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AN EXPLORATORY STUDY OF MINDFULNESS IN ADOLESCENTS DIAGNOSED WITH
CHRONIC PAIN

by

SHARON W. SHIH

Under the Direction of Lindsey L. Cohen, Ph.D.

ABSTRACT

Mindfulness has been touted as a potentially beneficial intervention for youth diagnosed with chronic pain. However, research to date has generally taken a downward translation approach, as opposed to an endogenous approach, to conceptualizing and applying mindfulness. The present study utilized grounded theory methodology to explore how adolescents diagnosed with chronic pain understand mindfulness and its application for chronic pain. Additionally, quantitative measures of participants' executive function were collected to further elucidate the cognitive developmental considerations underlying mindfulness. Semi-structured interviews were conducted with 7 adolescents (age 12-17). Findings revealed a theory of mindfulness composed of awareness of internal and external factors, objectivity, and nonreactivity to determine action. Application of mindfulness for chronic pain was divided into two categories – alleviation or prevention of exacerbation of pain, and confusion and contradiction. Participants with well-developed executive functioning discussed mindfulness in more abstract terms. These findings will guide future studies of mindfulness in youth.

INDEX WORDS: Pediatric Chronic Pain, Mindfulness, Executive Function, Grounded Theory

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SHARON W. SHIH

A Thesis Submitted in Partial Fulfillment of the Requirements for the Degree of

Master of Arts

in the College of Arts and Sciences

Georgia State University

2018

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Sharon W. Shih
2018

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1 INTRODUCTION

1.1 Overview of Mindfulness

Interest in the study of mindfulness has increased exponentially in recent years (Craighead, 2016; Van Dam et al., 2018). A common narrative definition of mindfulness is “the awareness that arises by paying attention on purpose, in the present moment, and non-judgmentally” (Kabat-Zinn, 2013, p. xxxv). Despite a growth of research in this area, a major challenge exists in operationalizing and measuring the construct of mindfulness (Van Dam et al., 2018). Within the field of psychological research, mindfulness has been conceptualized in a multitude of ways and prominent researchers have yet to settle on a unified operational definition despite general agreement on the common narrative definition (Chiesa & Malinowski, 2011; Davidson, 2010; Davidson & Kaszniak, 2015; Rau & Williams, 2016). A number of theoretical conceptualizations of mindfulness have emerged, such as Brown and Ryan’s (2003) notion of mindfulness as present awareness and attention, the two-component model of Bishop et al. (2004) consisting of self-regulation of attention and orientation to experience, and Marsha Linehan’s (1991) idea of attending to the present moment experience with acceptance and nonjudgment.

It is not clear how these discrepancies in the operationalization of mindfulness have developed, however, one explanation lies in the origins of mindfulness as a Zen Buddhism philosophy (Bodhi, 1984). The work of Jon Kabat-Zinn in the 1980s was influential in bringing greater awareness and acceptance of mindfulness to the Western world (Kabat-Zinn, 1982; Kabat-Zinn, Lipworth, & Burney, 1985). However, in achieving this end, a secularized form of mindfulness was created and introduced to the public and to the scientific field, stripping the

concept of its original context and resulting in variations in understanding (Bodhi, 2011; Dreyfus, 2011; Dunne, 2011).

Within the field of psychological research, operationally defining constructs is necessary to develop informed measurements. Therefore, it is not surprising that as a consequence of the variability in operationalizations of mindfulness, multiple measures of mindfulness have been created (Bergomi, Tschacher, & Kupper, 2013; Sauer et al., 2013). To ameliorate discrepancies in the measurement and operationalization of mindfulness in adults, Baer et al. (2006) conducted a multiple component study of five well-validated and widely used self-report measures of mindfulness – the Mindful Attention Awareness Scale (MAAS; Brown & Ryan, 2003), the Freiburg Mindfulness Inventory (FMI; Buchheld, Grossman, & Walach, 2001), the Kentucky Inventory of Mindfulness Skills (KIMS; Baer, Smith, & Allen, 2004), the Cognitive and Affective Mindfulness Scale (CAMS; Feldman, Hayes, Kumar, & Greeson, 2004; S.C. Hayes & Feldman, 2004), and the Mindfulness Questionnaire (MQ; Chadwick, Hember, Mead, Lilley, & Dagnan, 2005). An initial examination of internal consistency revealed significant intercorrelation amongst the five measures and each measure demonstrated the predicted relations with other theoretically convergent or discriminate variables such as self-compassion, thought suppression, and experiential avoidance. However, these correlations varied widely in strength between measures on the same variable, suggesting that these five questionnaires may be measuring different components of mindfulness or slightly different constructs.

In an effort to create an empirically based and theoretically inclusive measure of mindfulness, Baer et al., (2006) conducted an exploratory factor analysis using the combined 112 items from all 5 measures. A multifaceted construct consisting of five facets – describe, acting with awareness, nonjudging of experience, nonreactivity to inner experience, and observe –

emerged from the exploratory factor analysis. The describe facet refers to labeling or being able to put observations into words. The acting with awareness facet refers to fully engaging with and focusing on an activity. The nonjudging of experience facet refers to the degree one does not assign value or emotional valence (e.g., self-criticize, take pride) for having a particular experience. The nonreactivity to inner experience facet refers to not impetuously responding to internal experiences. The observe factor refers to the extent one is able to purposefully attend to thoughts, feelings, and bodily sensations.

Subsequently, a confirmatory factor analysis revealed that all of the factors except observe fit a hierarchical model of the mindfulness construct. Observe did not fit the general model but did significantly load on an overall mindfulness construct when examined with a sample of participants with meditation experience. These findings suggest that the observe facet of mindfulness may be more sensitive to individuals with meditation experience and was therefore retained in the final questionnaire for use with populations with meditation experience. As a result of this work, the 39-item Five-Facet Mindfulness Questionnaire (FFMQ) was created as a comprehensive measure, reflecting multiple conceptualizations of mindfulness in adults.

The development of the FFMQ contributed significantly to the field of mindfulness research by creating a broad measure that recognized multiple conceptualizations and a facet-level organization of mindfulness. Taking a facet-level approach to the study of mindfulness is useful because, in contrast, a total score on a given measure is unlikely to capture the complexity of this construct (Chiesa, 2012; de Boer, Steinhagen, Versteegen, Struys, & Sanderman, 2014; Leary & Tate, 2007). This conceptualization is supported by the increased predictive strength for the relationship between certain facets of mindfulness and mental health outcomes in comparison to using a total mindfulness score (Woodruff, Glass, Arnkoff, Crowley, Hindman, & Hirschhorn,

2013). Therefore, operationalizing mindfulness as a construct composed of describing, acting with awareness, nonjudging of experience, nonreactivity to inner experience, and observing has been shown to be a richer approach to mindfulness research in adults and taking a faceted approach to understanding mindfulness would likely offer similar advantages for younger populations as well.

1.2 Mindfulness in Children and Adolescents

In adult populations, mindfulness interventions have been associated with beneficial outcomes such as improvements in symptoms of anxiety and depression (Hofmann, Sawyer, Witt, & Oh, 2010), health related psychological and physical symptomology (Gotink, Chu, Busschbach, Benson, Fricchione, & Hunink, 2015; Grossman, Niemann, Schmidt, & Walach, 2004), mood and cardiovascular functioning (Zeidan, Johnson, Gordon, & Goolkasian, 2010), and stress coping (Khoury et al., 2013). Given the positive findings with adults, interest in the study and use of mindfulness has extended into child and adolescent populations (Burke, 2010; Greenberg & Harris, 2011). This includes a number of intervention studies examining mindfulness applications across child and adolescent ages in school settings (Zenner, Herrnleben-Kurz, & Walach, 2014), medical populations (Lagor, Williams, Lerner, & McClure, 2013), incarcerated youth (Himmelstein, Hastings, Shapiro, & Heery, 2012; Himmelstein, Saul, Garcia-Romeu, & Pinedo, 2014) and clinical samples (Biegel, Brown, Shapiro, & Schubert, 2009). Recent reviews have indicated that child and adolescent populations experience positive outcomes similar to those of adult populations following mindfulness-based interventions but effect sizes are smaller than those found in adult samples (Black, Milam, & Sussman, 2009; Kallapiran, Koo, Kirubakaran, & Hancock, 2015; Zoogman, Goldberg, Hoyt, & Miller, 2015).

This could be due to the emerging status of this specific line of inquiry and fewer numbers of randomized controlled trials available for review. In addition, pervasive methodological limitations are present in previous studies. These limitations are characterized by small sample sizes that prohibit the use of rigorous statistical tests; a lack of clarity surrounding specific intervention procedures; heterogeneous samples across studies; an insufficient number of randomized controlled trials; and variability in the measures and application of mindfulness (Black et al., 2009; Burke, 2010; Carona, Moreira, & Silva, 2016; Greenberg & Harris, 2011; Perry-Parrish, Copeland-Linder, Webb, & Sibinga, 2016). Due to these limitations, there is a lack of conclusive evidence to support the efficacy of mindfulness interventions for youth. In addition, while many studies have concluded that within child and adolescent samples, mindfulness-based interventions were generally feasible, acceptable, and well-tolerated, many of the same limitations that impact conclusions about the efficacy of interventions also impact conclusions about their feasibility (Black et al., 2009; Burke, 2010; Carona et al., 2016; Greenberg & Harris, 2011; Perry-Parrish et al., 2016).

To date, researchers have adapted adult mindfulness-based interventions for younger samples. Though certain recommendations have been set forth, interventions often differ from study to study and modifications are largely based on anecdotal evidence without specific tests for construct validity, which limits generalizability (Thompson & Gauntlett-Gilbert, 2008).

