreme emotions); thus, reducing prompt frequency or duration of signaling should be done cautiously.

Analysis of EMA Data. EMA data is necessarily complex as it is data nested within a person, within a day, and within a group. These multiple levels require hierarchical analytic methods to account for data correlation and draw group level comparisons (Hufford, 2007; Ram, Brinberg, Pincus, & Conroy, 2017). In this study, we conducted an analysis at the group-level using multi-

level modeling to examine changes in emotional patterns across the sample of adolescents (Results presented in Chapter 4). However, occupational therapists could examine individual level trajectories of occupational participation in order to identify particularly problematic areas in order to create targeted personalized medicine approaches. For example, in Figure 3.1, we present the trajectories of NA, PA, activity enjoyment, and enjoyment of the social experience for one participant in the TEMPO study whose enjoyment of the activity was often related to their level of negative affect. For another participant, long periods of homework were associated with decreasing positive affect. Though, our interests were not clinical in nature, we believe an occupational therapist could use this information to probe for reasons why this occupation was experienced so negatively. Likewise, occupations associated with increasing PA could be leveraged as an intervention to mediate periods of negative mood. In TEMPO, we found that social occupations, for many of participants, were associated with increasing positive affect. An occupational therapist could assist a client in purposefully leveraging social experiences to intervene during periods of negative affect. See Figure 2 for an example of four individual trajectories of emotions collected in TEMPO. Notice that each of these emotional trajectories is different. These data could be combined with qualitative information about occupational participation (See Figure 5.2) to understand how clients differentially experience their days and occupations.

Figure 3.1: Patterns of variation in emotions and occupational qualities for one participant

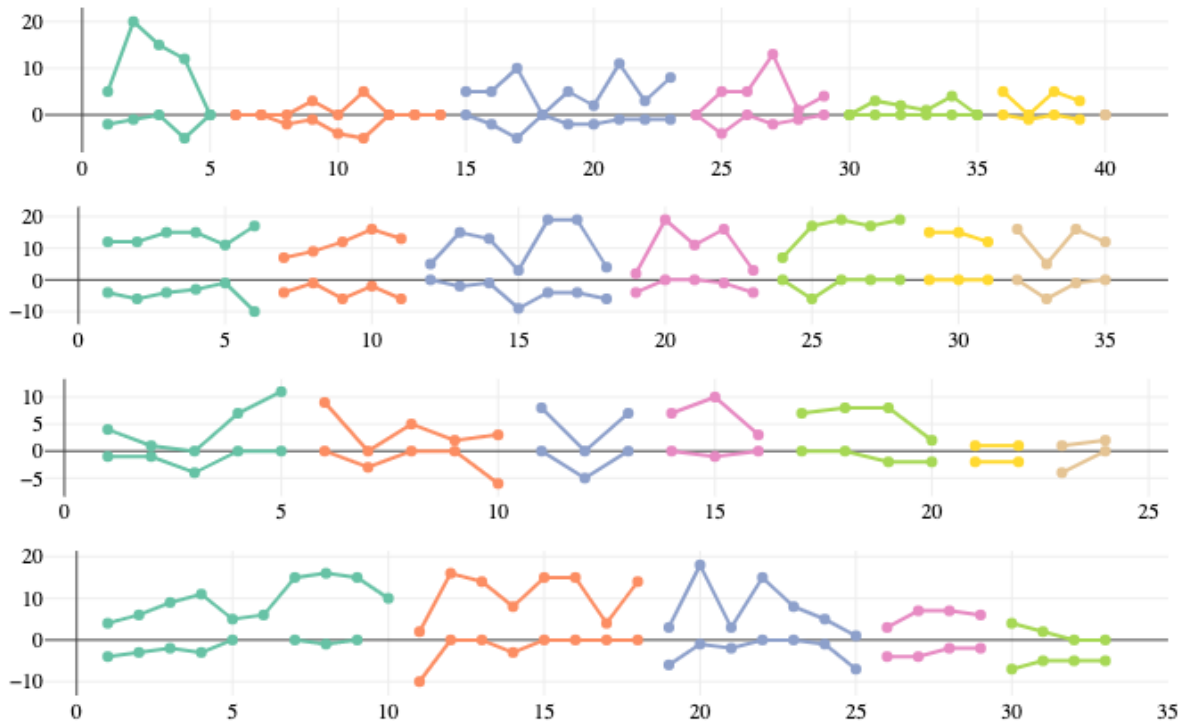


Note: Variation of negative affect (NA), positive affect (PA), activity enjoyment, and people enjoyment throughout the week for one participant. Negative affect is modeled such that a higher negative affect (i.e., sadder) would result in a greater negative point in the plot. All other variables were kept to scale.

Choosing between EMA Types in Occupational Therapy and Occupational Science

Research. All three approaches discussed in this paper (event-sampling, daily diaries, and random sampling) may be beneficial for both occupational therapy practice and research. We believe that the event-sampling approach, given its ease in implementation and reduced participant burden, may be the most advantageous for occupational therapy practice.

Figure 3.2: Patterns of emotions in four participants.



Note: Negative affect is modeled such that a higher negative affect (i.e., sadder) would result in a greater negative point in the plot. A separate color represents each day.

Event-sampling is valuable when practitioners are interested in understanding an occupation that occurs throughout the day or across the week, but also does not occur with sufficient frequency in which random sampling is preferred (i.e., attending sports events, using the restroom, or sexual intimacy). For example, in the treatment of food sensitivities among individuals with ASD, a therapist may have a parent complete a questionnaire with each eating occupation about foods tried, interventions used, and child reactions. Occupational scientists could use these findings to understand how family interactions change during occupations of eating, as compared to other occupations, with a child with ASD. A clinician could use these findings to have a detailed view of occupational barriers and potential treatment interventions. It may be that a parent often gives a child only a few minutes with a new food before allowing the child to eat

preferred food. However, upon identification of this need area, the therapist and parent could collaborate to develop new strategies, such as constructing a social story about the food, to increase food tolerance. Additionally, an occupational therapist interested in assisting a client with chronic disease management could have a client complete an EMA at set times during the day in which they report blood pressure, glucose levels, and taken medications. In this case, the therapist could assess how the occupations performed during the day, time of the report, and the client's affective experiences impact relevant health factors for disease management. The therapist may then bring this data to the client and collaboratively interpret factors for treatment moving forward. The data may also suggest new interventions, such as working with the medical doctor to adjust medication times, will serve an important role in disease management.

The event sampling approach is most advantageous for occupational therapy research questions related to a specific occupation (e.g., eating, sleeping, smoking). Particularly in the case of research, though, it is important to clearly define the event of interest. For example, if the researcher is interested in sensory experiences during eating occupations, a researcher may ask a participant to complete a questionnaire during each eating occupation. However, depending on the research question, it may be important to consider shorter episodes of eating, such as does eating a piece of candy count? It is also important for the participants to have a clear understanding of the event definition to avoid failing to complete the questionnaire during key occupational events. The increased granularity of event sampling also makes the approach advantageous when researchers are uncertain exactly what relationships they expect to find. An occupational science researcher interested in understanding the transactive experiences of diabetes management may include multiple open-ended questions (e.g., tell me about who is

around you, meal planning experiences, stress levels, and coping strategies) which enables for a more thorough qualitative exploration of the phenomenon.

The random-sampling approach may be most advantageous for occupational therapy and occupational science research questions when the researcher wants to be able to draw general conclusions about a participant's day, understand routines, or to draw comparisons across populations. Occupational concepts that may benefit most from the random sampling approach include studies that explore the relationship between occupation and factors such as: affect, time, and client symptomatology. Research in this area may uncover how negative affects reduce occupational performances or the specific temporal fluctuations that occur during occupational performances. In any case, ongoing data monitoring is an important concern and thus researchers should monitor for participant response rates and intervene if participants are not responding with appropriate fidelity. In this case, researchers will want to consider how to encourage continued participation in the EMA sampling scheme (See Hufford, 2007 for a review).

Clinical settings that may be most advantageous for the random sampling approach are those in which clients can respond throughout their day and include: group homes, senior-living homes, and in-patient rehabilitation. Corresponding areas of interest that may benefit from this approach include: occupational balance, satisfaction with occupational performance, and levels of arousal and co-occurring participation in occupations as each of these areas are likely to vary throughout the day. However, the random sampling approach is the most difficult to employ within the clinical context as it requires the most time up front in both thinking through issues of measurement and in creating the procedures for having participants complete the assessment. By deciding the frequency of EMA in collaboration with the client, clinicians will likely minimize invasiveness and increase acceptability. We suggest discussing with clients the advantages

(increased nuanced understanding) and disadvantages (fatigue associated with assessment completion) of increased assessment frequency to empower clients to choose their preferred level of participation.

The daily-diary sampling approach, however, is well-suited for both occupational therapy practice and research settings. The combination of ease of implementation, clear expectations for the data structure enabling one to estimate missing data, and the adaptability across settings, will be advantageous for both researchers and clinicians. Relevant clinical and research issues that could be addressed with this approach are vast as understanding any occupational situation, presuming that the situation is easily defined, can likely be understood through this approach.

Qualitative research may benefit most from the daily-diary sampling EMA approach as participants are asked to respond less frequently, enabling participants to provide more thorough information to open-ended questions than can be provided when individuals are signaled more frequently. However, less frequent sampling procedures also come with challenges. A recent meta-analysis of response compliance in EMA studies showed that too few signals per day significantly reduces participant fidelity (Wen, Schneider, Stone, & Spruijt-Metz, 2017). Regardless, we believe daily diaries may be advantageous to understand areas such as: occupational injustices, occupational balance, routines, and occupations that are unable to be assessed using surveys during the occupation (e.g., driving, intimacy). Areas such as occupational balance and routines are likely to remain relatively stable and may be best characterized by heuristic assessments, as opposed to specific counts of events such as the number of occupational injustices one experiences in the day. In contrast, while occupations such as intimacy are likely to vary from moment to moment; however, any attempt to sample during

the occupation itself is likely to grossly change the performance of the occupation. Either event-based sampling or daily-diary sampling completed after the event could be used in this case.

3.3 Implications for Occupational Therapy and Occupational Science Research

EMA is a feasible method for characterizing the relationship between occupational participation and other relevant client factors. While we demonstrate this utility among adolescents with ASD, EMA has been used successfully in other research contexts such as smoking cessation (Shiffman et al., 2002), mood dysregulation (Ebner-Priemer & Trull, 2009), and human immunodeficiency virus (HIV) experiences among older adults (Moore et al., 2017). Throughout this paper, we identify areas of research ripe for future work in occupational therapy. An important first step, though, is for occupational therapy researchers to develop and refine occupation-related questionnaires appropriate for EMA. The corpus of scholarship produced by occupational scientists will likely prove as key guides towards informing how EMA questionnaires are designed. Identifying what qualities of occupation are most relevant to assess and evaluate using an EMA will be fruitful in developing interventions and informing our understandings of humans as occupational beings.

3.4 Implications for Occupational Therapy Practice

Readers may be left with the question: can EMA, in particular technology-based EMA, actually be implemented in clinical practice settings? We hope that the guidance above will help practitioners begin to consider how to implement EMA in their practice. While this approach may be novel, technology-based EMA may enable practitioners to reach and assess clients who are not able to be physically present in the clinic. Geographical distance and novel problems, such as the COVID-19 pandemic, are but a few reasons why clients may be limited from being physically present in the clinical setting. If EMA approaches are able to reach clients in these

unusual circumstances, then they may offer significant advantages to occupational therapy practice. Technological approaches to EMA could also facilitate dynamic personalization of interventions (Depp, Moore, Patterson, Lebowitz, & Jeste, 2008) making the potential applications of EMA in occupational therapy vast. Dynamic personalization is the modification of an intervention in response to changing client factors, such as changing disease progression (i.e., providing new tools for energy conservation for a client when symptoms of fatigue are fluctuating). For example, if a parent reports through EMA increasing aggression from a child with ASD, the therapist can provide personalized strategies like routine modification at a quicker pace than when strategy development is limited to an occupational therapy treatment session that occurs once a week or month. Although clinical applications of EMA have been limited (Depp, Moore, Perivoliotis, & Granholm, 2016), the few exemplar studies demonstrating the early applications of EMA in clinical settings suggest that EMA may be a valuable tool for clinical practice (Mulvaney et al., 2012; Newman, Kenardy, Herman, & Taylor, 1997; Rodgers et al., 2005). EMA has been successfully employed to aid in the administration of cognitive-behavioral treatments for patients with panic disorder (Mulvaney et al., 2012), promote smoking cessation (Rodgers et al., 2005), and to promote diabetes management adherence (Newman, Kenardy, Herman, & Taylor, 1997). Using these early approaches as guides, occupational therapists can develop new and exciting approaches to optimize functioning in the context of daily life.

Practitioners may be concerned about the time burden associated with EMA procedures. In our experience, once a survey is ready for distribution, we are able to setup an automated sampling scheme for a person over the course of a week (for the intensive random-sampling approach used in TEMPO) in less than five minutes. A less intensive sampling procedure, for example one signal sent per day for 30 days would require less time to setup and may be

advantageous to understand participation issues that require less nuanced sampling, such as home program disease management progress.

Practitioners may also be concerned with the time burden associated with analyzing EMA data. We recommend therapists examine the output of the EMA with the client by looking for trends (e.g., increasing fatigue), peaks (e.g., sudden increase in pain when shopping), and other patterns (e.g., decreased happiness when socializing with one friend group). The therapist can also encourage and promote the client's self-reflection, promoting participant insight regarding relevant phenomena to their health. In so doing, clients will be empowered to assess their occupational performance problems, identify their present capacities, and evaluate their own personal and environmental resources (CAOT, 1999, p. 2). Also, by examining these data with clients, the therapists will reduce the time burden associated with analysis.

With these practicalities in mind, occupational therapists should consider combining EMA with traditional occupational profile assessments. While reflections of occupational participation are useful in evaluating how clients see their current performance, EMA offers the advantage of assessing the relationship between client factors, occupation, and the context in an ecologically valid and nuanced approach. Throughout this paper, we identify ways EMA can be incorporated into most practice settings. Both the daily diary approach and the event-based sampling methods offer great promise for clinicians. While we recognize that implementing EMA in practice contexts may seem daunting, we hope that occupational therapy teams should consider identifying relevant EMA methods for their practice area and working together to design a bank of EMA style assessments. Lists of relevant questions could then easily be integrated into an online survey platform.