Similar to the way in which intervention has been approached, measures of mindfulness in children and adolescents have been adapted from adult measures of mindfulness. To date, three measures of mindfulness in children and adolescents have been developed: the Child and Adolescent Mindfulness Measure (CAMM) adapted from the adult Kentucky Inventory of Mindfulness (Greco, Baer, & Smith, 2011); the Mindful Attention Awareness Scale for Children

(MAAS-C) adapted from the adult Mindful Attention Awareness Scale (Brown, West, Loverich, & Biegel, 2011); and the Comprehensive Inventory of Mindfulness Experiences-Adolescents (CHIME-A) adapted from the adult Comprehensive Inventory of Mindfulness Experiences (Johnson, Burke, Brinkman, & Wade, 2016a). The CAMM and the MAAS-C are both single facet measures of mindfulness whereas the more recently developed CHIME-A contains 8 subscales. This indicates that there may be evidence supporting a facet level approach to mindfulness research in adolescents. However, the CHIME-A did not find internal consistency for a total mindfulness score, which could reflect variation in how each facet relates to mindfulness in this age group. The development of each measure was in accordance with sound psychometric procedures and efforts were made to ensure items were age-appropriate in content and language; however, measures were not developed from a theory of mindfulness specific to children and adolescents. In other words, the assumption is that mindfulness –as it is understood in adults – is the same in children and adolescents. However, this belief has not been empirically investigated.

Having clear operational definitions of constructs is crucial to developing valid measurements and both are needed to develop and assess interventions. Given that most, if not all, child-adolescent interventions and measurements have been downward translations of mindfulness from adult research, it is likely that the operational definition of the mindfulness construct in younger populations is also imbued with primarily adult perspectives and there may be a lack of specificity of how mindfulness is understood in younger populations.

1.3 Cognitive-Developmental Considerations in Mindfulness

It is particularly important to appreciate the influence of cognitive developmental factors on understanding mindfulness (Carona et al., 2016; Greenberg & Harris, 2011). It has been

suggested that individuals in the adolescent period would be most receptive to ideas of mindfulness due to the manifestation of higher-level cognitive skillsets (Broderick & Jennings, 2014; Roeser & Pinela, 2014). However, this has not been formally investigated and there is a deficit in the literature examining the cognitive-developmental appropriateness of mindfulness-based interventions for youth (Carona et al., 2016; Greenberg & Harris, 2011). In short, it is critical that studies use “ground-up” approaches starting with the population of interest.

Mindfulness, as it is understood in adults, fundamentally requires the individual to be able to “think about thinking” and to monitor thoughts and feelings. It would seem that the ability to think abstractly and on a metacognitive level would be a necessary prerequisite skill for understanding the concept of mindfulness. It is well-known that the development of cognitive skills continues throughout childhood, adolescence, and even into early adulthood. For example, according to Piaget’s (1952) model of intellectual development, the adolescent period involves the development of abstract thinking, hypothetical reasoning, and cognitive self-regulation. This “formal operational stage” allows an adolescent to manage multiple cognitive tasks and tap into critical thinking and metacognitive strategies.

1.4 Executive Function and Mindfulness

Executive function refers to the specific cognitive-developmental ability encompassing abstract thinking and metacognition. Executive function has been positively related to the ability to think critically and mediates the relationship between mindfulness and critical thinking in adults (Noone, Bunting, & Hogan, 2016). Thus, executive function may be an important cognitive function to investigate in relation to mindfulness in children and adolescents.

Executive function is the ability to “direct and control goal-oriented cognitive, behavioral, and emotional functioning” (Gioia, Isquith, Retzlaff, & Espy, 2002, p. 249-250). Specific executive

functions include working memory, planning and organizing, initiation, inhibiting distractions, process monitoring, and cognitive flexibility (Gioia et al., 2002). Studies of executive function have found that these abilities begin to develop in childhood but only begin to stabilize in adolescence, around age 15, but continue to develop into early adulthood (Huizinga, Dolan, & van der Molen, 2006; van der Stel & Veenman, 2014). Given the overlapping cognitive mechanisms between executive function and mindfulness, it is possible that the ability to apply or even *understand* mindfulness related concepts could reflect a similar cognitive-developmental trajectory. Adolescence has been indicated as a cognitive-developmental period during which mindfulness work could be viable but the cognitive-developmental appropriateness of mindfulness-based interventions for adolescents has not been assessed and could explain the differences seen between adult and pediatric populations (Wagner, 2006). Specifically, it is not known whether the development of executive function skills is related to how adolescents understand mindfulness.

1.5 Mindfulness in Pediatrics

One population of interest for the study and application of mindfulness is youth with chronic illness. Pediatric patients often suffer from comorbid medical issues and social-psychological difficulties (Combs-Orme, Heflinger, & Simpkins, 2002; Lavigne & Fair-Routman, 1992; Martinez, Carter, & Legato, 2011; Piquart & Shen, 2011). Therefore, it is not surprising that an intervention such as mindfulness has been considered within pediatric populations (Riccio, Pliego, & Rae, 2016). For example, studies of mindfulness interventions have been conducted in adolescents with cardioverter defibrillators or pacemakers (Freedenberg, Thomas, & Friedmann, 2015), Prader-Willi syndrome (Singh, Lancioni, Singh, Winton, Singh, McLeavey, & Adkins, 2008), attention-deficit/hyperactivity disorder (Van de Weijer-Bergsma,

Formsma, de Bruin, & Bogels, 2012; Zylowska et al., 2008), and cancer (Jones, Blunda, Biegel, Carlson, Biel & Wiener, 2013; Malboeuf-Hurtubise, Achille, Muise, Bearegard-Lacroix, Vadnais & Lacourse, 2016; Wurz, Chamorro-Vina, Guilcher, Schulte, Culos-Reed, 2014). Results from these studies were generally promising and indicated improvements in psychological and medical disease symptomology. However, these results are limited by the same types of constraints present in the larger mindfulness and adolescent literature (i.e., small sample sizes and variability in intervention content) as well as variability in significance, effect sizes, and measured outcomes (Abujaradeh, Safadi, Sereika, Kahlee, & Cohen, 2018; Ahola Kohut, Sinston Davies-Chalmers, Ruskin, & van Wyk, 2017). Thus, there is a pressing need for further research to delineate the best approach to developing mindfulness-based interventions for pediatric chronic conditions. In initiating this endeavor, it may be beneficial to begin with more specific pediatric chronic conditions to consider unique contextual factors that could contribute to understanding and applying mindfulness.

1.6 Pediatric Chronic Pain

One pediatric population that might benefit from mindfulness interventions is youth with chronic pain. Chronic pain is typically defined as recurrent or persistent pain that exceeds the time of healing and lasts longer than 3 months (McGrath & Finley, 1999; Merskey & Bogduk, 1994). Chronic pain has been identified as a significant clinical concern in children and adolescents (Huguet & Miro, 2008; King et al. 2011; Perquin et al., 2000; Writers, 2015) with prevalence rates for common chronic pain syndromes estimated to be as high as 88% (King et al., 2011). The extant literature indicates prevalence rates of 8-83% for headaches, 4-53% for abdominal pain, 14-24% for back pain, 4-40% for musculoskeletal pain, 4-49% for multiple pains, and 5-88% for other pains (King et al., 2011). Moreover, approximately, 1-3% of children

and adolescents suffer from severe and disabling chronic pain (Eccleston, Bruce, & Carter, 2007).

In addition to having a chronic medical condition, pediatric chronic pain patients often report difficulties in multiple domains of life (Carter & Threlkeld, 2012; Konijnenberg et al., 2005; Roth-Isigkeit, Thyen, Stoven, Schwarzenberger, & Schmucker, 2005). For example, youth with chronic pain have decreased social functioning and diminished peer relationships (Forgerson et al., 2010), high rates of school absenteeism (Logan, Simons, Stein, & Chastain, 2008; Sato et al., 2007), increased sleep disturbances (Long, Krishnamurthy, & Palermo 2007; Palermo & Kiska, 2005), emotional distress (Varni, Rapoff, Waldron, Gragg, Berstein, & Lindsley, 1996), and poor overall quality of life (Gold et al., 2009; Knook, Lijmer, Konijnenberg, Hordijk, & Engeland 2012). Furthermore, chronic pain with onset in childhood has been shown to predict continued pain-related symptomology in adulthood (Brattberg, 1994; Solomon, Lipton, & Newman, 1992; Walker, Dengler-Crish, Rippel, & Bruehl, 2010).

Given the breadth of impairment in pediatric chronic pain and the potential for its continuation into adulthood, proper pain management in childhood is crucial. A biopsychosocial model of conceptualizing chronic pain has indicated the utilization of a multidisciplinary approach to optimally treat chronic pain (Gatchel, Peng, Peters, Fuchs, & Turk, 2007; Turk, 1996). This is particularly relevant given that pharmacological solutions have been criticized for lack of rigorous empirical support in the form of randomized controlled trials (Writers, 2015) and standard guidelines for pediatric drug treatments have mostly been extrapolated from adult literature (Landry et al., 2015). There has been an increase in the use of psychological treatments for pain management (Eccleston, Morley, Williams, Yorke, & Mastroiannopoulou, 2002; Palermo, Eccleston, Lewandowski, Williams, & Morley, 2010). One psychological intervention

that has been recommended for chronic pain is mindfulness-based treatment (Chiesa & Seretti, 2011; Kabat-Zinn, 1982; Kabat-Zinn, Lipworth, & Burney, 1985).