3.5 Limitations

While EMA offers many advantages for both occupational therapy practice and research, the intensive sampling procedures of EMA may not be suited for some research and clinical situations. EMA methods cannot capture all of the contextual information that may be relevant to understanding a particular phenomenon. While this limitation is not unique to EMA, we believe that EMA can capture factors related to occupational participation that cannot be captured otherwise, such as subtle changes in symptoms that impact occupational participation (i.e., pain) throughout a day and across a week. Additionally, EMA questionnaires can be easily combined with other methods better suited to obtain more granulated contextual information (i.e., interviews). The absence of a standardized questionnaire for use in occupational therapy EMA research and practice is a clear limitation. We recognize that implementing EMA in clinical practice may seem daunting at first. However, the accessibility and ease of technology is increasing, making EMA and other mobile health methods easier and quicker to implement than in the past. As researchers and clinicians begin to increasingly use these methods, we believe that standardized tools will be developed that can be used across the settings in which occupational therapists work. There may also be some clinical settings in which the implementation of EMA is not feasible. For example, in most in-patient psychiatric settings, the clients are not permitted to have mobile devices with them while on the unit. Similarly, a teacher with multiple students who have complex needs may be hesitant to adopt burdensome EMA procedures that distract from student learning.

3.6 Conclusion

Despite challenges in the implementation of EMA, we believe the advantages greatly outweigh the limitations. The recent advances of statistical methodologies provide new and

exciting ways to use EMA in research and model the complex relationships between humans and occupations. EMA can be implemented in both research and clinical settings. While each of three methods may be appropriate for both research and clinical settings, the unique features of each method may be particularly useful to consider. Semi-random sampling EMA is most advantageous for research settings. Event-based sampling is the most advantageous for clinical settings. Daily diary approaches are highly useful for both research and clinical settings. By adopting EMA into research and practice, we believe researchers will be able to adopt new ways of understanding occupational transactions.

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CHAPTER 4. IDENTIFYING PREDICTORS OF MOMENTARY NEGATIVE AFFECT AND DEPRESSION SEVERITY IN ADOLESCENTS WITH AUTISM

4.1 Background

Depression is a commonly reported and concerning mental health comorbidity in autism spectrum disorder (ASD; Mazefsky, Kao, & Oswald, 2011). Estimates of depression in the non-psychiatrically referred population with ASD range from 2% (Ghaziuddin, Tsai, & Ghaziuddin, 1992) to 44% (Strang et al., 2012) and as high as 56% in a clinically referred ASD population (Joshi et al., 2010). While there is no consensus regarding the prevalence of depression, researchers generally agree that individuals with ASD are at high risk for depression, especially compared to their typically developing peers (who have a prevalence of 7.5%) (Avenevoli, Swendsen, He, Burstein, & Merikangas, 2015).

The variance in prevalence can be explained in part because it is challenging to differentiate prototypical ASD symptoms from comorbid depression due to overlapping symptomatology. DeFilippis (2018) noted that common features such as an increase in obsessive and ritualistic thinking, agitation, self-injury, sleep disturbances and a decrease in former interests and adaptive functioning are part of the behavioral phenotypes of depression in this population and overlap with core features of ASD. In general, depression is often overlooked in adolescence (Leaf et al., 1996). The overlapping features of ASD and depression make the diagnosis in ASD, particularly during adolescence, difficult. Consequentially, there are no sensitive and specific measures of depressive symptomatology appropriate for the ASD population (DeFilippis, 2018). Given that the US Preventative Services Task Force (USPSTF)

(Siu et al., 2016) has recommended that all adolescents be screened for depressive symptomatology due to the relationship between depression and negative outcomes such as suicide, and that little is known about the phenotype of depression in the ASD population, identification of adequate screening tools is an urgent concern. We believe that the two-hit model of ASD may be a promising theoretical approach for understanding both risk and markers of depression in the ASD population.

Two-Hit Model of ASD

While adolescence can be a challenging time physically, socially, and academically for those with and without developmental disabilities, adolescence may be a particularly vulnerable time for individuals with ASD (Picci & Scherf, 2015). According to the two-hit model of ASD (Picci & Scherf, 2015), individuals with ASD experience the first *hit* with biological genetic variations that predispose them to typical challenges associated with the diagnosis such as deficits in social-emotional reciprocity, nonverbal communication, development, maintenance, and understanding of relationships (American Psychiatric Association, 2013), and altered sensory processing (Serafini et al., 2017). These initial vulnerabilities pose unique challenges for children in their social development.

The second *hit* occurs when children transition into the period of adolescence when their initial vulnerabilities worsen with the onset of the hormonal, social, and academic challenges typical of adolescence. In the typically developing population, the onset of puberty and concurrent hormonal changes has been linked to depression in females (Soares & Zitek, 2008); however, less is known about the role of hormones in males with depression. In addition to these hormonal changes, social challenges such as bullying (Cook, Williams, Guerra, Kim, & Sadek,

2010; Espelage & Holt, 2001), a common experience during adolescence, may further make this developmental stage prone to emotional disorders such as depression.

In support of this theoretical approach, recent empirical research has related social experiences to mental health among those with ASD. Individuals with ASD who are aware of their social deficits demonstrate increased depression (Day, McNaughton, Naples, & McPartland, 2019) suggesting that social experiences, such as those that increase one's awareness of social deficits, may be implicated in depression onset. While increasing ASD symptom severity has been linked to depression, loneliness and satisfaction with social support mediate this relationship (Hedley, Uljarević, Foley, Richdale, & Trollor, 2018). This suggests that interventions that decrease loneliness or increase satisfaction with social support may have an important role in alleviating depressive symptoms among those who perceive their social deficits as greater. It may further suggest that social experiences may play an important role in the screening of mental health conditions of this population. The constellation of potential factors impacting depressive symptomatology in this population indicates there is likely no singular cause of depressive symptomatology in ASD. However, theoretical and empirical research aligns in implicating social experiences in the onset of depression (Day, McNaughton, Naples, & McPartland, 2019; Picci & Scherf, 2015). Recently, researchers investigating depressive symptomatology have challenged monolithic research approaches (i.e., those that examine only a singular cause of depression) and suggested that network approaches better identify the constellation of factors that increase the risk for depressive symptomatology (Koval, Pe, Meers, & Kuppens, 2013).

Network View on Emotional Dynamics

In the typically developing population, features of decreased psychological functioning and emotional dysregulation (i.e., emotional instability, emotional inertia) are believed to increase vulnerability for depression (Koval, Pe, Meers, & Kuppens, 2013). *Emotional instability* refers to the magnitude of variation in an individual's emotional states across time and contexts (Houben, Van Den Noortgate, & Kuppens, 2015). *Emotional Inertia* refers to the continuance of emotions from one moment to the next. The inertia of positive emotions, such as happiness, can be protective of psychological disorders, while the inertia of negative emotions, such as sadness, can result in the onset of depression (Koval et al., 2013). Within the network view on emotional dynamics, microlevel emotional states can change over time, unnoticed by parents or caregivers. These microlevel changes are expected to vary across contexts in a way that would prevent parents or other individuals from bearing witness to the changes, because they will occur at school, at the mall, and in other settings where parents are not present. The theory suggests that singular emotional states may trigger subsequent emotional states leading to a cascade of emotions. Accordingly, successful identification of situations, such as positive social experiences, that prevent the inertia of negative emotions or reduce instability of emotions can be used to prevent the cascade of subsequent negative emotional states in an intervention (Fried et al., 2017, p. 6). The network theory of emotional dynamics integrates with other perspectives of mental health in arguing that decreasing psychological functioning (i.e., as demonstrated by the presence of affective instability) increases risk for mental illness (i.e., depression) (Caspi et al., 2014; Ward et al., 2017). While researchers have traditionally investigated emotional instability assuming a linear relationship between instability and depression, researchers have recently questioned whether this relationship would be better characterized using a model that better

incorporates the nuances of emotional instability (Houben, Van Den Noortgate, & Kuppens, 2015). It may be that there are optimal levels of emotional instability, which would reflect normal patterns of emotional variation. However, when emotional instability reaches a particular threshold, it leads to increased depression vulnerability.

High emotional instability coupled with high emotional inertia has been linked to depression in the typically developing population (Koval et al., 2013); however, this theory remains untested in the ASD population. In contrast to trait emotion, intraindividual state emotion reflects one's emotional regulation in response to everyday contexts and situations. Given that individuals with ASD are believed to have impaired emotional regulation (Mazefsky et al., 2013), we believe that the network theory may provide insight into the depressive profile of those with ASD. While it may seem that inertia of emotions may be protective against emotion instability, researchers have found that both features are present among depressed individuals (Kuppens, Allen, & Sheeber, 2010). The combination of negative emotional inertia and instability reflects a non-adaptive emotional pattern “that reaches more extreme emotional intensities and involves relatively large moment-to-moment fluctuations, but at the same time shows a stronger self-predictive lingering effect that makes the emotion slower to recover or be pulled back to a normative state” (Houben et al., 2015, p. 922).

There are several reasons why individuals with ASD may be susceptible to high emotional inertia. Early research has identified a high prevalence of rumination (Gotham, Bishop, Brunwasser, & Lord, 2014) among individuals with ASD. Rumination of past experiences may evoke similar emotions as those experienced during the original event, leading to an autocorrelative process in which future negative emotions are predicted by past emotions. Increased social demands in adolescence combined with perceived deficits in social

communication may evoke a torrent of negative thought that is maintained and reinforced through rumination. While evidence to this point is still emerging, early evidence notes that individuals with rumination react more negatively to stressful events (Ruscio et al., 2015) and therefore may be more vulnerable to negative social experiences. While it may seem that rumination would be protective of instability (and therefore lead to increased periods of negative affect), it may be that an individual's positive emotions quickly shift back to the negative domain due to rumination. Rumination may thus play a role in the autocorrelation of emotions, the extent to which an emotion predicts later emotions, and in the precipitation of quick shifts back into the negative domain resulting in a large overall magnitude of change. The bidirectional relationship between emotional dysregulation (emotional inertia and instability) and rumination is supported by recent research (Koval, Kuppens, Allen, & Sheeber, 2012). Even though there is increasing evidence that both rumination and emotional autocorrelation play a role in depression in the typically developing population, their effects have not been tested among individuals with ASD. We propose that a first step in understanding this relationship is to understand the profile of affective instability, emotional autocorrelation, and depressive symptomatology in the ASD population. However, little is known in this area, leaving a clear gap in our understanding of depression in this population.

This study sought to address the observed gap in understanding depressive symptomatology in ASD. We utilized ecological momentary assessment (EMA), an intensive longitudinal sampling approach, to accomplish the following aims: (1) identify factors that are protective of depressive symptomatology by eliciting positive affect and factors that are risk factors for depressive symptomatology by eliciting negative affect, (2) evaluate and characterize

the role of adolescent emotional instability and emotional autocorrelation in predicting parent-reported adolescent depression.

4.2 Method

Participants

Participants were 17 male adolescents with ASD aged 11-17 years (M=14 years, SD=2 years). Diagnoses were confirmed through parent-report and by the research registry who verified participants met cutoff scores on the Autism Diagnostics Observation Scale, 2nd Edition (ADOS-2; Lord et al., 2012) when available. Inclusion criteria were as follows: participants resided in Central and Eastern North Carolina, had a composite abbreviated intelligence quotient greater than 85, spoke fluent English, and had regular access to a mobile phone. Participants with co-occurring genetic syndromes were excluded from the study. Females were excluded due to the small sample size, the observed prevalence of ASD being much higher in males than females (1:4), and the exploratory nature of this study.

Procedure

The Institutional Review Board of University of North Carolina at Chapel Hill granted ethical approval for this research study. Parents were informed about the study through an ASD research registry, flyers posted on social media, and a central database of university-affiliated employees/students. Parents from the research registry mailed in a postcard indicating interest in the study and giving the researcher permission to contact them. Interested parents were then contacted and invited for participation. All participants were evaluated by the first author and a research assistant.

During the initial screening visit, participants completed the Stanford-Binet Intelligence Test, fifth edition (Roid, 2003) and a set of demographic questionnaires and assessments.

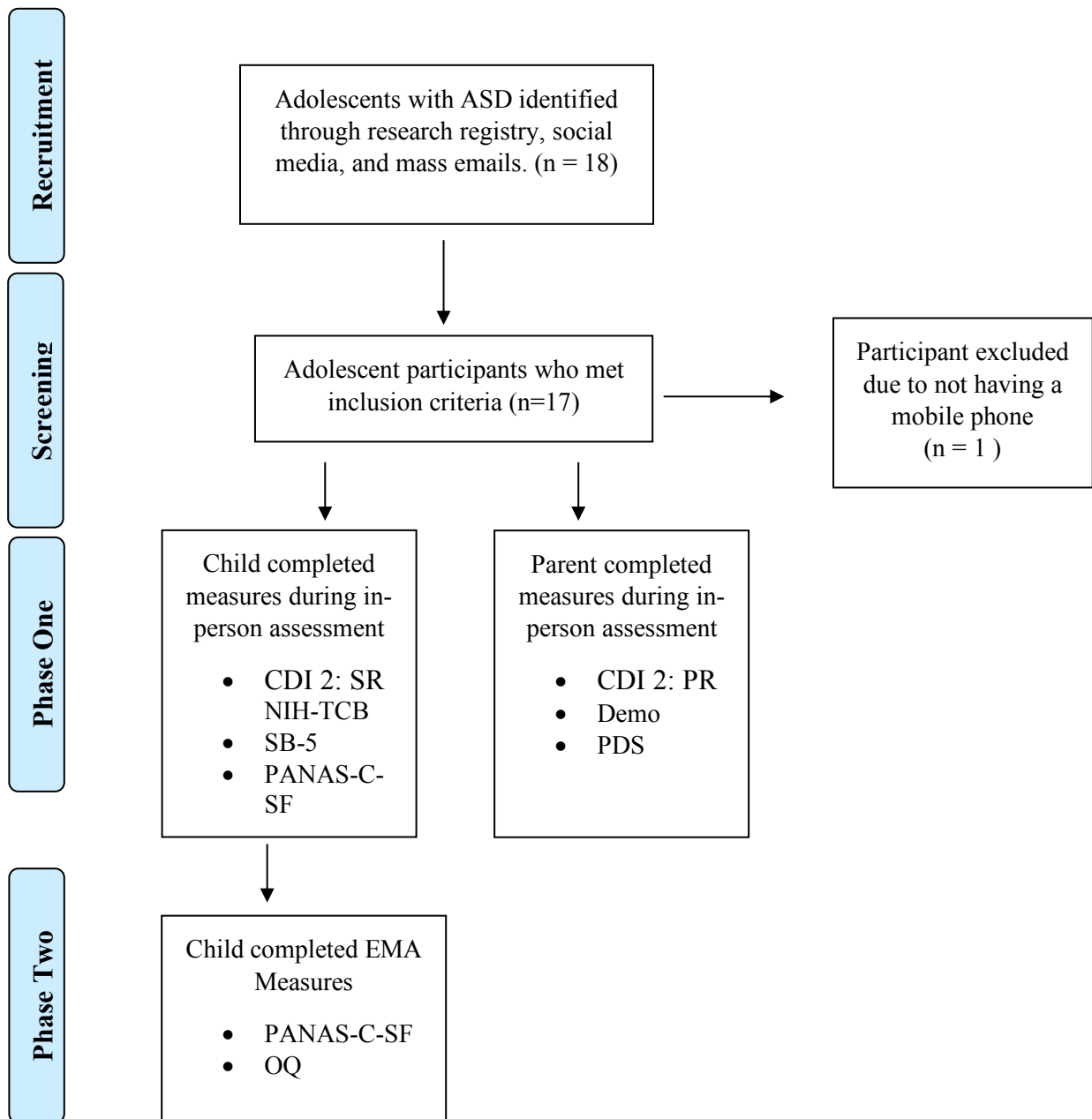
Caregivers also completed a set of demographic questionnaires about themselves and their child. Adolescents with ASD engaged in ecological momentary assessment (EMA) procedures, which consisted of being signaled six times a day, semi-randomly for seven consecutive days to complete a questionnaire (See Figure 4.1). EMA is an intensive sampling method in which participants complete the same assessments at multiple times (Stone & Shiffman, 1994). It is best if participants are unable to anticipate when they will be prompted to reduce the chance that participants will change their behavior. In this study, to reduce the chances of participants anticipating prompts, each participant's initial prompt was sent semi-randomly within two hours of their parent-reported waketime. Subsequent prompts were sent two hours after the initial message. Because the start time for each day was semi-randomly generated, we believe that participants were unlikely to anticipate when they would receive messages each day.

Measures

To characterize our sample, we administered clinical assessments of depression, cognitive ability, parent-rated autism severity, and adaptive behavior. Participants also completed a mobile assessment questionnaire, delivered as an EMA, providing us further information about the participants.

Stanford-Binet Intelligence Test, Fifth Edition (SB-5). All participants were administered the abbreviated SB-5 (Roid, 2003) by a graduate student or undergraduate research assistant to determine verbal, nonverbal, and general IQ (Table 2) to verify inclusion criteria. Participants completed the Object Series/Matrices Subtest, to assess nonverbal fluid reasoning, and the Vocabulary subtest, to assess verbal knowledge. Raw scores for verbal knowledge and nonverbal fluid reasoning were summed and standardized to generate abbreviated IQ (ABIQ) scores.

Figure 4.1: Study Procedures



Child Depression Inventory 2nd Edition: Self Report (CDI 2: SR). The CDI 2:SR is a standardized and clinically-validated self-report measure of depressive symptoms (Kovacs, 2010; Saylor, Finch, Spirito, & Bennett, 1984) that has been used in the ASD population (Mazefsky,

Kao, & Oswald, 2011). The 27 items of the CDI 2:SR are scored on a scale of zero to two (anchored by behavior frequency, e.g., I have trouble sleeping many nights, every night, or I sleep pretty well) and was divided into four factors including: negative mood/physical symptoms, negative self-esteem, interpersonal problems, and ineffectiveness. The CDI 2:SR was originally developed to be a measure of depression severity and not as a diagnostic instrument.

Child Depression Inventory 2nd edition: Parent-report (CDI 2: PR). The CDI 2: PR is a 17-item, Likert-type, parental or primary caregiver reported measure of a child's depressive symptoms (Kovacs, 2010). The CDI 2: PR items align with items on the self-report version of the CDI 2:SR. Respondents indicate if a behavior (i.e., crying) is observed in their child - not at all, a little, some of the time, moderately, or a lot. Similar to the CDI 2:SR, the CDI 2: PR was also developed to be a measure of depression severity and not as a diagnostic instrument. Additionally, the CDI 2 has been used previously to understand depressive symptomatology in this population (Gotham, Unruh, & Lord, 2015).

Pubertal Developmental Scale (PDS). In addition, parents completed the Pubertal Development Scale (PDS; Petersen, Crockett, Richards, & Boxer, 1988) to assess the development of secondary pubertal development characteristics, such as body hair growth, skin changes, and voice changes. Parents completed the five-item measure, indicating on a four-point scale ranging from: not yet begun to complete. The PDS was originally developed as a self-report measure of pubertal development; however, it also has been used as a parent-report pubertal development measure (Muscatello & Corbett, 2018). Given that depression has been found to be related to pubertal status, and not age, in adolescents (Mendle, Harden, Brooks-Gunn, & Graber, 2010), pubertal status will be used as a potential predictor variable in data-driven approaches and as a covariate in theory-driven analyses.

Positive and Negative Affect Scale, Children's Version, short form (PANAS-C-SF).

Adolescents completed the Positive and Negative Affect Scale, short form (PANAS-C-SF) (Sanmartín et al., 2018) to assess momentary positive affect and negative affect. Adolescents completed the 10-item measure, indicating on a four-point scale to what extent they are experiencing a particular emotion: none at all, a little, some, a lot.

Mobile Assessment Questionnaire. Adolescents completed an electronic questionnaire that was sent to them via text message link. The survey was adapted from previous EMA studies (Kovac, Mosner, Miller, Hanna, & Dichter, 2016). Participants received a total of 42 messages (six messages per day for seven days). The first message for each day was randomized to occur within the first two hours of the participant's wake-up time, likely preventing participants from anticipating when they would receive messages. Subsequent messages were sent exactly two hours after the initial message, enabling us to evaluate time-dependent characteristics such as instability. Each questionnaire included multiple surveys. Participants completed the Positive and Negative Affect Scale, short form (PANAS-C-SF) (Sanmartín et al., 2018) and a brief questionnaire about their current activities. The questionnaire included questions such as: what were you doing the moment you were beeped, how many people are around you, and how would you rate your enjoyment of your current level of social interaction.

Table 4.1: Participant Demographics

	<u>Mean(SD)</u>
Child Age in Years	14(2)
Number of surveys completed of 42	31.53(9.73)
Co-occurring Diagnoses	ADHD (n=15) Depression (n=8)
ABIQ	106.18(14.60)
CDI 2: SR Total	12.65(8.75)
CDI 2: PR Total	18.00(6.05)
Std. Differences in CDI (S/P)	-0.59(0.31)

ABIQ=Abbreviated Intelligence Quotient, CDI 2:SR=Child Depression Inventory Second Edition: Self Report, CDI 2: PR=Child Depression Inventory Second Edition: Parent Report, Std. Differences in CDI (S/P) is calculated as the standardized CDI 2:SR Sum score divided by the standardized CDI 2: PR score.

Statistical Analyses

Using a data driven approach, we identified predictors of momentary affect. We generated random forests in R (Version 3.5.3), inputting all 114 numeric variables (items from PDS, CDI 2: P, CDI 2: SR, demographic questionnaires, and the mobile assessment questionnaire) as predictors to model the importance of each variable to current positive affect scores and negative affect scores separately. We chose individual items, as opposed to subscale or total scores, to balance the depth of assessment and data sensitivity. Then we select the 10 variables with the highest relative explained variance to identify the most important predictors of momentary positive affect and negative affect. Next, we used these variables as predictors to fit a linear mixed effects model for momentary mean positive scores and momentary mean negative scores separately, with a random intercept for each participant to understand both risk and protective factors of depressive symptomatology.

To examine the impact of the pubertal stage on depression status we create a summary pubertal status indicator by summing all pubertal development items. We categorized pubertal development by scoring those who were -1 standard deviation from the mean on the total PDS score as 'early stage' and those who were +1 from the mean PDS score as 'late stage' (Smith-Woolley, Rimfeld, & Plomin, 2017). For all analyses, we used average as the reference category. Once again, we generated random forests to determine the relative variable importance and explained variance, of all numeric variables with the new categorical pubertal development variable. We subsequently fit a linear mixed effects model for momentary mean positive scores and momentary mean negative scores separately, with the pubertal stage as a predictor and a random intercept for each participant.

Lastly, we took a theory driven approach to estimate the importance of mean square successive difference (MSSD) (see Thompson et al., 2012; von Neumann, Kent, Bellinson, & Hart, 1941) and the autocorrelation of emotions to parent-reported depressive symptomatology. We use parent-reported depressive symptomatology, as opposed to child-reported depressive symptomatology because parents are believed to be better reporters of depressive symptoms (Lewis et al., 2012; Mazefsky, Kao, & Oswald, 2011; Strang et al., 2012). In this approach, we first examined the variance in momentary mean positive affect and mean negative affect. The variable with the greatest variance, mean positive affect, was chosen as the predictor for subsequent analyses. Then we fit a linear model in which MSSD of positive affect predicts parental reported depression levels for each participant, controlling for pubertal status. Since researchers have suggested a nonlinear relationship between these variables (Houben, Van Den Noortgate, & Kuppens, 2015), we explored linear, quadratic, and cubic relationships between MSSD and parent-reported depressive symptomatology using a mixed effects model, controlling

for the pubertal development stage. We evaluated the model's fit using adjusted R^2 (R^2_{adj}) and Akaike's information criterion (AIC) of model evaluation (Akaike, 1974), with higher R^2_{adj} and lower AIC interpreted as better model fit. Finally, we characterized the relationship between the autocorrelation of positive affect and parental reported depression levels by using a mixed effects model, by controlling for the pubertal development stage and fitting linear, quadratic, and cubic models. Once again, we evaluated model fit using R^2_{adj} and AIC.

4.3 Results

Sample Characteristics

The sample characteristics are presented in Table 4.1.

Predictors of Momentary Affect based on Random Forest

From the random forest, the nine variables with the greatest impact on momentary positive affect included both stable and time-varying variables. Of these nine, five stable variables had the greatest importance for momentary positive affect score: *non-verbal IQ*, *verbal IQ*, *abbreviated IQ*, *parent-reported overall child health*, and *parent-reported pubertal skin changes*. The following four time-varying variables also impacted momentary positive affect: *quality of social interaction*, *enjoyment of the current activity*, *level of social interaction*, and *duration of EMA response (seconds)*. Among these ten variables, the level of current social interaction ($p < 0.01$), quality of current social interaction ($p < 0.01$), parent-reported overall health ($p < 0.01$), and parent-reported hair changes ($p = 0.02$) have statistically significant effects on participants' momentary positive affect.

From the random forest, the following seven stable variables had the greatest importance for momentary negative affect: *nonverbal-IQ*, *presence of an ASD sibling*, *parent-reported pubertal hair changes*, *parent-reported pubertal changes related to skin*, *parent-reported pubertal*

changes related to voice, degree of sadness over the past two weeks, and medications. The following three time-varying variables had the greatest importance for momentary negative affect: *duration of the assessment, enjoyment of the current activity, level of present social interactions.* The only significant time-varying predictor of momentary negative affect was *the quality of current social interaction* ($p < 0.01$). Poorer quality of social interaction corresponds to a higher negative score, which is consistent with the estimation result for positive scores.

In our next model, we examined the effect of overall current pubertal status on momentary positive and negative affect. For momentary positive score endpoints, significant effects (p -value < 0.05)(see table 4.2) were detected on the interaction of the level of social interaction and pubertal status. This interaction indicates that for participants in early pubertal stages, higher levels of social interaction corresponds to higher PA scores. The interaction between the quality of social interaction and late stage pubertal status indicates that for participants with “late” sum PDS scores, responses of higher quality social interaction corresponded to higher endpoint positive scores. This finding suggests that puberty status may play an important role in differentiating risk factors for negative affect.

As expected, for momentary negative affect scores, significant effects (p -value < 0.05) were detected for the interaction between quality of social interaction and late pubertal status (negative estimated coefficient). This suggests that for participants with later pubertal development, a higher score on the quality of social interaction corresponded to lower negative endpoint score.

Table 4.2: Fixed Effect Parameter Estimation – Positive Score

Predictor Variable	Estimate	Std. Error	DF	p-value
<u>Positive</u>				
Intercept	-3.26	37.36	466	0.93
Day	-0.02	0.02	466	0.23
Level of Current Social Interaction	0.14	0.04	466	<0.01*
Quality of Current Social Interaction	0.13	0.01	466	<0.01*
Enjoyment of Current Activity	0.02	0.01	466	0.11
Duration of Assessment	0	0	466	0.79
Verbal IQ	-0.38	2.74	7	0.89
Non-verbal IQ	-0.54	2.67	7	0.85
IQ	0.12	0.91	7	0.9
Genetic Sibling with ASD	0.66	0.61	7	0.32
Parent-Reported Overall Health	-0.77	0.26	7	<0.02*
Parent-Reported Pubertal Skin Changes	0.54	0.6	7	0.39
Parent-Reported Pubertal Hair Changes	1.34	0.46	7	0.02*
Parent-Reported Pubertal Voice Changes	-0.96	0.51	7	0.1
<u>Negative</u>				
Intercept	-13.9	22.49	466	0.5368
Day	-0.002	0.01	466	0.8060
Level of Social Interaction	0.02	0.02	466	0.5280
Quality of Social Interaction	-0.04	0.01	466	<0.01*
Enjoyment of Current Activity	0.005	0.01	466	0.4654
Duration	0	0	466	0.2402
Verbal IQ	-1.23	1.65	7	0.4794
Non-verbal IQ	-1.24	1.61	7	0.4646
ABIQ	0.42	0.55	7	0.4726
Genetic Sibling with ASD	-0.12	0.37	7	0.7520
Parent-Reported Overall Health	0.05	0.16	7	0.7664
Parent-Reported Pubertal Skin Changes	-0.3	0.36	7	0.4286
Parent-Reported Pubertal Hair Changes	-0.45	0.28	7	0.1480
Parent-Reported Pubertal Voice Changes	0.31	0.31	7	0.3417

Note: For brevity, only 14 variables for positive momentary affect and negative momentary affect (total of 28 variables) are presented. These variables were chosen to be presented because they explained the most variance in depressive symptomatology.