1.7 Pediatric Chronic Pain and Mindfulness

Given the bevy of conditions comorbid with pediatric chronic pain, it has been suggested that mindfulness would be a valuable treatment to consider for targeting comorbid mood disorders and functional disability as well as physical pain symptomology (Riccio et al., 2016). In adult populations, there is evidence that mindfulness-based interventions ameliorate pain, optimize coping abilities, improve mood, and increase quality of life (Hilton et al., 2016; Kabat-Zinn, 1982), which suggests that mindfulness approaches might be promising for younger populations with chronic pain.

To date, approximately 9 studies of mindfulness have been conducted in pediatric chronic pain samples (Ali et al., 2017; Chadi et al., 2016; Hesse et al., 2015; Jastrowski-Mano et al., 2013; Lovas et al., 2017; Ruskin, Gagnon, Ahola Kohut, Stinson, & Walker, 2017; Sansone et al., 2018; Waelde, Feinstein, Bhandari, Griffin, Yoon, & Golianu, 2017). These were predominantly pilot studies assessing acceptability and feasibility with only 1 study utilizing a wait-list control group; therefore sample sizes were fairly limited (range [n] = 4 to 21). Recruitment was reportedly challenging across many studies due to scheduling issues and maintaining interest in potential participants prior to the start of interventions. For example, 80.7% of participants who agreed to participate in one study withdrew prior to the start of group (Jastrowski-Mano et al., 2013). In the Lovas et al., (2017) study, 48 individuals expressed interest, 18 individuals met with study staff and consented to the study, but only 7 were successfully recruited. Study samples were also predominantly or only females, which is an additional limiting factor. Attrition was also variable across studies ranging from no dropouts

(Lovas et al., 2017) to 25% attrition rate (Hesse et al., 2015). Chadi et al. (2016) suggested meeting with participants prior to initiation of intervention to encourage commitment and adherence to the intervention. In general, these studies demonstrate variable acceptability of mindfulness interventions in adolescents diagnosed with chronic pain with a minority of participants stating dissatisfaction with the intervention (Hesse et al., 2015; Lovas et al., 2017; Waelde et al., 2017).

The diversity in structure and content across these studies is of empirical concern. The structure of the interventions ranged from 6 to 8 week sessions, with or without a retreat component, and session duration ranged from 45 minutes to 90 minutes. Criteria for attendance also differed by study, such that standards for completing the intervention were inconsistent across studies. In addition, the content of sessions was challenging to compare, as each study appeared to have developed its own intervention protocol. Interventions were derived from a combination of investigator expertise (Chadi et al., 2016; Ruskin et al., 2015), existing adult protocols (Ali et al., 2017; Ruskin et al., 2017; Sansone et al., 2017), or previously developed general mindfulness protocols for children and adolescent (Hesse et al., 2015; Jastrowski-Mano et al., 2013; Lovas et al., 2017; Waelde et al., 2017). Modifications to protocols were also variable with a few studies incorporating a pain specific focus while others did not. Changes to protocols were typically not described in detail; therefore, replicability and comparison across studies is limited.

Conclusions about efficacy are difficult to substantiate due to small sample sizes and variability in outcome measures. For example, Chadi et al. (2016) found no changes in quality of life, depression, anxiety, pain perception, or psychological distress post-intervention but noted that participants reported a positive change in the way they coped with pain. Interestingly, this

study also evaluated changes in salivary cortisol levels pre- and post-session, as well as from baseline to intervention completion. The investigators found a significant decrease in salivary cortisol levels pre- and post-mindfulness session but not from pre- to post-intervention. Ruskin et al. (2017) observed increased pain acceptance between baseline and a 3-month follow up; however, no difference was found pre- to post-intervention on pain coping, anxiety, depression, pain catastrophizing, mindfulness, or pain. Of concern, functional disability increased over time. Waelde et al. (2017) found no significant changes in pain or depression but observed non-significant, small effect size in decreased functional disability and frequency of pain complaints. Ali et al. (2017) reported a significant decrease in functional disability, pain symptomology and anxiety following intervention but no change in quality of life or perceived stress. In this study, participants reported that social support obtained from the group setting was a significant benefit. Lovas et al. (2017) identified no change in anxiety and depression, a significant reduction in pain intensity, a non-significant reduction in somatic symptoms and functional disability post-intervention but a significant decrease at 3-months post intervention.

In summary, these studies indicate that there is limited evidence for the efficacy of mindfulness-based interventions for pediatric chronic pain in adolescents. Recruitment and attrition were challenges in all studies and variable outcome data led to a decreased ability to draw specific conclusions about mindfulness as an effective intervention. Moreover, program content and structure significantly differed across studies. This inconsistency makes it difficult to understand if the trends reported were program specific or globally attributable to mindfulness-based concepts. Given the inconclusive evidence provided by these studies, it is of great interest to consider why challenges in recruitment and retention exist, why some patients do not appear to engage with the content presented in the mindfulness intervention, and if there is a

fundamental difference in how we should approach the study of mindfulness in younger populations.

1.8 Executive Function in Pediatric Chronic Pain

To date, executive function has not been well investigated in pediatric chronic pain patients. Only one study of executive function in pediatric chronic pain exists and suggests that there may be subclinical struggles with executive functioning in adolescents diagnosed with chronic pain due to half of the sample indicating difficulties in either sustained attention or working memory (Weiss, Harbeck-Weber, Zaccariello, Kimondo, Harrison, & Bruce, 2018). However, a recent review found small to moderate executive function deficits in adults with chronic pain (Berryman, Stanton, Bowering, Tabor, McFarlane, & Moseley, 2014). In addition, there is evidence for cortical differences between healthy controls and fibromyalgia patients in inhibition networks, which suggests overlapping neural networks between pain perceptions and executive function (Glass et al., 2011). Due to the lack of literature available for executive functioning in pediatric chronic pain, it is unclear if similar executive function deficits exist in child and adolescent populations. In fact, on average, pediatric chronic pain patients perform at age-expected levels on assessments of general intelligence as well as academic achievement (Ho, Bennett, Cox, & Poole, 2009). Therefore, it is not known to what extent problems in executive function begin to develop for chronic pain patients or if a subset of chronic pain patients are more vulnerable to deficits in executive function. Regardless of whether executive function presents differently in pediatric chronic pain versus normal controls, it is feasible that the cognitive skills associated with executive function are not entirely disparate from the ability of an individual to understand the concept of mindfulness.

1.9 National Institutes of Health Stage Model of Behavioral Intervention Development

The National Institutes of Health (NIH) Stage Model for Behavioral Intervention Development provides a conceptual framework for intervention development. The goal of the model is to identify the requisite steps for developing the most potent and implementable interventions (Onken, Carroll, Shoham, Cuthbert, & Riddle, 2014). The six stage model consists of: Stage 0 basic research, Stage I intervention generation/refinement, Stage II efficacy (research clinics), Stage III efficacy (community clinics), Stage IV effectiveness, and Stage V implementation and dissemination. Stage 0 can lay the foundation for generating a new intervention but it is also incorporated into each stage of intervention development as a fundamental informer of intervention development. As such, Stage 0 can also occur after an intervention has been developed in order to provide guidance on modifications.

This framework has been indicated as particularly useful for the study of mindfulness-based interventions (Dimidjian & Segal, 2015). As a result of the mixed evidence for mindfulness-based interventions in children and adolescents and in pediatric chronic pain specifically, it is helpful to conduct basic research with youth to better explain how they understand mindfulness. This will allow for optimization of mindfulness-based interventions and inform future research in the field of mindfulness for youth with chronic pain.

2 CURRENT STUDY

Consistent with the NIH Stage Model for Behavioral Intervention Development (Onken et al. 2014), in the present study, I elucidated how adolescents with chronic pain understand the concept of mindfulness in order to inform future intervention development. In this study, I used concurrent, embedded mixed methodology to (1) develop a theory of how adolescents diagnosed with chronic pain understand mindfulness and (2) describe how executive function could be related to understanding of mindfulness.

2.1 Primary Aims and Hypotheses

SPECIFIC AIM 1: Via a semi-structured interview and grounded theory approach, I examined how adolescents diagnosed with chronic pain understand mindfulness. Themes and categories of understanding were integrated into a theoretical framework. In line with qualitative methodology, no specific hypotheses were posited.

SPECIFIC AIM 2: I examined how executive function is related to the theoretical framework developed in specific aim 1 to create an exploratory cognitive-developmental understanding of mindfulness in adolescents diagnosed with chronic pain. Consistent with mixed-methods perspectives, no specific hypotheses were posited.

3 METHOD

3.1 Participants

Participants were adolescents diagnosed with chronic pain (ICD-9 code 338.2 or 338.4, ICD-10 code G89.29 or G89.4), or they had pain occurring consistently for a minimum of 3 months at least 3 days a week. Seven adolescents between the ages of 12 and 17 were included in this study in order to assess variability in cognitive-development across adolescence. Participants were required to be able to read and write fluently in English and be able to provide written assent. Due to the cognitive element of the proposed study, exclusionary criteria included individuals with severe developmental delays. A legal guardian able to fluently read and write in English was present to provide written consent on behalf of the minor child. Both males and females and patients from all ethnic/racial backgrounds were included.