Table 4.3: Fixed Effect Parameter Estimation, Including Pubertal Status– Positive Score

Predictor Variable	Estimate	SE	DF	p-value
<u>Positive</u>				
Intercept	-34.53	84.42	460	0.68
Level of Social Interaction	0.03	0.05	460	0.56
Quality of Social Interaction	0.13	0.02	460	<0.01*
Enjoyment of Current Activity	0.04	0.01	460	<0.01*
Non-verbal IQ	-2.74	6.07	7	0.66
IQ	0.91	2.07	7	0.67
Genetic Sibling with ASD	0.35	0.93	7	0.72
Pubertal Status – Early Stages	-0.25	1.09	7	0.83
Pubertal Status – Late Stages	-1.58	1.16	7	0.22
Level of Social Interaction*Pub. Status – Early	0.53	0.11	460	<0.01*
Level of Social Interaction*Pub. Status – Late	0.07	0.11	460	0.49
Quality of Social Interaction* Pub. Status – Early	-0.04	0.03	460	0.16
Quality of Social interaction* Pub. Status – Late	0.09	0.03	460	<0.01*
Enjoyment of Current Activity* Pub. Status – Early	-0.04	0.03	460	0.17
Enjoyment of Current Activity* Pub. Status – Late	-0.02	0.03	460	0.48
<u>Negative</u>				
Intercept	-25.68	32.05	460	0.42
Level of Social Interaction	0.06	0.03	460	0.05*
Quality of Social Interaction	-0.03	0.01	460	<0.01*
Enjoyment of Current Activity	-0.01	0.01	460	0.15
Duration	0	0	460	0.29
Genetic Sibling with ASD	0.32	0.35	7	0.4
Pubertal Status – Early Stages	0.48	0.43	7	0.31
Pubertal Status – Late Stages	0.63	0.46	7	0.21
Number of Medications	-0.19	0.32	7	0.57
Degree of Sadness over the past two weeks	-0.08	0.36	7	0.83
Level of Social Interaction*Pub. Status – Early	-0.15	0.06	460	0.02*
Level of Social Interaction* Pub. Status – Late	-0.1	0.06	460	0.11
Quality of Social Interaction* Pub. Status – Late	-0.07	0.02	460	<0.01*
Enjoyment of Current Activity*Pub. Status – Early	0.03	0.01	460	0.03*
Enjoyment of Current Activity* Pub. Status – Late	0.04	0.02	460	0.06

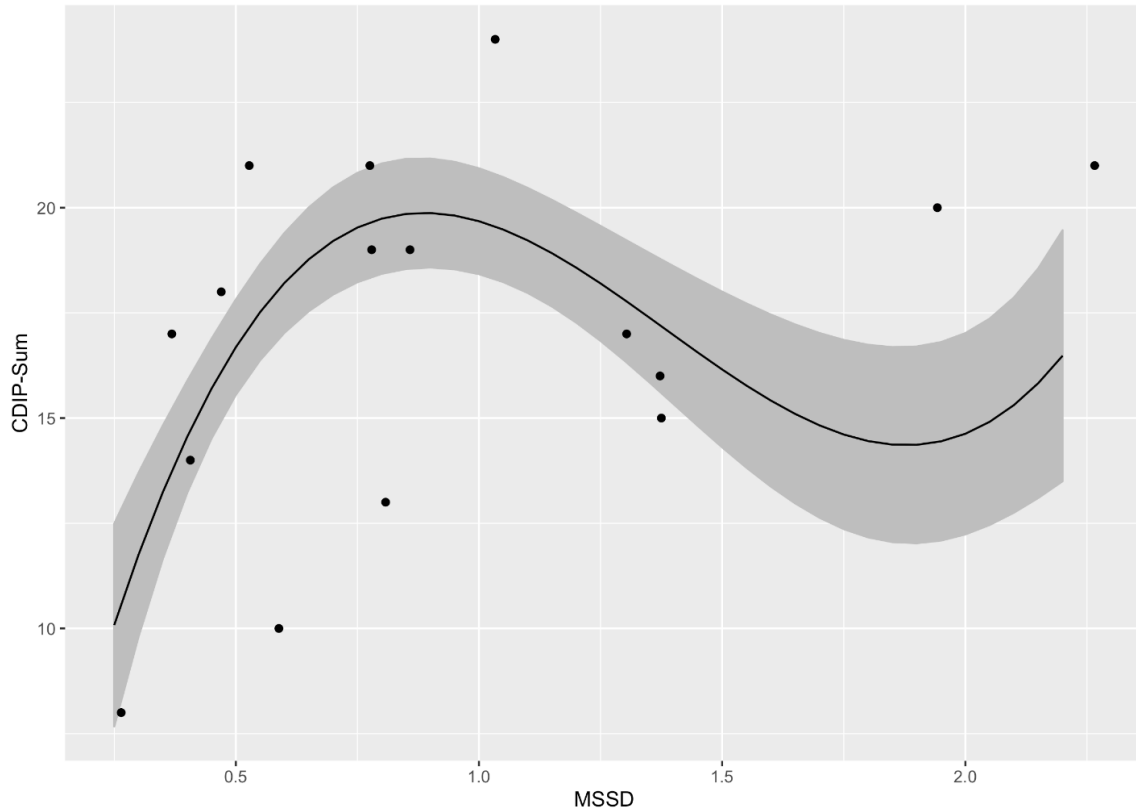
Note: For brevity, only 14 variables for positive momentary affect and negative momentary affect (total of 28 variables) are presented. These variables were chosen to be presented because they explained the most variance in depressive symptomatology.

Predictors of Parent-reported Depressive Symptoms

We estimated a significant positive relationship between positive affect instability (as estimated by MSSD of positive affect) and parent-reported depression symptomatology. The cubic model ($R^2_{adj} = .45$,

AIC=41.1; see figure 2) fit the data better than either the linear model ($R^2_{adj}=0.17$, AIC=46.2) or the quadratic model ($R^2_{adj}=0.25$, AIC=45.3). Autocorrelation of positive affect, however, was not related to parent-reported depressive symptomatology when we fit a linear ($R^2_{adj}=0.16$, AIC=46.36), quadratic ($R^2_{adj}=0.16$, AIC=46.49), or cubic model ($R^2_{adj}=0.16$, AIC=48.36).

Figure 4.2: Relationship between instability and depressive symptomatology



MSSD=Mean square successive difference of positive affect, CDIP-Sum=Child Depression Inventory Second Edition: Parent Report Sum of all items

4.4 Discussion

In the present study, we identified risk factors for both momentary negative affect and depressive symptomatology in adolescents with ASD. We also identified protective factors (i.e., factors that promote positive affect) in the hopes that our findings could be leveraged in the development of interventions targeting depression in adolescents with ASD.

Identifying risk factors that can increase momentary negative affect is important because long periods of negative affect are a transdiagnostic symptom implicated in depression (APA, 2013). For study participants, reduced quality of social interaction had significant effects on their momentary negative affect. In light of the two-hit model of ASD, we believe that this suggests social experiences are a key differentiating factor in the onset of depression. To our knowledge, this is the first study directly investigating the impact of negative social experiences on depressive symptomatology, though researchers have previously hypothesized this relationship (Chandrasekhar & Sikich, 2015). While increased perceived impairments and lower perceived social support had been linked to depression, the role of negative social experiences in predicting perceived social deficits remains unclear. It may be that individuals who have social experiences they perceive as negative attribute these negative experiences to their ASD diagnosis. They may then anticipate future social experiences will be negative, which may lead to a cycle of depressive symptoms. The findings of this study suggest that individuals with ASD who report feeling negative social experiences often should be further screened for potential depressive symptomatology. The development of screening tools that evaluate subjective social experiences for this population may thus be an important step in identifying those at risk for depression.

Social experiences play a significant role in the manifestation of depression (Day, McNaughton, Naples, & McPartland, 2019). While negative social experiences can be a risk factor for depression, we found that positive social experiences can serve as protective factors in preventing depressive symptomatology by leading to positive affect. For participants in early pubertal stages, higher levels of social interaction (i.e., being around more people) was related to positive affect. This suggests that for younger children, being around more people might help decrease opportunities for negative affect. However, for children at later pubertal stages, only the

quality of social interaction was identified as a significant predictor. This suggests that the types of friendships that are protective of depressive symptomatology may change throughout adolescence. Previous studies have found that younger adolescents perceive equal social support coming from both parents and friends, while older adolescents perceive more support from their friends (Bokhorst, Sumter, & Westenberg, 2010). In light of our findings, it may be that younger children seek more friendships, including those provided by the parents, while older children seek intimate friendships with only their close friends.

To further understand the profile of depressive symptomatology in ASD, we verified the network theory of depression hypothesis. We found that increased affective instability leads to increased parent-reported depressive symptomatology. The significant relationship between emotional instability and depressive symptoms may suggest that reducing the overall variability of emotions may be an important step in targeting depression in this population, regardless of the cause of instability (i.e., ruminative thoughts lead to instability, certain sensory experiences may lead to instability, or increased perceptions of ASD related social deficits). Further, this suggests that emotional instability, as manifest by high variations in emotions, may be a key factor in the emergence of depressive symptomatology in the ASD population. While future research will be needed to explore to what extent emotional instability is normal and expected versus unhealthy, these findings suggest that emotional instability may be an appropriate intervention target in future intervention research.

While it is important to interpret these results with caution, our finding of the cubic relationship between emotional instability and depressive symptomatology has important implications for emotional regulation research. While more research is needed to determine exact cutoffs, our findings suggest there may be an optimal level of emotional instability in reducing

depressive symptoms. This would indicate that ideal emotional regulation is characterized by subtle fluctuations in emotional variability (i.e., not happy all the time, sad all the time, nor characterized by extreme patterns of emotional variation). Instead, subtle variations may be a key factor in emotional functioning patterns that are protective of depressive symptomatology. Although more research is needed to verify this hypothesis in larger samples and in other populations, we believe that, in general, child-reported emotional stability may serve as a useful target and outcome measure in intervention studies.

We were surprised to find that autocorrelation of affect did not predict depressive symptomatology in this population. This finding is in contrast to previous literature, which suggests that autocorrelation of affect is a hallmark feature of depressive symptomatology (Wichers, Groot, & Psychosystems, ESM Group, EWS Group, 2016). Our failure to find a significant effect may be related to our small sample size. It may also be that the emotional regulation profile in ASD is characterized by greater instability than in other clinical populations associated with depressive disorders, leading to a decrease in affective autocorrelation. This would suggest that individuals with ASD experience depression differently, and consequentially, researchers must use caution in the application of depression measures normed on other populations to the ASD population.

4.5 Conclusions and Limitations

In this pilot study, we identified risk factors for depressive symptomatology in adolescents with ASD. We found that social experiences are implicated in the mental health of adolescents with ASD. For adolescents at earlier pubertal stages, larger social networks and friend groups may be important for positive mental health. However, as adolescents age, it may be important for them to develop deeper, more meaningful friendships. The type of friendships

that promote optimal psychological functioning may shift throughout the lifespan, which would suggest that the types of skills needed to develop these friendships are also likely to change.

Therapists who aim to optimize adolescents' mental health must consider what types of friendships are most important for that individual. The social skills required to develop and form large groups are different than those required to foster intimate friendships (Glick & Rose, 2011). Accordingly, interventions should be tailored to meet the specific needs for the types of friendships an adolescent with ASD might be seeking.

There are several limitations to the present study. The small sample size of this study makes these findings exploratory. Future studies should verify the findings from the present study using a larger sample size. In particular, studies should concentrate on the recruitment of samples from diverse socioeconomic backgrounds. A limitation of the present study is that adolescents were required to have regular access to a mobile phone to participate in EMA procedures. This required participants to have sufficient economic resources to own a phone, and thus, these results cannot be interpreted as describing the full population. Further, females were excluded from this study. Future studies should investigate emotional patterns among females with ASD. The present study is also limited in that no formal diagnostic assessments were administered to confirm ASD diagnosis. Since all participants were recruited from an ASD registry that verifies diagnosis, this limitation is minimal. However, future studies may benefit from the use of gold-standard diagnostic instruments, such as the ADOS-2 (Lord et al., 2012), to examine how autism symptom presentation and severity may impact depressive symptomatology. Likewise, we used parent-reported pubertal status, which has proven unreliable when compared to physician administered assessments (Rasmussen et al. 2015). Future studies should augment parent-reported pubertal status with physician-measured pubertal level.

Additionally, this study was limited in that we only included individuals with ASD and an average ABIQ. It remains unclear to what extent individuals with lower IQs may experience depression like symptoms in comparison to their higher-functioning peers. Moreover, the absence of a control group prevents us from indicating whether these findings are limited to the ASD population or characteristics of adolescence in general.

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CHAPTER 5. SUBJECTIVE EXPERIENCES OF OCCUPATIONAL PARTICIPATION IN ADOLESCENTS WITH ASD: A MULTIPLE-CASE STUDY USING EXPERIENCE SAMPLING METHODOLOGY

5.1 Background

Individuals' occupations and their experience of these occupations is a core interest of occupational therapists and occupational scientists. Occupation “enables humans to be economically self-sufficient and is a primary organizer of time and resources” (Yerxa et al., 1990, p. 5) and also serves as an important driver for health and well-being. For the purposes of this paper, occupations are considered primary organizers of time (Yerxa et. al, 1990) and thus patterns of occupations are an important component of time use.