The qualitative portion of the study utilized theoretical sampling. Specifically, data collection and data analysis were interwoven, such that analysis can direct the sampling of data (Strauss, & Corbin, 1990). Thus, sampling was not predetermined to be representative of a specific population but rather as a way to construct theory and test emerging conceptualizations of the data (Charmaz, 1996). A stratified sampling approach was used to ensure each age (12 – 17 years) was included in the sample. In line with a mixed methods approach, a combination sampling approach dictated that at least one participant from each age was included in the sample, and then sampling was subsequently data driven (Teddlie & Yu, 2007). Participants continued to be enrolled until data saturation was reached, indicating that no new themes or categories emerged from data collected. Participant characteristics are presented in Table 1 in the order in which they were recruited. Diversity of race, sex/gender, chronic pain type, and new onset (past 6 months) were also considered as part of the sampling approach to allow for

variability in experiences. The final sample was similar to the samples included in randomized-controlled trials of mindfulness in pediatric chronic pain, which were also characterized by primarily females with variable chronic pain types.

Table 1. Participant Characteristics

<i>Participant</i>	<i>Age</i>	<i>Race</i>	<i>Chronic Pain Type</i>	<i>New Onset</i>
1	16	Caucasian	Hypermobility (EDS)	No
2	15	Asian	Neurofibromatosis	No
3	17	Caucasian	Amplified Musculoskeletal Pain	No
4	12	African American	Amplified Musculoskeletal Pain	No
5	12	Caucasian	Complex Regional Pain Syndrome	Yes
6	13	African American	Abdominal Pain	No
7	14	African American	Amplified Musculoskeletal Pain	Yes

Note. Patient sex/gender removed to protect confidentiality. Females ($n = 5$), Males ($n = 2$)

3.2 Procedures

3.2.1 Recruitment

In collaboration with a local children's hospital in the southeastern United States, participants were recruited from the weekly outpatient pain clinic. Clinic staff (physicians, psychologists, and nursing staff) were informed of the research project in order to assist with identifying eligible participants and to provide logistical assistance. When an eligible patient was identified, the child's provider or staff member informed the patient and legal guardian of the study and directed interested families to speak with a trained study staff member. The study staff member explained the study procedures in detail to the family in a private clinic room and emphasized the voluntary nature of participation. If the family wished to participate, the process of obtaining written consent and assent was conducted by reviewing the content of the consent and assent forms. The study staff member was trained to probe for participant comprehension by

asking the participants to restate study procedures, risks, and benefits of participation in their own words. Ample time was provided for participants to ask questions and review the consent and assent forms.

3.2.2 Compensation

Families received a \$15 Target gift card for their participation. Regardless of completion of all study procedures, families were provided the gift card when they left the clinic on the day of recruitment.

3.2.3 Data Collection

After the family provided consent and assent for study participation, the legal guardian was escorted to the waiting room and the following study procedures were conducted in a private clinic room. The quantitative data was collected first, then the qualitative data. Given the seemingly unrelated content across the qualitative (i.e., mindfulness) and quantitative (i.e., executive function) aspects of the study, carryover effects are not suspected.

3.3 Measures

3.3.1 Qualitative – Mindfulness

Quantitative measures of mindfulness in adolescents have demonstrated poor specificity and construct validity (Pallozzi et al., 2016). Thus, a qualitative approach might be the most appropriate methodology for developing a theory of how adolescents understand mindfulness. A semi-structured interview schedule was developed to include open-ended questions to allow patients to generate data content (Appendix A). The semi-structured interview schedule remained flexible to the emerging design of the study, such that it was changed to further clarify or test conceptualizations that arose as data was collected and analyzed (Charmaz, 1996). The initial

interview schedule reflected the following general areas of inquiry: (1) What are some of the challenges of having chronic pain? (2) What are the current coping skills used and how effective are they? (3) What do each of the 5 facets of mindfulness mean (refer to section 1.1)? (4) Could these be used to handle challenges, and, if so how? Establishing the challenges of having chronic pain created a context for the patient and assessing current coping skills assessed how well the participant is managing these challenges. It also revealed if mindfulness-related coping skills are already in use by the individual.

Through the iterative nature of the grounded theory approach, the interview schedule was modified three times. The first change was made after receiving suggestions by qualitative experts to adjust the flow of the interview to ask about mindfulness at the beginning of the interview. The second change was to drop the 5 facets of mindfulness from the questions because the questions appeared confusing to participants and did not seem to generate meaningful data. This occurred after completing 2 interviews. The third change was to more specifically probe for application of mindfulness to chronic pain, which was incorporated into the interview script for the third interview. The final interview guide is included in Appendix B. The comprehension level of the questions was set at the 5th grade level to ensure patients felt comfortable with the content of the interview. The interview took approximately 30-45 minutes. The interview was also audio recorded and data was immediately downloaded and transcribed following the conclusion of an interview session.

3.3.2 Quantitative – Executive Function

Given the exploratory nature of the current study and the absence of literature on executive functioning in pediatric chronic pain, both a self-report and a parent-proxy measure of executive function were included in the study. The Behavior Rating Inventory of Executive

Function-Self-Report (BRIEF-SR; Appendix C) and the Behavior Rating Inventory of Executive Function-Parent-Report (BRIEF Parent; Appendix D) were administered to participants and their parents to determine child executive functioning.

The BRIEF-SR is a standardized self-report measure of executive functioning in adolescents age 11-18 with at least a fifth-grade reading level (Guy, Isquith, & Gioia, 2004). The paper-and-pencil form includes 80 questions that query about the adolescent's experiences in the past 6 months. The response options given are *Often*, *Sometimes*, and *Never*. The measure consists of two broad index scores, Behavioral Regulation and Metacognition, which are combined to create a total score, the Global Executive Composite. Theoretically and statistically derived scales make up each of the broad indices as follows: Behavioral Regulation (Inhibition, Shifting, Emotional Control, and Monitoring) and Metacognition (Working Memory, Planning, Organization of Materials, and Task Completion). The measure was standardized on a sample of 1,000 children designed to represent the demographics of the 2002 U.S. Census Bureau and separate norm groups were created by age and gender (Guy, Isquith, & Gioia, 2004). The internal consistency of the measure ranged from $\alpha = .72$ to $\alpha = .96$ for the two broad indexes and the overall score (Guy, Isquith, & Gioia, 2004). Overall, this measure has demonstrated sound psychometric properties (Walker & D'Amato, 2006). The BRIEF-SR has been utilized and validated in adolescents with chronic illnesses such as epilepsy, attention deficit hyperactivity disorder (ADHD), and abdominal pain (Hocking, Barnes, Shaw, Lochman, Madan-Swain, & Saeed, 2011; Slick, Lautzenhiser, Sherman, & Eyrl, 2006; Toplak, Bucciarelli, Jain, & Tannock, 2008).

The BRIEF-Parent is a standardized parent-proxy measure of executive functioning in adolescents age 11-18 with at least a fifth-grade reading level (Gioia, Isquith, Guy, Kenworthy,

2000). The paper-and-pencil form includes 86 questions that query about the adolescent's experiences in the past 6 months. The response options given are *Often*, *Sometimes*, and *Never*. Similar to the BRIEF-SR, the measure consists of two broad index scores, Behavioral Regulation and Metacognition, which are combined to create a total score, the Global Executive Composite. However, the subscales and factor structure differs in that the Behavioral Regulation Index is composed of the Inhibit, Shift, and Emotional Control subscales and the Metacognition Index is composed of the Initiate, Working Memory, Plan/Organize, Organization of Materials, and Monitor subscales. Normative data is based on child ratings from 1,419 parents from diverse demographic backgrounds representing 1999 U.S. Census estimates for gender, ethnicity, and socioeconomic status (Gioia et al., 2000). The internal consistency of the two broad indexes and the overall score ranged from $\alpha = .80$ to $\alpha = .98$ (Gioia et al., 2000). The BRIEF-Parent has been utilized in clinical samples including spina bifida and hydrocephalus (Brown, 2005; Burmeister et al., 2005; Mahone et al., 2002), sickle cell (Kral et al., 2004), and ADHD (Jarratt et al., 2005; Kenealy, 2002). The value of using both self-report and parent-proxy is indicated by moderate interrater reliability between parent and self-report ($r = .56$) (Gioia et al., 2000).

4 DATA ANALYTIC PLAN

In the current study, the goals were to develop a cognitive-developmental theory of mindfulness in adolescents with chronic pain and evaluate the theory across executive functions. To achieve this goal within a constructivist paradigm, a concurrent, embedded mixed methods approach was taken. The inductive nature of the project – the exploration and formation of a theory – lends itself to a primarily qualitative approach, specifically grounded theory (Glaser & Strauss, 1967). A grounded theory approach as developed by Glaser and Strauss (1967) refers to a systematic method of collecting and analyzing data to allow for the discovery of a theory grounded in the collected data. The quantitative aspect of the project was implemented simultaneously with the qualitative component. This study utilized a flexible, emergent design, which allowed for modifications to the stated procedures as determined by the data.

4.1 Qualitative

QSR International's NVIVO 10 software was used to manage qualitative data analysis. The form of analysis used in grounded theory methodology is coding, or the process by which data is segmented, conceptualized, and then reintegrated in new ways (Strauss, & Corbin, 1990). Grounded theory utilizes a constant comparative approach to data analysis, which requires the researcher to continuously make comparisons and ask questions of the data. It is important to note that there are three main coding types but they do not necessarily take place in stages. Strauss and Corbin (1990) explain that the boundaries between each type of coding are artificial and it is easy for coders to move between different types of coding, especially open coding and axial coding, which are discussed below. In addition, while certain forms of coding are more likely to happen towards the beginning of the coding process, they may also occur at the end to clarify or supplement concepts that have emerged. Coding occurs throughout the process of data

collection and each participant's data were coded as they became available. The principal investigator primarily conducted the coding and another member of the study staff was included as a secondary coder.

Once data collection began, interviews were transcribed immediately to initiate the process of initial *open coding*, which involves coding the data in multiple different ways to maximize the number of categories that could fit the data (Glaser, 1978). During this stage, coding was conducted line-by-line and major themes or categories consisting of characteristically similar phenomena were identified and named (Glaser, 1978). Category labels were created using the words or phrases provided by participants in the study to ensure the analysis remained grounded in the data and was not unduly influenced by existing theory.

During *axial coding*, the focus is on further specifying categories and the conditions under which they occur. The categories identified during open coding were analyzed for their relational properties. Similarities and differences between categories were identified in order to create linkages amongst categories. Similarities and differences within categories were also identified to expand the complexity and depth of more general categories. This involves defining the context, strategies, and consequences that give rise to a category. These aspects are seen as properties of a category and identification of these properties allow the researcher to determine a coding paradigm (Strauss & Corbin, 1998). Upon establishing a preliminary coding paradigm, 35% of the data was independently double-coded by two members of the study team to determine intercoder reliability. Data from each participant was extracted to provide a representative sample of data as opposed to whole transcripts from only a select number of participants (MacPhail, Khoza, Abler, & Ranganathan, 2016; Morse, Barrett, Mayan, Olson, & Spiers, 2002). Krippendorff's alpha reliability estimate was then calculated using the KALPHA

macro and a bootstrapped sample of 10,000 (Hayes & Krippendorff, 2007). The result of the intercoder reliability was $\alpha = 0.93$ [95% CI = 0.87 – 0.98], suggesting sufficient reliability (Krippendorff, 2011).

In *selective coding*, a core category is selected and related to other categories, relationships amongst categories are validated, and categories are further refined and developed (Strauss & Corbin, 1990). Through this process of integration, a theoretical framework was determined, which addressed Specific Aim 1.

Every participant's data was open coded and evaluated for fit within the coding paradigm determined by axial coding. When new categories or themes appeared in open coding, they were subjected to the same process of axial coding wherein conditions and properties of a category were identified. In this way, coding was a continuous process that was not time or stage limited. As categories became substantiated and new categories were not emerging from the data collected, selective coding was undertaken.

Throughout the process of data collection and analysis, memo writing was utilized to track how categories were determined, how connections between categories were conceptualized, and how emerging themes were progressively integrated. Another method of establishing validity in qualitative methodology is member checking (Guba, 1981). Upon establishing themes that emerged from the qualitative data, this information was brought back to participants to ensure the researcher's conceptualization accurately represents the experience of the participant. Attempts were made to conduct member checking with 4 of the 7 participants as 3 of the other participants either did not wish to be contacted or did not provide a phone number. 1 phone number was disconnected and 2 other participants were unable to discuss research over the phone due to logistic reasons or parent preference (e.g., child was not home and child could

not be reached on additional attempts to contact). Therefore, member checking was conducted with 1 participant in-person during the participant's clinic visit. Categories were first explained to the participant and fidelity to the participant's experience was solicited. The participant reported that the categories were representative so no adjustments were made to the categories or definitions. The participant then viewed a rudimentary figure depicting the thematic paradigm and the relationship amongst categories. The participant verified the paradigm, and provided additional statements that supported the conceptualization of the data. These statements will be integrated into the results.

4.2 Quantitative

The BRIEF-SR and BRIEF-Parent were scored with the computer scoring system to produce a profile of executive functioning. Scores were obtained for each of the 8 subscales, the two broad indices, and the overall score. Higher scores represent greater impairment, with T scores > 70 indicating clinical elevation. As the primary emphasis of this mixed methodology was on the qualitative portion of this study, the quantitative portion was not analyzed as an independent data set. In addition, the sampling procedures produced a small sample size, which would result in a statistically underpowered quantitative analysis. As a result, this quantitative data was only analyzed in the context of the qualitative data.

4.3 Integrating

Specific a priori methods of data integration were not established due to the exploratory nature of the study, as well as the emergent aspect of qualitative methodology. As such, data were integrated following an initial read through of the interviews to determine a global quality upon which the interviews could be ranked. It was determined that the interviews ranged widely in how concretely to abstractly participants discussed mindfulness. As a result, the transcripts

were ranked from abstract to concrete. In the results, each participant's interview will be described in greater detail to illustrate the abstract to concrete quality of the transcript. Participant BRIEF-Parent Report scores will then be discussed in conjunction with the transcript. Graphical integration of the qualitative and quantitative data was done via a matrix (Creswell, 2009), with results from the BRIEF on the horizontal axis and coordinating participant responses in cells ranked from abstract to concrete on the vertical axis.

Within the cells, quotes were used to present how individuals with a certain executive function profile discussed mindfulness. This qualitative and quantitative data were not integrated to produce one sum score; instead they reside side by side to create a composite of how these two sets of information are related. This will address Specific Aim 2.

5 RESULTS

The primary purpose of this study was to understand how adolescents diagnosed with chronic pain understand the construct of mindfulness. The secondary purpose of this study was to explore the relationship between participants' understanding of mindfulness and executive function. The results from the qualitative portion of the study will be presented first organized by the questions posed to participants, followed by a description of the quantitative executive function results, and lastly, these data will be integrated.

5.1 Qualitative

Through the iterative process of data collection, data analysis, and adjusting the interview script, the data appeared to answer two separate but related questions – “What is mindfulness?” and “How can it be applied to chronic pain?” As a result, a set of categories associated with each question emerged. Each set of categories will be described and then integrated. The first set of categories that focused on defining mindfulness and were 1) Awareness [subcategories: awareness of external factors (sub-subcategory: caution), awareness of internal factors], 2) Objectivity (subcategory: perspective-taking and respecting others) and 3) Nonreactivity to Determine Action. The second set of categories on applying mindfulness to chronic pain were 1) Confusion and Contradiction (subcategory: preference for distraction) and 2) Alleviating or Not Exacerbating Pain (subcategory: balancing awareness of pain). Quotes from participants are presented without grammatical edits to preserve the integrity of the data.

5.1.1 Qualitative – What is mindfulness?

5.1.1.1 Awareness (Category 1)

The core category that emerged was from participants' describing mindfulness as “being aware” or “paying attention.” In each interview, participants generated “awareness” as an

integral component of the mindfulness concept. The quality of “awareness” was frequently further defined as awareness of external factors and awareness of internal factors.

5.1.1.1.1 Awareness of External Factors (Category 1.1)

Many participants stated that mindfulness was awareness or attention towards external factors and experiences outside of the individual such as other people, school, or general surroundings. This is exemplified in the following quotes:

“I think it means like being aware of your surroundings” (Participant 7).

“I’m mindful of the people around me or like things that are around me”
(Participant 3).

In discussing mindfulness, participants expressed that awareness of external factors is also helpful in being careful and cautious. These participants provided examples of using mindfulness to ensure safety in daily life. For example, in response to the question, “Tell me about a time you were mindful?” this participant responded,

“When I’m crossing the street...I’m trying to make sure a car isn’t coming”
(Participant 5).

Another participant responded, “I was mindful of the people around me because some of the people were kind of like sketchy” (Participant 3).

This suggests that the awareness to external factors that is part of mindfulness serves a purpose in maintaining vigilance over safety concerns. This also appears to reflect exposure to layman’s use of the word “mindful,” which is commonly utilized as a synonym for being attentive in risky situations.

5.1.1.1.2 Awareness of Internal Factors (Category 1.2)

Many participants stated that mindfulness was awareness of internal experiences such as feelings, thoughts, and physical sensations. Examples include the following: “Be aware of what’s going on in your mind emotionally and physically” (Participant 2); “Knowing yourself and how you react to and feel about different things” (Participant 7).

The core category of “Awareness” appeared across participant responses and was identified as a foundational component of mindfulness. This was further explained as awareness of external and internal factors; however, participants were able to discuss awareness of external factors in more detail than awareness of internal factors. When probed to expand upon their awareness of internal factors, most participants struggled to provide more information on what that means or how to develop awareness of internal factors. Interestingly, participants did not specifically relate awareness to awareness in the present moment.

5.1.1.2 Objectivity (Category 2)

Awareness was described as a foundational component of mindfulness that subsequently allowed participants to engage in objectivity or the ability to evaluate a situation from a neutral, factual perspective as opposed to an overly personalized, or subjective perspective. For example,

“You are seeing something not necessarily a bad thing or a good thing you don’t, just as it is, not with any of your personal things attached to it, it’s just this is what it is; I understand that this is what it is, now how do I work with” (Participant 1).

“Well, you’re observing it and knowing about it and keeping watching over it” (Participant 5).

This emphasis on objectivity was also further extended into being able to take on the perspective of others.

5.1.1.2.1 Taking the perspective of and respect for others (Category 2.1)

A component of remaining objective, or neutral, in a given situation was also discussed in conjunction with perspective taking and not being egocentric, reflecting an emphasis on not being overly subjective. Participants noted the importance of being aware of how others may be experiencing a particular situation and stepping outside of their own worldview to consider those of others.

“It’s less about me and more about everything, including other people. So it’s not, it is helpful to keep yourself in check, that you are not thinking all about just yourself” (Participant 1).

The orientation to the perspective of other individuals was also related to being respectful as exemplified by this statement, “Just being mindful of how they might feel about something, respecting that” (Participant 2).

The link between the theme of Objectivity and taking the perspective of others, suggests an orientation to others that may be unique for this sample. In addition, objectivity was emphasized as the most important aspect of mindfulness during member checking.

5.1.1.3 Nonreactivity to Determine Action (Category 3)

Participants also discussed how being objective and aware of external and internal factors allows them to consider the potential outcome of certain behaviors. This can then dictate which action to engage in. In this way, mindfulness is also about not reacting rashly but being intentional in your actions.