Decades of research have found that individuals with disabilities, particularly those with intellectual and developmental disabilities (ID/DD), organize and experience their time differently (Brown & Gordon, 1987; Hilton, Crouch, & Israel, 2008; Orsmond & Kuo, 2011), suggesting that time use may be particularly important construct for those with developmental disabilities. Indeed, the growing corpus of narratives by individuals with developmental disorders like autism spectrum disorder (ASD), such as those by Temple Grandin (2008), suggest that individuals with ASD may engage in different patterns of occupations and that these occupations may be experienced differently. Grandin characterized her adolescence as being in a state of constant anxiety and hypervigilance and she stated that she used writing as a tool to cope with constant anxiety. She recounts, through deeply visual and metaphorical narratives, how these anxious moments were characterized by somatic experiences of headaches and how she

used occupations such as writing as a way to cope with being in a state of anxiety. Grandin's account suggests that occupations and their subjective experiences are a key component to understanding time use in the ASD population. This brief example highlights the importance of using subjective experience as the primary driver of time-use research in this population, because clearly observation alone may fail to adequately identify internal experiences like Grandin's somatic experiences that impact the well-being.

Moving beyond the narratives of those with autism spectrum disorder (ASD), researchers in the ASD field have also identified differences in the pattern of time-use among pediatric populations. Adolescents with ASD spend the majority of their waking time doing discretionary solitary activities such as watching television, playing on the computer, doing physical activity, or listening to music (Orsmond & Kuo, 2011), which are, in general, less diverse than their typically developing peers (Hilton, Crouch, & Israel, 2008). Because studies characterize adolescent time-use from the perspective of their caregivers (e.g., Orsmond and Kuo (2011)), it is unclear how the adolescents themselves experienced these patterns of occupations. While differing patterns of occupational engagement are not problematic per se, occupational scientists have emphasized the importance of a harmonic mix of occupations composed of varying subjective experiences towards overall well-being (Eklund et al., 2017).

Noticeably absent from the literature, though, is a comprehensive understanding of time use among adolescents with ASD from the perspective of the adolescent themselves that includes objective elements, such as specific occupations, along with other more subjective elements, such as emotions. The majority of what we know about adolescents' use of their time has relied on parent report (Orsmond & Kuo, 2011) and has rarely directly investigated the emotional experiences of individuals with ASD in the context of occupation, leaving an important gap of

understanding into the subjective experiences of time use among individuals with ASD.

However, a few studies by occupational scientists are of note in addressing this area. Researchers have used retrospective self-report to examine overall enjoyment of occupations characterized into the following categories: overall, formal, informal, recreational, physical, social skill based, and self-improvement (Hilton, Crouch, & Israel, 2008), which provides some insight into how subjective experiences map onto research created categories of occupation. In this case, individuals with and without ASD reported similar levels of enjoyment when participating in similar occupations.

Researcher created categories, though, may risk the miscategorization of occupations of individuals with ASD. Spitzer's (2003) ethnographic study illustrates how subjective experiences of occupational participation of those with ASD may vary from their neurotypical peers. Occupations such as hand flapping may serve as emotionally regulatory tools that increase positive affect for those with ASD, but be uncommon or serve a different role for those who do not have ASD (Spitzer, 2003). Indeed, the majority of studies investigating the connection between subjective experiences and occupation in this population, have relied on researcher-driven taxonomical categorizations of occupation where occupations are characterized solely based on the type of occupation (i.e., leisure) (e.g., Hilton, Crouch, & Israel, 2008). Spitzer's (2003) important study brought to light the limitations of applying researcher generated categories to the occupations of children with ASD. In her research on young non-verbal children with ASD, she found that fitting the complex continuum of activities of those on the autism spectrum into previously defined taxonomies of occupation was problematic. Children with ASD often engage in repetitive behaviors that may seem to the researcher as non-directed, yet may be meaningful to the child herself (Spitzer, 2003); in these cases, participant observation

alone will always fail to completely explicate participant meanings (Jorgensen, 2015, p. 7). Recent work in occupational science has also identified heterogeneity in the experience of occupational participation (Hammell, 2009; Hemmingsson & Jonsson, 2005). Categorizing occupation using taxonomical categorizations, such as those listed above, assumes experiences are homogenous both within individuals and across individuals. High degrees of variance in subjective experience would likely obfuscate any attempts to find effects in the relationship between occupation and health and prevent important breakthroughs about the role of occupation in health and well-being. However, in recent years, a growing body of researchers from occupational science (Hammell, 2009) and psychology (Stone & Mackie, 2013) have focused on categorizing activity by the subjective experience of the activity, paving the way for important methodological approaches in occupational science research. While these subjective experiences are often only captured through emotion words (e.g., Bergström, Guidetti, Tham, & Eriksson, 2016), a growing body of work suggests that bodily feelings and experiences may serve as a keystone to understanding affective experience variability (Colombetti, 2011; Mauss, Wilhelm, & Gross, 2004).

Research explicitly investigating the relationship between occupations, time-use, and well-being is particularly important in populations at risk for decreased health, such as those with ASD. Individuals with ASD are at increased risk for co-occurring mental health conditions such as depression (Magnuson & Constantino, 2011; Strang et al., 2012). Depression has been associated with patterns of subjective experiences in typically developing populations (Houben, Van Den Noortgate, & Kuppens, 2015) and patterns of occupational engagement (Twenge, Joiner, Rogers, & Martin, 2018), but the link between patterns of time-use, subjective experiences, and mental health remains unclear.

Given the dearth of literature directly examining the affective experiences and occupations in individuals with ASD, research that explicitly investigates this relationship will have a significant contribution to the occupational science literature. Knowledge in this area will provide insight into the experience of occupations in these populations. High degrees of variance in momentary subjective experiences have been linked to mental health conditions (Jahng, Wood, & Trull, 2008), in which individuals with ASD are believed to be at increased risk (Magnuson & Constantino, 2011). Insights into the experiences of individuals with ASD will likely expand current conceptualizations of occupations by moving beyond neurotypical perspectives and towards neurodiverse perspectives, enabling a complete picture of the heterogeneous experience of occupation.

The purpose of this paper is to explore how individuals with ASD report they spend time along with their subjective experiences during their participation in occupation, with the view to understanding the multiple facets of subjective occupational experiences, including those within the affective dimension. We were guided by two aims: (1) to understand how individuals with ASD report spending their time during the summer months, and (2) to understand to what degree and in what profile affective experiences (e.g., bodily feelings and emotions) are reported during occupational participation.

Conceptual Framework

A conceptual framework built around embodiment (see Bailliard, Carroll, & Dallman, 2018; Meier, Schnall, Schwarz, & Bargh, 2012), the transactional perspective (see Cutchin & Dickie, 2013; Dickie, Cutchin, & Humphry, 2006), and time (See Roberts, 2005; Williams, 2011) focused data collection and analysis on how adolescents with ASD experience and participate in occupations. Drawing from the literature in psychology (Barrett, Mesquita,

Ochsner, & Gross, 2007; Barrett, 2006; Houben, Van Den Noortgate, & Kuppens, 2015), child development (Muscatello & Corbett, 2018; Thapar, Collishaw, Pine, & Thapar, 2012), disability theory (Goodley, Liddiard, & Runswick-Cole, 2018), and occupational science (Bailliard, Carroll, & Dallman, 2018; Dallman & Triplett, 2019), affective experiences are a functional tool that (1) provide a window into individual experiences; (2) inform how and why individuals organize their time; and (3) help identify similar experiences across participants. Here, we view bodily experiences and emotions as intricately intertwined (Barrett, Lindquist, & Gendron, 2007; Barrett, Mesquita, Ochsner, & Gross, 2007; Barrett, 2017), such that bodily sensations may serve to magnify, dampen, or transform emotional experiences and vice versa. Because bodies are undoubtedly part of occupation (Bailliard, Carroll, & Dallman, 2018), it is key to understand bodily experiences in order to understand occupational experiences. Likewise, time is an essential component of occupational experiences (Hunt & McKay, 2015) that enables occupations to be experienced dynamically (Roberts, 2005). We further believe that subjective experiences are likely to vary across individuals and across diagnostic groups (Goodley, Liddiard, & Runswick-Cole, 2018), highlighting the importance of examining both individual and group level trajectories.

5.2 Method

In the present study, we used ecological momentary assessment (EMA) methodology to examine subjective occupational experiences and the reported areas of occupational participation in adolescents with ASD. EMA is a method pioneered by Larson and Csikszentmihalyi (1988). Ecological momentary assessment yields both quantitative and qualitative data. Participants are signaled via text message to complete a survey at semi-random intervals throughout the day.

Participants

Participants were 17 male adolescents with ASD aged 11-18 years ($M=14$ years, $SD=2$ years, range= 11-17). ASD diagnoses were confirmed through parent-report. Inclusion criteria included the following: participants must reside in Central and Eastern North Carolina, have a composite abbreviated intelligence quotient greater than 85 (as determined by the Stanford-Binet Intelligence Test, fifth edition), speak fluent English, and have regular access to a mobile phone. Participants with co-occurring genetic syndromes were excluded from the study.

Procedures

Parents of potential participants were informed about the study through an ASD research registry, flyers posted on social media, and a central database of university-affiliated employees/students. Parents were then invited to indicate interest by contacting the researcher. All adolescent participants were then screened for eligibility by the first author and a research assistant. First, parents completed a screening phone call in which they verified their child had regular access to a mobile phone, that their child was potentially interested in participation, and their child had a diagnosis of ASD. Afterwards, eligible adolescent participants were screened in-person using the Stanford-Binet, fifth edition (SB-5) (Roid, 2003) for the inclusion criterion of an abbreviated intelligence quotient (ABIQ) greater than 85. Participants then completed a set of demographic questionnaires and assessments, including Child-Depression Inventory Second Edition: Self-Report (CDI 2: SR); Child Depression Inventory Second Edition: Parent Report version (CDI 2: PR) (Kovacs, 2010), and the Pubertal Developmental Scale (PDS; Petersen, Crockett, Richards, & Boxer, 1988). During the next phase of the study, participants received a text message which signaled them to complete a questionnaire. At each EMA signal, participants completed the Positive and Negative Affect Schedule, Children's Version – Short Form

(PANAS-C-SF)) (Sanmartín et al., 2018) and a brief occupational questionnaire (See Table 2). Each item of the PANAS-C-SF is scored on a scale of one (none at all) to five (extremely).

We used a semi-random sampling EMA. EMA is an intensive sampling method in which participants complete an assessment protocol multiple times, usually in relatively close time periods (i.e., multiple times a day, or multiple days in a week). EMA is advantageous as it captures the variation of an individual's momentary experiences, assesses the relationship between contextual factors and individual experiences, and examines variations of a phenomenon of interest over time (Stone & Shiffman, 1994). Participants were signaled to report their affective experiences and occupational participation six times a day for seven consecutive days. Each participant's initial prompt was sent via text message semi-randomly within two hours of their parent-reported waketime. Subsequent prompts were sent two hours after the initial message. Because the start time for each day was semi-randomly generated, we believe that participants were unlikely to anticipate when they would receive messages each day.

To capture social experiences, we asked participants to tell us how many people they were currently with and how much they were enjoying the people they were around. Participants were instructed to report how many people they felt they were around, as opposed to the number of people in the room, to characterize their social experiences. Each participant was given the example of going to a restaurant. Sometimes one may go to a crowded restaurant and be eating at a table alone and feel alone, despite having a large number of people around. At other times, one may be in the same situation and yet feel like they are in a large group (such as when watching a sports game). Participants were instructed to choose whatever they felt (i.e., they could choose alone or more than 10 people), because both could be true in the aforementioned example. This enables us to capture whether an occupation was subjectively experienced as social.

In this paper, we conceptualize the affective dimension of occupation with three broad categories, each derived from the PANAS-C-SF: positive affect (PA) (five items from the PANAS-C-SF including cheerful, happy, lively, joyful, and proud), negative affect (NA) (five items from the PANAS-C-SF including miserable, mad, afraid, scared, and sad), and neutral affect. Mean PA and NAs thus range from one to five. We define neutral affect as experiences characterized by neither high PA nor high NA (i.e., a mean ≤ 2 on both PA and NA). The broad nature of these three categories can capture the affective experiences during engagement in all occupational participation because we believe that no experience is void of some emotional quality.

We included a list of bodily sensations to capture one dimension of our participant's subjective experience of occupations. The list of bodily sensations was adapted from previous emotion research (See 5.1) (Breugelmans et al., 2005); one item was split into two (“breathing changes” was modified to “quick breathing” and “slow breathing”) to capture the nuances of breathing changes that may be associated with emotional changes. In addition, we modified one item to reflect more commonly used language: “hot in the eye” was changed to “blood pressure rising.” We added “sleepy” as an item because research indicates that adolescents with ASD often experience sleepiness or tiredness (Baker, Richdale, Short, & Gradisar, 2013). While medications commonly explain sleepiness, we believe that, regardless of the cause, sleepiness will impact subjective occupational experiences. Participants reported their bodily sensations as either present or not. All participants received training in how to complete the EMA by the first author. During their training, participants were also asked questions to clarify their understanding of the EMA questions (e.g., What are goosebumps? When might you feel goosebumps?). If participants answers did not indicate understanding, the researcher would clarify with the

participant the definition of the phrase. It is important to note that we encouraged participants to describe their current activity using as much detail as they would like. Throughout this paper, we use the participants' language to describe their current activities.

Table 5.1 Mobile Assessment Questionnaire

<u>Question</u>	<u>Response Type</u>
PANAS-C-SF (10 questions like <i>How happy are you?</i>)	Likert-type (1-5) with visual anchors (visuals adapted from Kovac, Mosner, Miller, Hanna, & Dichter, 2016)
What are you doing right now?	Open-ended
How many people are around you right now?	Ordinal (four levels: (1) no one, I am alone, (2) 2-5 people, (3) 6-10 people, or (4) more than 10)
How much are you enjoying your current level of social interaction (the people you are around)?	Likert-type (1-10)
How much are you enjoying your current activity?	Likert-type (1-10)
How does your body feel right now?*	Choose all that apply: <ul style="list-style-type: none"> • Lump in the throat • Quick breathing • Slow breathing • Stomach sensations • Feeling cold • Feeling warm • Feeling hot • Heart beats faster • Sweating • Goosebumps • Blushing • Weak in the knees • Blood pressure rising • Sleepy

PANAS-C-SF=Positive Affect and Negative Affect Schedule, Children’s Version, short form, PA= positive affect, NA= negative affect,

*This list was adapted from Breugelmans, Ambadar, Vaca, and Poortinga (2005)

Data Analysis

All EMA data was coded and entered into R (Version 3.5.3). We used thematic cross-case analysis to explore the responses of the 17 participants to the qualitative question about their current occupational participation (Clarke & Braun, 2014). This method enables the identification, analysis, and reporting of the themes within the data (Sibeoni et al., 2018). Coding was done through five steps, in line with other studies using thematic analysis with qualitative case study data (Sibeoni, Chambon, Pommepuy, Rappaport, & Revah-Levy, 2017) . We (1) repeatedly read through the cases; (2) coded the cases and made notes corresponding to units of meaning of each response; (3) made conceptual notes about codes and the relationship between codes; (4) generated initial themes by collapsing codes into broad units of meaning; and (5) identified recurrent and divergent themes across cases. We also used the computer program R (Version 3.5.3) to summarize and synthesize themes.