“It makes me think to just stop and think before you do, like think about what you’re going to say before you do it cause you might blurt something out that you shouldn’t be saying like that happens to me sometimes because I do say things without

thinking and it usually has a negative effect... I speak before I think about it and I instantly regret it and it just makes me remind myself to think before I say something” (Participant 2).

“A couple days ago, like somebody was talking to me in a way which I did not appreciate and like I was about to start getting upset and then I had to like stop and think I was like I probably shouldn’t do that I probably should like ignore it cause it wouldn’t be worth it to get into it like that. I had to like be aware of my surroundings and who was around” (Participant 7).

5.1.2 Qualitative – How can mindfulness be applied to chronic pain?

5.1.2.1 Confusion and Contradiction (Category 4)

Many participants expressed confusion in using mindfulness to cope with pain. They predominantly discussed how being aware of pain or attending to pain could lead to noticing pain more and exacerbating the pain experience.

“I don’t think it would make a lot of sense to be mindful of pain” (Participant 7).

“If you’re thinking about it you’re going to worry about it then you might end up feeling more pain, that’s what generally happens, like when we have the doctors ask where it hurts, I might come in not hurting but then it gets your attention like actually this does hurt, you know” (Participant 7).

“Cause if you’re going to focus on the pain, you’d become, you’d always want to focus on the pain, it’ll only make it seem like it hurts more” (Participant 5).

5.1.2.1.1 Preference for Distraction (Category 4.1)

In part, this confusion was due to receiving messages from their pain management team and others to avoid overly focusing on pain. In fact, one of the most commonly recommended coping strategies for chronic pain is distraction or purposefully engaging in activities to take your mind off of the pain (Bushnell, Ceko, & Low, 2013; Johnson, 2005). “Most of the time people tell you try not to think about it” (Participant 2).

As such, many participants shared that distraction is their primary and preferred pain coping strategy, which appears to be in direct contradiction to being mindful of pain:

“I listen to music...it helps me focus less on the pain so it pretty much does [help]” (Participant 5).

“Well I try not to think about [pain] and when I’m around people that I like and watch things that I like and do things that I like, I think about it less” (Participant 6).

“Most of the time I don’t pay attention to [pain] and I don’t always realize I’m in pain and stuff but like one of my friends will notice like, ‘you’re kind of walking weird’ or my hands look weird or something like that...then I notice [the pain]” (Participant 7).

5.1.2.2 Alleviating or Not Exacerbating Pain (Category 5)

On the other hand, participants also shared that mindfulness could be used as a way to find coping strategies or to not exacerbate or aggravate pain. In this way, mindfulness could be used to identify a course of action to minimize pain by thinking through potential outcomes. The idea of planning ahead to prevent exacerbation of pain was emphasized during member checking.

“If you were to not be mindful about [pain], it would just get worse” (Participant 5).

“Mindfulness can help with pain if you’re, if you know you can’t do something like other kids, you shouldn’t do it because you might hurt yourself” (Participant 4).

“Maybe if I’m thinking about it, trying to think about ways to get rid of it, things like that, maybe it’ll be easier” (Participant 6).

5.1.2.2.1 Balanced awareness of pain (Category 5.1)

When discussing mindfulness and distraction, participants described efforts to balance their attention to and distraction from pain.

“Not ignore it but go past it” (Participant 7).

“Kind of ignoring it like focusing on something else but still focusing on the pain a little“ (Participant 5).

“You should be mindful but you shouldn’t be too focused on it” (Participant 7).

5.2 Theory of Mindfulness in Adolescents Diagnosed with Chronic Pain

In integrating the themes, mindfulness can be described as comprising three dimensions or components. The core component is awareness of both external factors (e.g., aspects of your surroundings) and internal experiences (i.e., thoughts, feelings, and physical sensations).

Attending to external factors can also be in service of ensuring safety, so in this way, mindfulness may entail a quality of caution. Another component of mindfulness discussed by participants was remaining objective and factual in interpreting a situation. Awareness of internal and external factors allows the individual to engage in objectively evaluating a situation, including taking the perspective of others. Lastly, mindfulness is the ability to pause and think through potential outcomes of a behavior to determine the best course of action to take. By objectively evaluating a situation, it makes it possible to proceed intentionally as opposed to reactively. In sum, these data suggest that mindfulness is composed of objective awareness of

internal and external factors in a given situation to allow the individual to think through potential outcomes of a behavior prior to engaging in an action.

In considering how this may be applied as an intervention for pediatric chronic pain, participants expressed confusion and discord between mindfulness and messages they typically receive about ignoring or not paying excessive attention to pain. In fact, many of the participants spoke of how bringing their awareness to pain typically exacerbates the pain experience. As a result, participants indicated that mindfulness was in contradiction with a commonly used and emphasized coping strategy, distraction. In considering this, it seems that if mindfulness is understood as simply “being aware,” then using mindfulness to cope with pain does not make sense. However, including the additional components of mindfulness, namely objectivity and thinking through outcomes to determine action, revealed a beneficial application of mindfulness for chronic pain. Specifically, mindfulness might be the awareness of factors that could exacerbate or alleviate pain. In this way, mindfulness might be defined and described as awareness of pain to determine behaviors to engage in without becoming overly focused in the experience of pain. This theory is displayed in Figure 1.

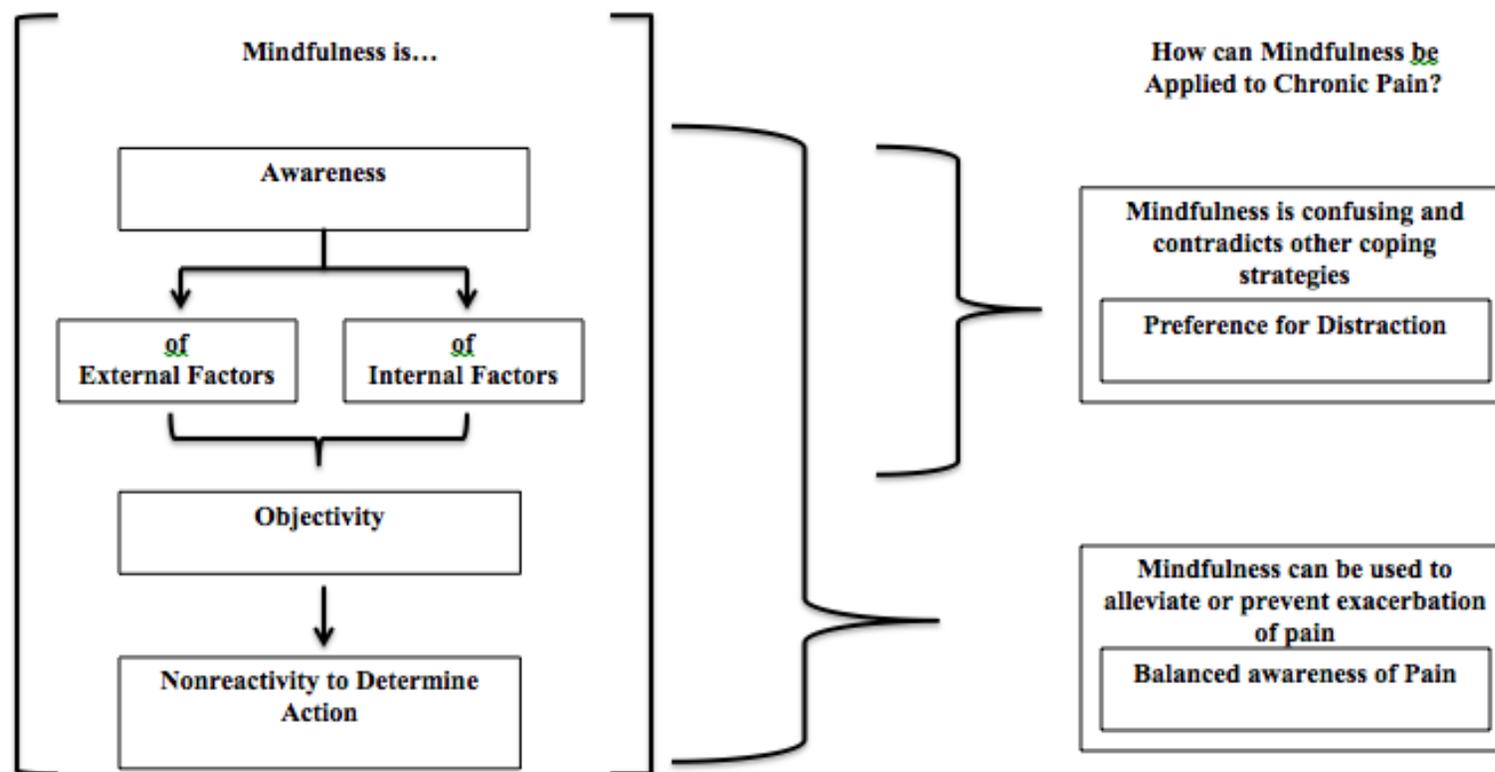


Figure 1. A theory of mindfulness in adolescents diagnosed with chronic pain. Mindfulness can be defined as awareness of internal and external factors that allow for objectivity and nonreactive evaluation of a situation to think through potential outcomes of a behavior prior to engaging in an action. If mindfulness was primarily understood as just awareness, participants indicated that mindfulness contradicts other coping strategies, particularly distraction. If mindfulness was also understood as a strategy to objectively and non-reactively determine an action, it was deemed potentially useful for identifying ways to alleviate pain or prevent exacerbation of pain by having a balanced awareness of pain and not overly focusing on pain.