5.3 Results

In-depth analysis revealed a multitude of relationships between subjective occupational experiences and the occupation itself. Four themes emerged in the data analysis: (1) adolescents with ASD participate in a range of occupations, most commonly screen-time occupations; (2) adolescents with ASD spend significant time spent in enjoyable occupations with others; (3) adolescents with ASD report more PA than NA; and (4) high variability characterizes the subjective experiences of adolescents with ASD.

Adolescents with ASD Participate in a Range of Occupations, Most Commonly Screen-time Occupations. Participants reported a variety of activities during the summer months (see Table 5.2) such as playing video games (n=100), activities of daily living (n=24),

attending a cookout with their family (n=2), lying down (n=7), and driving or riding in a car (n=21).

Participants spent a significant amount of time engaged in screen time occupations. Playing video games was the most common occupation reported (n=130, 18.5% of all occupations reported). The vast majority of these responses included a general description such as “playing a game”. However, participants did report some specific video games including ©Roblox or ©Mario Kart. The average PA for all video game occupations was 4.25 while the average NA was 1.13, suggesting that video games were generally experienced with high levels of PA. The second most common screen time occupation included watching videos either online or on the television (n=95, 17.6%). Watching videos was generally less enjoyable than playing video games (M PA=3.67, M NA=1.18), but still a high PA activity. In sum, screen time occupations comprised over 1/3 of the occupations.

Table 5.2: Affect Associated with Differing Types of Occupations

Occupation	Number of Endorsements	PA	NA
Screen time	225	3.12	1.34
Video game	130	4.25	1.14
Television	95	3.67	1.18
Activities of daily living	24	4.2	1.15
Work occupations	19	4.6	1.59
Riding in a car	21	4.7	1.59

Activities of daily living (ADL), including eating, preparing food, and hygiene routines, were minimally endorsed (n=24, 4.4%). In this area, participant reports included information about occupations such as “about to take a shower,” “making dinner,” “and “eating dinner.”

ADL occupations were experienced with similar levels of enjoyment as playing video games ($M_{PA}=4.2$, $M_{NA}=1.15$).

Of the five participants who were above the legal working age of 16, two endorsed some type of work occupation. We followed the tradition of taking a broad approach in defining work occupations (Farrell & Bryant, 2009) and included occupations under this category that are described by participants as “working,” “volunteering,” or preparatory job activities (i.e., applying for a job). One participant reported volunteering at a camp and working as a lifeguard. Another participant reported completing a job application at one time point. Employment type occupations were rarely endorsed by our sample.

We also include school-type occupations under the category of work. Across our 17 participants, completing schoolwork was mentioned 11 times, likely a low number due to data collection occurring during the summer months. Emotions during schoolwork activities were understandably varied, but in 9 of these 11 moments, PA was higher than NA. In these cases, PA was, on average, 0.28 more intense PA than degree of NA. Given that PA and NA are measured on a range of 5-25, this small effect suggests that school type occupations were experienced with minimally more PA than NA. The most common NA emotion endorsed during homework type occupations was feelings of miserableness. The NA emotions of afraid, scared, or sad were never endorsed by our sample during school-type occupations. The most common PA emotion was happy, and each of the other four PA items was endorsed at the level of two or greater at least twice. Homework is often assumed to be experienced as a negative activity that leads to stress (Kouzma & Kennedy, 2002); but in our sample, homework was often either a neutral activity or one that increased feelings of pride. Generally, our sample endorsed homework as a positively experienced activity. This finding challenges normative assumptions regarding the subjective

experience of homework (i.e., as a negative experience) and should caution against normative assumptions of experiences in relation to any occupation.

Our participants reported a range of occupations that are typical of adolescence such as screen time (Cain & Gradisar, 2010), employment (Kalenkoski & Pabilonia, 2012), and ADLs. Like their typically developing peers, adolescents with ASD spend significant time playing video games and watching TV, but they also expend time engaging in other activities like filling out job applications, going to work, and doing homework.

Adolescents with ASD Spend Significant Time Participating in Occupations with Others. Participants frequently engaged in occupations with others, defined as occupations in which they reported that they did not feel alone. There was high variability among the type of occupations participants reported in this theme (e.g., playing video games, driving, and cooking). Participants reported spending over 45% of their time in small groups (two to five people), 8% of their time in moderate-sized groups (six to ten people), and 4% of their time in large groups (more than 10 people). Generally, participants reported the most PA during occupations with moderately sized groups and large size groups (i.e. six or more people). Adolescents reported the lowest PA when they were alone, indicating that participants enjoyed being around others (regardless of group size) more than being alone (See Table 5.3).

Table 5.3: Influence of Group Size on Affect

Group Size	Number of Endorsements	PA	NA
Alone	225	3.12	1.34
2-5 People	244	3.49	1.25
6-10 People	43	4.10	1.16
11+ People	24	3.70	1.32

There was a strong association between momentary positive affect and enjoyment of the people participants were around ($r=0.49$) which provides further evidence that participants' PA was likely intimately tied to who they were around. Additionally, there was a moderate association ($r=0.36$) between enjoyment of the people they were around and enjoyment of the activity itself, indicating that participants were not only experiencing more PA when participating in occupations with others, but their enjoyment of their experiences in this area affected their enjoyment of the occupation itself. Not only were adolescents enjoying being in large groups, but they were also enjoying being with moderate-sized groups of people. Participants experienced the most PA when in groups sized 6-10. The level of enjoyment of who one is around is thus a key driver in the subjective experiences associated with participation in occupations among/adolescents with ASD.

Clearly, adolescents with ASD are participating in a range of occupations with others, and these occupations occur in a variety of different contexts. Adolescents on the autism spectrum experience a range of social circumstances and demands much like their typically developing peers (Valle, Bravo, & Lopez, 2010). Also, much like their typically developing peers, participants greatly enjoyed their experiences with others.

Adolescents with ASD Report More PA than NA. Participants reported a range of emotions throughout their occupations. We examined the frequency participants reported an emotion at or above a moderate intensity (emotion ≥ 3). PA was experienced at moderate or higher levels of intensity most frequently, with happiness ($n=305$) being the highest, followed by cheerful ($n=301$), lively ($n=292$), joyful ($n=248$), and proud ($n=215$). NA was endorsed much less frequently at the moderate or higher level of intensity. The most common NA were miserable ($n=22$), followed by mad ($n=10$), sad ($n=10$), afraid ($n=7$), and scared ($n=7$). In this

study, adolescents with ASD reported PA much more often than reporting NA. Social desirability bias may have played a significant role. Social desirability bias indicates that individuals are less likely to report emotions the individual views as negative, such as those we grouped as NA. Adolescents may be more prone to report variability in PA, because they believe PA is more acceptable to report. Accordingly, PA may be a more useful indicator of the affective variability adolescents with ASD experience during occupational engagement.

We also captured variations in subjective experience through reports of bodily feelings. Because the bodily feelings included in our list could occur during periods of both PA and NA, we choose not to group them as PA or NA indicators. Instead, we report only the broad frequency of each of these experiences. Also, participants were not required to choose any of the bodily feelings. The most common bodily feelings included: sleepiness ($n=191$), warmth ($n=112$), and slow breathing ($n=106$). The least endorsed bodily feelings included blushing ($n=4$), goosebumps ($n=7$), and a lump in the throat ($n=2$). The adolescents with ASD in this study experienced a variety of bodily feelings throughout their occupational engagements and were able to look inwards and reflect on their bodily feelings and emotional episodes during occupational participation.

High Variability Characterizes the Subjective Experiences of Adolescents with ASD.

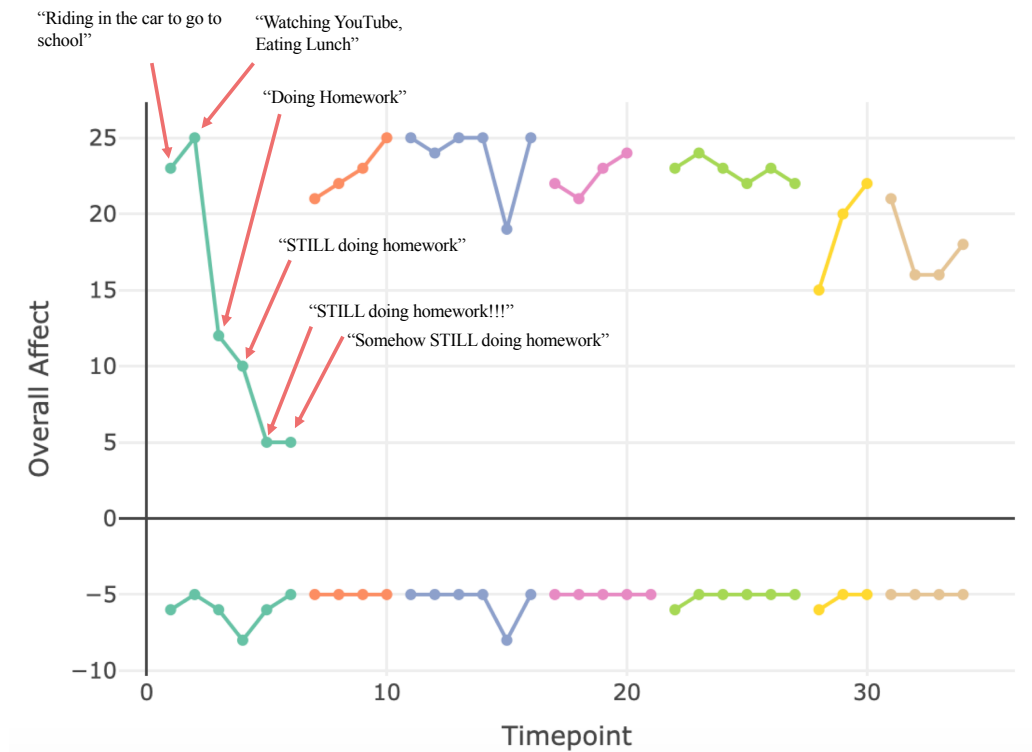
Across all participants, we observed high degrees of variation within individuals and across individuals in the affective experiences they associated with a singular occupation. Ultimately, this suggests that occupations may be experienced differently at different times. Lifeguarding, for example, was endorsed by one participant on days two and three of their signal period and was associated with different levels of positive and negative affect (e.g., on day two $M PA=1$, $M NA=2$, on day three $M PA=2.6$, $M NA=1$) and varying bodily experiences (e.g., feelings of weak

in the knees on day two; feelings of weak in the knees, slow breathing, and sleepiness on day three). For this participant, lifeguarding was an occupation that was experienced at different times with a pleasant, neutral, or negative affect. Though our assessment protocol did not have sufficient granularity to identify when shifts in affect occurred; broad periodic fluctuations occurred while participating in the same occupation. Across all participants, we found no cases where the same occupation was always reported with the same profile of PA, NA, and bodily feelings.

Participants also described high degrees of affective variation when one occupation was completed for a long period (i.e., for multiple concurrent signals). Completing schoolwork, for example, was endorsed by participants at multiple signals. On one day, a participant returned home from school and spent the majority of the evening completing homework alone (See Figure 5.2). First, he reported doing homework and feeling miserable (2/5) and sleepy (2/5). This activity resulted in a sharp change in his current enjoyment of activities (from 10 to 6). At his next signal, his negative affect increased ($M=1.6$), his enjoyment of the activity further decreased (6 to 3), and he reported he was “STILL” [emphasis in original] doing homework. This was also associated with increasing feelings of miserableness (4/5) and heat. At the next signal, he continued to report that he was “STILL” [emphasis in original] doing homework, but his feelings of miserableness had returned to 2 out of 5. Over the course of engaging in this one activity for approximately five hours (completing homework) this participant experienced a gradually decreasing PA trend (M PA changed from 2.4 to 2 and subsequently down to 1). His NA gradually increased while he was completing his homework (M NA changed from 1.2 to 1.6), though when he neared completion, his NA returned to neutral (M NA=1.2). In his final signal of the day, this participant reported no salient affective experiences (M PA=1, M NA=1), and

reported feeling both hot and sleepy while he was “somehow” still doing homework. In this case, affective experiences shifted gradually while completing homework, which provides evidence for the temporal and dynamic nature of occupational experiences. Indeed, for this participant, the occupation of completing homework was not associated with one singular feeling or bodily sensation and instead was characterized by increasing NA and a variety of bodily sensations, providing further evidence of the dynamism of affective, subjective, bodily, and emotional experiences during participation in one occupation.

Figure 5.1: Relationship between Affect and Occupational Participation for One participant



Note: Positive affect (PA) is scaled positively (i.e., higher PA number indicates more PA while negative affect (NA) is scaled negatively (i.e., higher NA number indicates more NA). For brevity, we only present the occupations this participant reported on Day 1

Playing video games was another common occupation in which participants reported dynamic and varying emotional, affective, and bodily experiences. Experiences varied both across individuals and within one individual at concurrent timepoints. Participants’ reports of

playing games ranged from the highest possible PA ($M PA=5$) to very low PA ($M PA=1.2$). For example, one participant, was playing video games and experiencing the highest possible level of PA ($M PA=5$). Later that day, this participant was playing video games, but with high degrees of variation in his subjective experiences. The first signal ($M PA=3.8$, $M NA=1.6$) was characterized by an increased challenge as the participant reported that he was “having a hard time” completing the video game and was experiencing quick breathing. At his next signal, this participant reported that he had completed the game and that his feelings of pride had increased from four out of five to five out of five ($M PA=5$, $M NA=1$). The challenge associated with playing the game was likely a key driver in the subsequent feelings of increased PA and pride upon completing the game. This finding complicates research or intervention approaches that assume occupations will have a direct effect on affect or emotions.