5.3 Exploratory Quantitative Results – Executive Function

The BRIEF Parent Report and BRIEF Self Report did not concur in regards to frequency of clinical elevations as well as subscales that yielded elevations (see Table 2). This is consistent with previous studies in which Parent Report and Self Report do not coincide, characterized by parents reporting greater dysfunction than adolescents on the BRIEF (Wilson, Donders, & Nguyen, 2011). For this reason, the BRIEF Parent Report was utilized as the primary measure for integration with qualitative data. In addition, a clear pattern of elevations was not observed on either BRIEF, such that multiple, different subscales yielded clinical elevation. Only 6 of 7 participants completed the BRIEF Self Report. Of the 6, 3 participants reported at least one clinically elevated subscale. Per parent report, 5 of the 7 participants exhibited at least one clinically elevated domain of executive functioning (see Table 3).

Table 2. Participant Scores on the BRIEF-Self Report

BRIEF-Self Report Subscales	Participant Scores						
	1	2	3	4	5	6	7
BRI	43	48	64	-	63	49	48
Inhibit	44	42	64	-	41	47	54
Shift	49	43	64	-	59	55	53
Emotional Control	43	59	57	-	76*	50	45
Monitor	37	47	62	-	73*	44	37
MCI	56	51	64	-	58	54	62
Working Memory	52	56	63	-	61	56	81*
Plan/Organize	44	47	63	-	51	53	51
Organization of Materials	72*	61	61	-	60	52	49
Task Completion	60	44	60	-	55	53	55
GEC	50	50	65	-	61	52	56

Note. Clinically Elevated Scores*

Table 3. Participant Scores on the BRIEF-Parent Report

BRIEF-Parent Subscales	Participant Scores						
	1	2	3	4	5	6	7
BRI	52	61	73*	76*	55	58	63
Inhibit	54	58	67	63	49	78*	55
Shift	54	54	66	77*	56	48	72*
Emotional Control	48	66	75*	80*	59	40	59
MCI	59	55	88*	56	58	69	61
Initiate	63	56	68	56	63	62	59
Working Memory	50	58	92*	52	52	71*	64
Plan/Organize	61	47	89*	47	51	70*	63
Organization of Materials	58	59	68	64	70*	60	50
Monitor	57	50	81*	61	55	66	53
GEC	57	58	83*	64	58	67	62

Note. Clinically Elevated Scores*

5.4 Integrated Mixed Methods Results – Relationship between understanding of Mindfulness and Executive Function in Adolescents diagnosed with Chronic Pain

Two raters independently rank-ordered the participants’ transcripts from the most abstract and sophisticated discussion of mindfulness to the most concrete. Abstract responses were characterized as using more sophisticated and abstract language and exhibiting metacognitive thought processes. Concrete responses were characterized as using examples rather than explanations; and repeating similar responses without expanding or adding complexity. One rater (JLM) was blind to BRIEF-Parent Report scores. The other rater (SWS) had previously scored the questionnaires and been exposed to the participants’ scores; however, SWS tried to remain unbiased in conducting rank ordering. The raters agreed on 5 out of 7 rankings and the 2 disagreements were within 1 ranking of each other (see Table 4). The coders discussed the disagreement and reached consensus in rankings. These data – along with the executive functioning results – will be presented in order of rankings from the most abstract to the most concrete. Participant transcripts will be discussed in depth to provide context for rankings and integration with executive functioning results.

Table 4. Interrater Rankings of Participant Responses from Abstract to Concrete

<i>Participant Number</i>	<i>SWS Initial Ranking</i>	<i>JLM Initial Ranking</i>	<i>Final Ranking</i>
1	1	1	1
2	2	2	2
3	7	7	7
4	5	6	5
5	6	5	6
6	4	4	4
7	3	3	3

Note: Rankings are from 1 (most abstract/least concrete) to 7 (most concrete/least abstract)

Participant 1. This participant did not have any clinically elevated scores on the BRIEF-Parent Report. Participant 1 was the only participant to have substantial exposure to mindfulness. This participant's parent is familiar with Buddhism and had reportedly shared this knowledge, including tenets of mindfulness, with the participant. The participant also indicated learning about mindfulness in conjunction with biofeedback during the course of psychotherapy. Thus, not surprisingly, this participant's transcript was unanimously ranked as number 1 for being able to discuss mindfulness at an abstract level. For example, this participant defined mindfulness as, "observing with compassion." In addition, participant 1 emphasized objectivity as essential to mindfulness in this statement, "If you can identify what you are looking at then you can separate yourself from it." However, the participant had difficulty in applying mindfulness to chronic pain as illustrated by this quote,

"My brain is kind of a jumbled mess...identifying what has happened, just figuring out what is going on, I would say that would be the easier part. I would say separating myself from [pain] would be more difficult. And identifying it without judgment."

In discussing recommendations for teaching mindfulness to adolescents, the participant suggested,

"Not everybody's minds work the same. So figure out how that adolescent's mind works and then try and tailor the way you explain mindfulness to how it is explained to the way the adolescent's mind works."

Participant 2 was ranked as the second in terms of discussing mindfulness at an abstract level, and this participant had no clinically elevated scores on the BRIEF Parent Report. This participant denied previous exposure to mindfulness and defined it as, "Thinking something

through... trying to understand something from another's point of view." In addition, this participant frequently referenced considering other individual's perspectives as a component of mindfulness. For example,

"Well I guess I would say just to be able to be aware of what's going on with yourself with others being fully understanding, not judging anyone, not judging yourself, just try to be aware of what's going on, just be accepting of others too."

A unique theme expressed by this participant was positivity as part of mindfulness. This is exhibited in the following quotes:

"You just gotta try to get your mind out of the gutter."

"It is like building up inner strength, like kind of shaping your mind in a positive way of thinking about bad things."

At the end of the interview, the participant also appeared to have gained new insight on how to approach pain in the future:

"I guess I know what mindfulness is – it's being aware, being aware of yourself...I think because I think just talking about it made me really think about what's been going on through my mind, I didn't want to think about it before but now it's kind of made my more aware of what's going through my head."

[Interviewer: Yeah, so what do you think about that, how does that feel?]

"Kind of surprising, cause I didn't really think too hard about it about putting all of these different things together so it's just now kind of nice to, good to hear cause in the future, now I know that I could be try to be nonjudgmental and be more accepting, more than I already am, and be more aware of what's going on."

Participant 7 was ranked as having the third highest ability to discuss mindfulness at an abstract level. Participant 7 had one clinically significant score on the BRIEF Parent Report, namely on the Shift subscale. The Shift subscale measures the ability to adjust to changes in routine or task demands. When asked about previous exposure to mindfulness, this participant stated, “I’ve heard the word but I don’t really know what it means.” This participant reported learning of mindfulness in a chronic pain coping skills workshop but indicated, “They just kept using the word mindfulness but they didn’t say exactly what it meant.” In defining mindfulness, this participant suggested, “It means like being aware of your surroundings, and what happens and knowing yourself and how you react to and feel about different things.” Similar to Participant 2, Participant 7 frequently referred to considering other individuals’ reactions as part of mindfulness. For example,

“I mean depending on what you say or how you react to something somebody else could react in a good or bad way about that like keeping in mind your facial expressions your body language and different comments you make.”

In addition, this participant highlighted the role of mindfulness in being able to think through outcomes and incorporated the need to pause and think before acting, as exemplified in the following quote:

“I mean, I don’t know I just thought about it I’m like I don’t, I don’t want to spend time on this cause we have lunch late and the day was almost over, it was a Friday, I did not want to get into anything on a Friday cause I had plans that day...it depends on how I feel like it’s going to react the rest of my day and if it’s going to interrupt my schedule like something I might say something about but then other times it’s like will this actually help me later on or in the end.”

The application to pain included the idea of planning ahead to identify potential alleviating or exacerbating factors as evidenced here,

“I mean I feel like it depends on if I have, if I think I’m going to have the time or a break between one activity to the next, like school then going somewhere after school because if I have a break in between, I can say if I need to I could take a Tylenol before, I can lay down or something, like if I think I can like not fix it but improve it a little bit before I can go do something, then that’s how I make a decision about it or if I feel like I can do anything to help it, I try to go and do that.”

Participant 5 was ranked as number 4 for discussing mindfulness at an abstract level. Participant 5 had one clinically elevated score on the BRIEF Parent Report on the Organization of Materials subscale. This subscale measures the ability to organize the individual’s environment and materials. This participant did not endorse any prior exposure to mindfulness and defined it as, “That you’re minding your surroundings and paying attention.” Although this description is relatively concrete, the participant spoke at a more abstract level as the conversation continued, including describing mindfulness for pain as, “Just kind of, kind of ignoring it like focusing on something else but still focusing on the pain a little.”

Patients typically will cease use of the affected pain area, which leads to increased functional disability. This appears to be a similar experience for this participant as well – “It just starts feeling heavier in one area and just tightness and throbbing in one area and it kind of feels like the other areas go numb.” Patients are encouraged to engage in activity and distraction in particular to reengage the affected area. As such, this participant identified engaging in distraction as the primary coping strategy used and subsequently seemed to describe confusion between mindfulness and distraction as seen in this statement: “If you’re going to focus on the

pain, you'd become, you'd always want to focus on the pain, it'll only make it seem like it hurts more." But she also suggested that not being mindful would make pain worse because then you would not be vigilant of signs of increasing pain as seen in this statement, "Well, if you don't keep watch over it, it will start getting dry skin and it will lock up and you won't be able to feel your fingers."