Across all participants, occupations were not universally described as enjoyable or unenjoyable. All but one participant reported at least one occupation as highly enjoyable (as indicated by the highest score possible on the question “how much are you enjoying your current activity?”). Over 150 occupations were described as enjoyable and included occupations such as playing games, family gatherings, resting/lying down, reading, riding in the car, making breakfast, watching TV, talking with friends, playing sports, attending a party, waking up, snuggling with a pet, and doing homework.

Conversely, only six participants endorsed an occupation as very unenjoyable (the lowest possible score to “how much are you enjoying your current activity?”). The majority of these occupations ($n=13$, 54%) were described by one individual, who was in the 94th percentile on the self-reported CDI. The other participants who indicated at least one occupation as highly unenjoyable had CDI scores that ranged from the 25th percentile to the 94th percentile. These

occupations were: reading, shopping, watching television, sleeping, going to an appointment of a family member, riding in a car, walking a dog, chores, working, and trying to fall asleep. In sum, highly unenjoyable occupations were endorsed only 24 times, which is 127 fewer endorsements compared to highly enjoyable occupations. This implies that individuals with ASD are generally enjoying their occupations during the summer months.

5.4 Discussion

In this study, we examined the connection between occupation and subjective experiences among individuals with ASD. Through EMA, we assessed occupational participation in real time, providing insight into the daily lives and range of occupations in which adolescents with ASD participate. Our findings revealed the complex interplay between participation and subjective experiences.

In general, our findings suggest that individuals with ASD participate in diverse occupations during the summer months. Adolescents with ASD frequently engage with screen time occupations such as video games or watching videos online. In our study, participants generally reported their most positive emotions during screen time occupations. Because the most common occupation reported by participants was playing video games, video games are likely an important leisure activity for adolescents with ASD that could potentially be leveraged in therapeutic and educational contexts to improve subjective experiences during these occupations. A strong body of evidence suggests that video games impact the emotions of typically developing players (Marco, Hinkley, Hill, & Nagarajan, 2011). Our findings extend this perspective by highlighting how engaging in this occupation can impact the subjective experiences of adolescents with ASD. Playing video games, though, was not universally associated with PA (i.e., most participants reported the most enjoyment during screen time

participants, but not every single participant in every occasion), which supports our finding that it is not the activity itself, but the features of the occupation that likely play a role in the subjective experiences of that occupation. More research is needed to help define what features of video games are most advantageous for eliciting PA.

It was also interesting that occupations which might typically be categorized as ADLs such as preparing meals were endorsed at similar levels of PA as video games. Families of children with ASD often report that routines are important for daily functioning (Rodger & Umaibalan 2011; Schaaf et al. 2011). This study extends this finding by suggesting that routine occupations, such as ADL occupations, were reported as high PA occupations. ADLs are often conceptualized within occupational science as a category separate from leisure (e.g., Cogan, Haines, Devore, Lepore, & Ryan, 2019). However, we found significant similarities in the subjective experiences of occupations that could be characterized as ADLs and leisure. It may be that these occupations share characteristics that overlap, such as being highly structured, and that these shared characteristics are primary drivers of the affective experiences our participants reported. Video games often have very clear goals and directions. Likewise, ADLs often have very similar levels of structure. It may be that these shared qualities in the performance of these occupations led to these subjective experiences. Future work in this area should continue to forefront neurodiverse perspectives to understand the many diverse influences into the subjective experiences of occupation.

Both ADL and employment type occupations were rarely endorsed in our sample. Random sampling EMA ensures that all times during the waking hours have an equal chance of being sampled. However, because many self-care ADLs are shorter in duration, they had a lower probability of being sampled, which may have led to them being under-reported during random-

sampling procedures. Also, because ADLs can occur at a variety of times, we were unable to know if a participant's ADL participation occurred outside the bounds of the signals. Employment type occupations, though, are not expected to be shorter in duration. It is problematic that these employment type occupations were rarely endorsed, because adolescent work activities have been related to subsequent successful employment (Scott et al., 2019). Furthermore, social skills are a key deficit among those with ASD (American Psychiatric Association, 2013), and employment occupations are important in the development of social skills that are essential for later educational and employment outcomes (Coleman, 1988; Leventhal & Graber, 2001).

In the study of occupation, our most significant finding was that occupational participation was characterized by heterogenous subjective experiences. We found that the combination of self-reported emotions and bodily sensations together provided a nuanced view of subjective experiences during occupational performance, which enabled us to better understand an individual's experiences during occupational engagement. While our study was limited by not assessing other factors that are important for occupational experiences, such as meaning or level of challenge, we believe that our findings provide some insight into heterogenous experiences of occupations. No singular occupation was connected to the same emotion or bodily experience in our cross-case analysis, which suggests that occupational participation alone also does not predict bodily experiences, nor should affective experiences during occupational participation be considered universal. These findings challenge notions of health and well-being that imply a balance of specific types of occupation are necessary for well-being (Wilcock et al., 1997) and instead provide support for perspectives that emphasize the subjective experiences associated with occupational participation (Jonsson & Persson, 2006).

These subjective experiences are likely to be dynamic; thus, it cannot be assumed that an individual will always characterize an occupation into the same subjective category. Occupations are serial and are impregnated with past experiences that transact with the present (Cutchin, Aldrich, Bailliard, & Coppola, 2008). When subjective experiences are viewed as they are here, dynamically, we anticipate that bodily experiences during occupations will vary day to day. Understanding these day-to-day fluctuations and how they transact with emotions will likely serve as a key guide for understanding disease phenomenology that is located primarily in the body, such as chronic pain. In sum, these findings strongly suggest that occupational scientists must move beyond research approaches that assume occupations are experienced statically in favor of approaches that situate the subjective experience as dynamic.

In particular, investigating how the experience of occupational participation changes in response to other important factors such as subjective elements that suffuse through past performances and how present social experiences impact occupational experiences are fruitful avenues for future research.

5.5 Limitations

In this exploratory study, we sought to examine the connection between bodily sensations, emotions, and occupation. We acknowledge this application of EMA is limited as it prevents us from knowing when a participant reports a broad category, such as “playing games,” whether they are playing video games, board games, or something else. By sampling participants only six times per day, we were generally only able to examine a cross-section of emotional experiences and were frequently unable to examine how emotions and bodily experience may change during engagement in the same occupation. Additionally, we were unable to examine how past occupational experiences impacted present experiences, which could be problematic

given that occupations are serial (Cutchin, Aldrich, Bailliard, & Coppola, 2008). Researchers should continue to explore this area as we believe it will be a fruitful avenue for examining the role of occupational participation in emotional regulation. Additionally, by including only a relatively small number of participants, we encourage caution in the interpretation of patterns of emotion and occupational participation.

Our findings also suggest that while a brief set of bodily sensation words may capture some of the nuances of bodily experiences during emotion, the 14 items we used are unlikely to capture the full breadth of these experiences. Thus, it may be important in future research to expand this list or develop a new list tailored to the bodily experiences for individuals with ASD. Specifically, qualitative data collection approaches that are embedded in real-time engagement may be an advantageous path for identifying additional items to add to this list.

The present study is also limited by only including sampling through EMA. We created cases from the results of the EMA. However, future research will benefit from including other qualitative research methods, particularly ethnographic methods, to understand how individuals with ASD describe their emotional experiences using their own language. Researchers could then triangulate those findings with those from the EMA to create a more thorough understanding of the emotional and occupational lives of individuals with ASD.

5.6 Conclusion

In the present study we identified patterns of time use and affective experiences among adolescents with ASD. Participants reported frequent participation in screen time occupations such as watching television, along with other more diverse occupations such as sleeping, riding in the car, and attending events with families. Additionally, participants reported high degrees of participation in occupations with others. We found that most adolescents experienced their most

PA during occupational participation with other individuals. Our findings highlight that individuals with ASD are motivated to be around others and experience a variety of enjoyable occupations during their days. In future work, more research is needed to understand occupational experiences of individuals with ASD.

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CHAPTER 6. INTEGRATED DISCUSSION AND CONCLUSION

6.1 Introduction

As a whole, Project TEMPO addressed gaps in the literature related to understanding the affective dimension of occupation among adolescents with autism spectrum disorder (ASD). In this project, we viewed all occupational performance as impregnated by affective experiences which can be captured in two parts: (1) affectus, the beginning state of emotions that emerge through the body and continue throughout occupational participation and (2) emotion, which is the subjective, socio-linguistic fixing of an affectus experience. In this dissertation, we include emotion concepts, captured by emotion words such as “happy” that are grouped into the domains of PA and NA, and affectus, obtained through reports of bodily feelings during an occupational performance. Bringing both emotions and affectus into focus with this population enabled us to create a sensitive picture of the lived experiences in the affective domain and to connect psychological functioning with subjective experiences of occupation. Specifically, I connected psychological functioning with subjective social experiences during occupational participation to understand the transactions between occupational participation and mental health.

I sought to understand patterns of time-use among adolescents with ASD. I found that adolescents with ASD, much like their typically developing peers, spend significant time engaged in screen-time occupations. During the summer months, adolescents with ASD spent long periods playing video games with peers online, watching television, and watching videos online. In many of these cases, participants were with friends connected through virtual spheres.

Adolescents with ASD also spent time engaged a variety of other occupations such as doing homework, completing ADLs, and socializing with family members. In sum, this research suggests that adolescents with ASD participate in a range of occupations similar to their typically developing peers and experience those occupations with a diverse range of emotions and bodily sensations.

6.2 Exploring the transactions in the affective dimension of occupation among those with ASD

In Aim 2 and 3 (Chapters 4 and 5), I fore fronted the value of understanding emotions of individuals with ASD in occupational science by evaluating risk factors for depression at both the state level (i.e., predicting negative affect) and at the trait level (depressive symptomatology). I also explored the emotions experienced during occupational engagement among this population. Importantly, I found a significant relationship between elements of the social dimension of occupation (i.e., self-reported quality and amount of a momentary social interaction) and state emotional experiences. This finding is in line with the transactional perspective (Cutchin & Dickie, 2013) and reinforces the notion that the dimensions of occupation transact throughout performance and subjective experience (Dickie, Cutchin, & Humphry, 2006). These transactions within the affective dimension have clinical implications, particularly in understanding the experiences of affective/mood disorders such as depression. Our findings suggest that the social dimension of occupation may be particularly important for the emotional and affective experiences of individuals with ASD and also that social occupations may play a key role in the maintenance of mental health.

Conceptualizations of ASD posit decreased social motivation; however, in the present study, participants experienced their greatest PA during social activities. Researchers have

posited a link between social anhedonia and social motivation in this population (Novacek, Gooding, & Pflum, 2016). Social anhedonia is often measured by attentional biases and not subjective experiences reported by the individual with ASD (e.g., Dawson, Meltzoff, Osterling, Rinaldi, & Brown, 1998), which could reflect biases in attention, but not subjective experiences. In the present study, participants frequently reported enjoying a variety of social situations and diverse occupations. It may be that social anhedonia is not as widespread in the ASD phenotype as previously thought. This finding highlights the importance of understanding subjective experiences from the perspective of the individual with ASD. If researchers assume attentional patterns represent subjective experiences, then they may inaccurately assume that individuals with ASD do not enjoy social participation.

For example, many of the TEMPO participants reported that social video games were highly enjoyable. This finding somewhat contrasts with the Social Motivation Theory of ASD that posits decreased social orienting, social reward, and social maintaining and overall reduced social motivation in this population (Chevallier, Kohls, Troiani, Brodtkin, & Schultz, 2012). Instead, these findings point to a more complex picture of social motivation in adolescents with ASD. While individuals with ASD often demonstrate preference towards non-social activities and stimuli, such as decreased visual attention to social versus non-social objects and scenes (Chevallier et al., 2015; Klin, Jones, Schultz, Volkmar, & Cohen, 2002), features of the activity may be key drivers in the individuals social motivation. This theory would suggest that adolescents with ASD would generally have selective social anhedonia, demonstrating lower preference towards stimuli that require higher levels of social processing, but higher motivation in activities that require less labor in interpreting and understanding others social cues (Chevallier, Grèzes, Molesworth, Berthoz, & Happé, 2012). Social video games may be fertile

ground for socially motivating activities as they include more concrete social tasks (i.e., communicating via typing that members of a team should proceed towards a common goal) that require less social processing of complex stimuli like facial expressions. In light of the social motivation hypothesis, the high degree of positive affect during social video games has important clinical implications.

Social motivation models of ASD posit that early impairments prevent typical social learning that impacts social development throughout the lifespan, but if adolescents demonstrate selective social motivation towards video games, then adolescence may be a critical period in which these selective social occupations could be used to specifically promote the development and fostering of social skills. Previously, video games have been used to teach social skills related to sportsmanship (Ferguson, Gillis, & Sevlever, 2013), cooperation, and making new friends (Ducheneaut & Moore, 2005). A growing body of literature also indicates that video games have positive impacts on health (Casiano, Kinley, & Katz, 2012; Gao, 2017; Kovess-Masfety et al., 2016) and multi-player video games can foster social skill development (Boyle, Connolly, & Hailey, 2011; Maitland et al., 2018). Multiplayer video games and other online based social interactions are virtual spaces where children learn new ways of socialization, develop identities, and explore new social contexts. As discussed in Chapter 4, EMA may be a key tool in an effort to understand the experience of social video games. The high ecological validity of EMA in combination with the possibility for the sensitive understanding of occupations provides the opportunity for rich theory into how the occupation promotes or hinders social development, fosters identity formation, and teaches new skills. Event-based EMA sampling allows the researcher to assess multiple instances of social video game playing to parse out how differing ecological occupational features transact with subjective experiences.

By asking participants what they are doing and how much they are enjoying their current activity, I am able to see how individuals describe their occupations (i.e., what elements of the occupation are most salient to them in the moment) and how the occupation is experienced. This enabled us to see the high levels of social enjoyment reported by participants and that this enjoyment was experienced throughout a variety of types of occupations. This approach further enabled us to see how one occupation might be described differently (e.g., how completing homework is different from “STILL doing homework). I was able to then examine how these differing descriptions of occupations were connected to different emotions.

I further explored transactions in the affective dimension in Aim 3 (Chapter 5), as I presented the relationship between emotions, bodily sensations, and occupational participation. I found support for theories of emotion (Barrett et al. 2011, 2016; Oosterwijk et al. 2012) that posit emotions, bodily sensations, and occupational participation transacts such that neither element alone can explain the affective dimension of occupation. Importantly, this model integrates well with Pierce’s (2001) model of occupation in explaining the variability evident in participants' accounts of occupation. In this study, there was heterogeneity in the relationship between the domains of emotions, bodily sensations, and occupational participation both within and across individuals, which suggests that occupations are personally constructed, nonrepeatable events (Pierce, 2001). Occupations were often described using varying descriptions. Occupations such as “doing homework” shifted to “STILL doing homework”; likewise, the occupation of hanging out with lifeguards shifted to “hanging out with lifeguard but very bored.” The affective experience associated with these occupations shifted and appropriately, so did the occupation itself. This finding also reinforces Pierce’s (2001) definition of occupation and provides additional evidence that subjective experiences in occupation

constantly shift. Occupations are laden with affective experiences that are in themselves constantly changing in response to participation. Occupations then are non-repeatable as they are impregnated with personal affective experiences organized through constantly emerging predictive codes. Overall, it is clear that occupations have a central role in affective experiences as they transact with subjective experiences (i.e., social experiences) such that occupation must play a significant role in future affective research. I also believe these findings provide support for EMA as a tool for understanding this complex relationship. Semi-random sampling EMA offers strong methodological advantages for occupational therapy and occupational science research, because it allows for the generalization of findings and also the obtainment of occupational factors that persist or vary throughout the day; Semi-random sampling EMA findings can be combined with other EMA-style occupational science assessments such as the Occupational Experiences Profile (Atler & Berg, 2018) to further investigate the complex relationship of occupational participation and affective experiences.

6.3 Factors Influencing the Affective Dimension of Occupation

A central concern in the design of this project was to build a better understanding of the affective dimension of occupation. Here I review our findings, in general, and how they relate broadly to the study of occupation

The relationship between occupation and emotions is complex. While it is true that occupations do have an influence on emotions, occupations cannot predict emotional experiences; occupations and affective experience evolve and unfold together throughout participation as predictions of occupation are either satisfied or revised in response to activity (Hoemann, Gendron, & Barrett, 2017). For adolescents with ASD, social experiences appear to play a significant role in this heterogeneity. Positive social experiences may serve to transform

occupations that would be otherwise unpleasant. When these transformations occur repeatedly, an individual's affective expectations regarding an activity may be modified. Successful transformations of expected experiences may have significant clinical implications as it could lead to increased satisfaction and possibly have implications for an individual's well-being. This finding also demonstrates that providing adolescents with social experiences not tailored to their preferences (e.g., social skill groups) will likely not be enough for the adolescent to experience an occupation positively; for the experience to promote PA, the social experience must be perceived as high quality. In therapy, targeting occupations and their respective subjective experiences *in vivo* will better ensure affective expectancies are associated with the targeted occupation and not an activity foreign to the daily life of the individual that is limited to the therapeutic context. More research is needed to determine what occupational features encourage an individual to experience these social occupations positively. Occupational features such as level of challenge, sensory experiences, time of day, and bodily experiences may be potential avenues for research seeking to understand the transactions in the affective dimension. As discussed in Chapter 6, I believe EMA may be a fruitful approach for researching this relationship.

The field of occupational science would benefit from future work explicating this relationship by using event-based EMA sampling approaches to investigate how emotional experiences may fluctuate within one occupation. As discussed in Chapter 3, I believe that the event-based sampling approach of EMA may be an important avenue for exploring this relationship as it enables the sensitive assessment of emotional and occupational variation. Additionally, by adopting a less invasive sampling scheme, researchers can ask more detailed questions about emotional experiences, thereby leading to a more in-depth understanding of what

facets of occupation may explain the heterogeneity of the affective dimension. Because emotion concepts are by definition, a categorization of a constellation of experiences, researchers could employ qualitative questions to ascertain more about what experiences are contained within this shifting constellation. Open-ended questions about present affective experiences, sensory experiences, bodily feelings, and other salient environmental features should serve as an initial step into understanding affective experiences.

Social experiences clearly play a central role in the subjective experiences of adolescents. When viewed in the context of broad research approaches, this finding suggests that it is important to recognize that the presence of the researcher or an occupational therapist changes the social experience of occupation and thus may change the affective dimension itself during the occupation. This finding is in line with a long tradition of research finding that the presence of a researcher impacts participant experiences (Cañigüeral & Hamilton, 2019; Göbel, McCrink, Fischer, & Shaki, 2018; Tracey, 2016). In this study, I used a research method in which the distance between the researcher and participant is increased (though not completely removed as the virtual meeting space of text messages sent to prompt participants to complete surveys still remained), which allows us to better understand the social and affective dimensions of occupation. However, when researchers or therapists employ other methods that involve direct presence, it is important to consider what effects the individual is having on the affective experiences of the participant. In spite of the potential influences of researcher presence on occupational experiences, direct observational assessment methods do offer several advantages as they allow for the researcher to observe many more factors than what can be obtained through EMA, adapt research questions in response to emerging findings, and intervene at moments where safety may be a concern (e.g., if a participant expresses suicidal ideation). Largely, the

influence of the clinician problematizes interventions such as social group interventions that ignore the ecological significance of occupational participation and create situations that are alien to real-world community experiences.

A second important finding is an interaction between the quality of social interaction and pubertal status. This finding first suggests that those at earlier pubertal stages will benefit from occupations that encourage large social groups. Structured activities such as sports, chess clubs, and band may offer great promise for adolescents at earlier pubertal stages with ASD. These activities provide ample opportunities to develop larger social networks and be around more people. Yet, these occupations are also very structured, which are generally preferred by those on the autism spectrum (Miller & Neuringer, 2000). For those at the later pubertal stages, though, the development of more intimate friendships will be more important for promoting positive affect. Online video games may be one way for older adolescents to develop these closer and higher quality friendships. Video games enable adolescents to work on remote servers in which they can play with the same team at multiple times. Friends can bond over competing towards similar goals, communicating new objectives, and coordinating their gaming efforts.

Researchers in occupational therapy often use age as the primary demographic or control variable in their research (e.g., Asbjørnslett & Hemmingsson, 2008; Ratzon, Lunievsky, Ashkenasi, Laks, & Cohen, 2017), but findings from this research study implicate pubertal stage as a key explanatory variable as opposed to chronological age. Other qualitative studies include adolescents from wide age groups without considering pubertal status as a key demographic variable (e.g., Absolom & Roberts, 2011; Widmark & Fristedt, 2018). While parent-reported pubertal status is problematic because it does not show great reliability in light of doctor reported pubertal status (Rasmussen et al. 2015), I believe that it is an acceptable proxy when the gold

standard is not possible. Research that includes adolescents should carefully consider how pubertal status is impacting the variability in responses. If adolescents at differing pubertal stages value different qualities of occupation, then it is likely that their reports of occupational participation will vary greatly. The developmental period of adolescence should not be conceived as one categorical period, but instead adolescence should be considered as a dynamic period. Future work is also needed to better understand how the relationship between occupation and emotion changes over the life course.

6.4 Implications for Future Research

In this project, I found empirical support for both the two-hit model of ASD and the network theory of depression. Our findings suggest that social situations and occupations play a significant role in the experience of depressive symptomatology (as measured by the CDI 2:SR), implicating the second hit as a key factor in understanding depression in this vulnerable population. For adolescents in the early stages of puberty, increasing the number of friends or social groups may serve an important role in encouraging positive affective experiences. Findings from this study also suggest that, at later pubertal stages, decreased quality of social interactions will lead to a higher negative affect. To more fully explicate this relationship, researchers should consider implementing longitudinal studies investigating emotional instability both prior to the onset of puberty and after to see how these experiences change over time and may relate to depression onset in a sample that is not yet diagnosed with clinical depression.

Our project also found support for the network theory of dynamics by finding that emotional dysregulation in the ASD population may manifest as emotional instability (Houben, Van Den Noortgate, & Kuppens, 2015). I failed to find evidence that emotional dysregulation is characterized by autocorrelation of affect. I believe examining emotional instability using

retrospective accounts is difficult; thus, EMA approaches may be critically important for future research in ASD. Our findings in Chapters 5 and 6 indicate a relationship between emotions and occupation, suggesting that occupations may influence emotional instability. Given that the present study was not an intervention study, I was unable to fully explore this relationship. However, I believe future intervention research in occupational therapy and occupational science will benefit from exploring how occupation and what qualities of occupation can be leveraged to reduce emotional instability and lessen the impact of depression on the lives of individuals with ASD.

Future research should also consider the role of adolescent identity towards social and subjective experiences. Specific to those with ASD, a large body of work has suggested that identity and self-conceptualization of the diagnosis of ASD impact mental health and well-being (Bagatell, 2007; Cooper, Smith, & Russell, 2017; Davidson & Henderson, 2010). As individuals with ASD negotiate these identities throughout the lifespan, it is likely that their subjective experiences shift. Individuals who view their ASD status negatively may be more prone to have negative social experiences. While those who have positive self-conceptualizations may demonstrate greater resilience (Bletzer, 2007). More research is needed to understand how these fluctuating identities impact psychological well-being.

A third avenue for future research is to explore the connection between sensory processing patterns of individuals with ASD, depressive symptomatology, and affective instability since sensory processing patterns have been linked to depressive symptomatology (Serafini et al., 2017). In Aim 3, I found that body experiences are a significant aspect of the affective dimension. However, I did not directly examine the sensorial experiences of the environment. Given that I adopt a transactional approach, I view bodily experiences and sensory

experiences as part of one transactional whole. However, more information about the relationship between how individuals experience their sensory environments (e.g., experiencing the light environment as more intense), bodily experiences, and emotions will further our understanding of the affective dimension of occupation. Further exploration of this relationship may help occupational therapists in identifying groups of individuals at risk for depressive symptomatology (i.e., those with differing patterns of sensory responsiveness).

6.5 Implications for Future Practice

While the present study is not epidemiological in nature, I believe these findings provide further support for the screening of individuals with ASD for depression. In line with the recommendations from the US Preventative Services Task Force (USPSTF) (Siu et al., 2016), I believe that occupational therapists have a direct role screening individuals for depression (Kneebone, Stone, Robertson, & Walker-Samuel, 2013). While it may seem that screening for depression should be relegated to the field of psychology and psychiatry, there is growing consensus in the literature that individuals with ASD have high rates of unmet mental health needs (Chiri & Warfield, 2012). Researchers have also previously argued that clinicians and educational professionals alike should routinely screen for cyberbullying, negative emotions, and suicide risk (Hu et al., 2019; Mayes, Gorman, Hillwig-Garcia, & Syed, 2013), suggesting that mental health screenings are not just the task for the mental health professionals that individuals with ASD regularly encounter. Because the ultimate objective is to identify underserved children with ASD with mental health problems, the sobering reality is that current efforts are insufficient (Jensen et al., 2011). The expertise of occupational therapists in assessing contextual transactions will be a key element in this area, as contextual transactions certainly serve an important role in the experience and manifestation of depressive symptomatology. If occupational therapists are

able to accurately screen for depression and suicide risk and refer at risk individuals for psychological services, then the pipeline for those with ASD to receive mental health treatment may be streamlined. Clearly, more work is needed in order to determine what methods are best in the effort to screen for depression in this population, but a transdisciplinary approach involving occupational therapy is likely to be a key step in moving forward.

This project as a whole moves towards deepening understandings of the relationship of occupational participation, affective experience, and emotions for adolescents with ASD. Aspects of this knowledge can be directly applied to practice. Next steps in this area include examination of key features of occupation that impact quality of social experiences, examination of how the relationship between affective instability and occupational participation changes across the lifespan, and development of novel treatment targets specific to the practice of occupational therapy that can be used to alleviate negative experiences such as depressive symptomatology.

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APPENDIX 1. ECOLOGICAL MOMENTARY ASSESSMENT QUESTIONNAIRE

Section 1: How do you feel?

How much do you feel the following? (1-5)

1. Cheerful
2. Lively
3. Happy
4. Joyful
5. Proud
6. Miserable
7. Mad
8. Afraid
9. Scared
10. Sad

Section 2: What are you doing?

1. What were you doing the moment you received our message?
2. How many people are around you?
 - a. No one (alone)
 - b. Less than 5
 - c. 5-10
 - d. More than 10
3. How much were you enjoying what you were doing when you received our message? (

1-10 Likert type question)

4. How much are you enjoying your current level of interaction? (1-10 Likert type question)
5. Choose all the words that describe how your body feels right now.
 - a. Lump in the throat
 - b. Quick Breathing
 - c. Slow breathing
 - d. Stomach sensations
 - e. Feeling cold
 - f. Feeling warm
 - g. Feeling hot
 - h. Heart beats faster
 - i. Sweating
 - j. Goosebumps
 - k. Blushing
 - l. Weak in the knees
 - m. Blood pressure rising
 - n. Sleepy

APPENDIX 2. GLOSSARY OF TERMS

Autocorrelation of affect	The self-predictive nature of emotions (i.e., how emotions at one timepoint are predicted by previous timepoints.
Affective Instability	(see MSSD)
Affectus	Affectus is the incipient state of emotion that occurs while participating in occupation (Dallman & Triplett, 2019) and continues to persist throughout the occupational performance. Embodied experiences such as unease in the gut when approaching a meeting with one's boss, or tightness in the hands when waiting on hold with a cable company, are examples of affectus by this definition.
Emotion	An emotion is a subjective content created through socio-linguistic fixing of affectus. Emotions include terms such as "happy," "sad," and "angry."
Mean Square Successive Difference (MSSD)	Defined by Von Neuman et al. (1941), MSSD is a measure of variability that examines gradual shifts in the mean. Defined as the variability of moment to moment observations $\sigma^2 = \sum(x_i - x_{i+1})^2 / (n - \text{lag})$; where MSSD = σ^2 , x_i = observation of emotion i , x_{i+1} = observation of emotion $i+1$