Participant 6 was ranked as number 5 for discussing mindfulness at an abstract level. This participant had clinically elevated scores on the BRIEF Parent Report on the Inhibit, Plan/Organize, and Working Memory subscales. Inhibit measures the ability to self-regulate at a basic level, including the ability to inhibit impulsive responses. Plan/Organize measures the ability to plan and organize problem-solving approaches. Working Memory measures the ability to sustain working memory, or the cognitive ability to hold information in mind and manipulate that information. This participant noted some previous exposure to mindfulness but could not recall where or when. Mindfulness was defined as, "not sure, uh maybe using their mind and thinking about the pain, maybe?" This participant spoke frequently of using distraction as a coping strategy and also indicated preference for using distraction. For example, when asked what would be challenging about applying mindfulness to pain, the participant stated, "Put all my attention to it and not judge it...cause normally when I am in pain, I try not to think about it at all."

Participant 4 was ranked as number 6 for discussing mindfulness at an abstract level. On the BRIEF Parent Report, Participant 4 was clinically elevated on the Shift and Emotional Control subscales and the Behavioral Regulation Index. Shift is the ability to adjust to changes in routine or task demands and Emotional Control is the ability to modulate emotions. This participant denied previous exposure to mindfulness and defined it as, "To think...to be careful."

The participant described an example of using mindfulness for pain in daily life that appeared to reflect thinking through outcomes before deciding in an action to take:

“As first, I was like, “if you just get one scoop [of ice cream]” nobody would know and then I was like but it won’t be right because you know you not supposed to, then I was like well you might not hurt you never know, then I said, no you not gonna take no chances, then I just didn’t eat it.”

Participant 3 was ranked as the most concrete and least abstract in discussing mindfulness. On the BRIEF Parent Report, Participant 3 was clinically elevated on all 3 index scores and on the following subscales: Emotional Control, Working Memory, Plan/Organize, and Monitor. Emotional Control is the ability to modulate emotions. Working Memory measures the ability to sustain working memory, or the cognitive ability to hold information in mind and manipulate that information. Plan/Organize measures the ability to plan and organize problem-solving approaches. Monitor measure the ability to monitor one’s own behavior. This participant indicated hearing of mindfulness in the context of moods but did not elaborate on this. Participant 3 described mindfulness as, “mmm probably...oh no... probably being aware I guess? Cautious comes to mind. Being aware is probably the main thing.” This participant provided many examples during the conversation. For example,

“I’m not very good about being mindful of my mood I guess, sometimes when I’m upset at my mom or something, she’ll be like, “What kind of mood are you in?” And that’ll just make me even more angry, but um, ah man, I don’t know... this may not be what you’re looking for but um like I’m mindful of the people around me or like things that are around me, except for that bird I didn’t see... it just startled me cause I was walking around like look it’s my neighborhood and then a bird just flies away, and it’s

like oh! But other than that, I don't know...I guess...being mindful of when I'm crossing the line of the rules, like I don't like to break the rules but sometimes I might be like oh whatever, and a friend of mine will be like, "Okay that's not right' or something and I'll be like "Oh you know, you're right, aw man."

The integration of participants' executive function abilities and the abstract/concrete quality of their perspective on mindfulness is exhibited in Figure 2.

In analyzing the data and the integrated matrix, there was no clear pattern of executive dysfunction in regards to consistent clinical elevation in specific domains or subscales. However, it appears that in general, the more executive dysfunction across all domains, the more concrete the discussion of mindfulness (Figure 2). In addition, while age tended to be associated with level of executive function, this was not consistent and there were notable exceptions. More specifically, although Participant 3 was the oldest, that individual had the most diffuse executive dysfunction and spoke about mindfulness most concretely. This suggests that age alone may not be the best measure of cognitive development and particularly in regards to determining how an individual understands mindfulness. Lastly, sex was not included in the matrix to preserve patient confidentiality; however, no patterns of sex differences emerged, such that males and females were distributed across both executive function and abstract quality of mindfulness discussion.

Concrete (bottom) to Abstract (top) ↑	“Observing with compassion” “If you can identify what you are looking at then you can separate yourself from it.” - Participant 1 , Age 16						
	“Thinking something through... trying to understand something from another’s point of view.” - Participant 2 , Age 14						
	“It means like being aware of your surroundings, and what happens and knowing yourself and how you react to and feel about different things.” - Participant 7 , Age 14						
	“That you’re minding your surroundings and paying attention.” - Participant 5 , Age 12						
	“Uh maybe using their mind and thinking about the pain, maybe?” - Participant 6 , Age 13						
	“To think...to be careful.” - Participant 4 , Age 12						
	“Cautious comes to mind. Being aware is probably the main thing.” - Participant 3 , Age 17						
# Clinically elevated subscales on BRIEF-Parent Report	0	0	1	1	2	3	4
# Clinically elevated subscales on BRIEF-Self Report	1	0	1	2	0	0	0

Figure 2. Participant responses were ranked from abstract to concrete and stratified by number of clinically elevated subscales on the BRIEF-Parent Report. More diffuse executive dysfunction appeared to be associated with more concrete responses. BRIEF-Self Report did not concur.

6 DISCUSSION

The current study aimed to first describe an endogenous theory of mindfulness in adolescents diagnosed with chronic pain using a grounded theory approach. Although mindfulness has been more thoroughly investigated in adult populations, there are still disagreements within the field about how mindfulness is understood in younger populations and how that may or may not differ from conceptualizations of mindfulness in adults (Creswell, 2017; Quaglia et al., 2015). As such, recent efforts to downward translate mindfulness interventions to adolescent populations appear to lack the same robust outcomes often found in adult studies of mindfulness interventions (Abujaradeh et al., 2018; Ahola Kohut et al., 2017; Zoogman et al., 2015). In considering how to best tailor and develop mindfulness interventions for adolescent populations, it is important to first explore how mindfulness is understood in adolescent populations. Given that many adult-to-adolescent translations of mindfulness have been insufficient, it is worthwhile to take an exploratory ground-up approach to answering this question with a specific group that has demonstrated a need for more psychosocial interventions, such as mindfulness. Therefore, the question of, “What is mindfulness?” was investigated in adolescents diagnosed with chronic pain. In the process of conducting the qualitative portion of this study, it became clear that separating the construct of mindfulness from mindfulness intervention was challenging for participants and it was also apparent that both questions were important to address. As a result, the iterative and emergent design of this study warranted reflection on the study aims and modification of the interview guide. Subsequently, the question of, “How can mindfulness be applied to chronic pain?” was explored with participants as well. These questions together informed a theory of mindfulness in adolescents diagnosed with chronic pain.

In the current study, I also aimed to consider cognitive-developmental factors that are relevant to how adolescents understand mindfulness. Specifically, I explored how executive function is related to the way participants discussed mindfulness in this study. Participant responses were examined for qualities of abstractness and concreteness and then rank ordered from abstract to concrete to integrate responses with executive function results.

6.1 Theory of Mindfulness in Adolescents diagnosed with Chronic Pain

6.1.1 What is mindfulness?

First the question of, “What is mindfulness?” was explored with adolescents diagnosed with chronic pain. Results indicate that mindfulness consists of three related dimensions, or components – awareness of internal and external factors, objectivity, and nonreactivity to determine action. All participants brought up awareness as part of mindfulness but only participants who spoke at a more abstract level discussed the components of objectivity and nonreactivity to determine action. This suggests that there are differences in how individuals may understand mindfulness, such that for some adolescents mindfulness is unidimensional and for others, it is multidimensional. This is consistent with a recent review that found that existing studies of mindfulness in adolescents utilize both unidimensional and multidimensional conceptualizations of mindfulness, but in general, all conceptualizations include a component of awareness or attention (Johnson et al., 2016; Pallozzi et al., 2017; Van Dam et al., 2018). In sum, across existing conceptualizations of mindfulness, awareness or attention serves as a core factor of mindfulness (Creswell, 2017; Van Dam et al., 2018).

Participants discussed awareness of both internal and external factors; however, they were able to provide more details about external factors as compared to internal factors. For example, external factors were further delineated to include an element of caution while internal

factors were fairly limited to general statements about thoughts, feelings, and physical sensations. Perhaps this is due to the more tangible nature of external factors, which facilitates providing more examples or details and could be representative of normal cognitive development. The CHIME-A mindfulness measure (Johnson et al., 2016a) also confirmed a separate internal awareness subscale and a separate external awareness subscale, which suggests that there is a true divide in the characteristic of awareness. This distinction may allow for the identification of important differences in the experience of mindfulness in adolescents.

Awareness of internal and external factors is a component of mindfulness that is not unique to this sample of adolescents diagnosed with chronic pain. However, participants spoke about awareness somewhat more generally and did not specifically state that awareness was *present moment* awareness, which is typically how mindfulness is conceptualized (Creswell, 2017; Kabat-Zinn, 1994; Van Dam et al., 2018). In fact, participants spoke more about being oriented towards outcomes versus the present as illustrated by the category of nonreactivity to determine action. This differs from most conceptualizations of mindfulness, which focus on acting with full engagement in the present moment (Baer et al., 2006). It could be that adolescents are more likely to see mindfulness as goal-oriented or problem solving based.

It was also notable that the theme of objectivity, or remaining factual or neutral in a situation, emerged from the interviews but a theme of nonjudgment did not. Nonjudgment is typically considered an important quality of mindfulness and is often defined as acceptance of an experience without evaluating it as good or bad (Baer et al., 2006; Grossman & Van Dam, 2011; Kabat-Zinn, 2003). It is frequently discussed in the context of mindfulness meditation. For example, Jon Kabat-Zinn (1982) explained that during mindfulness meditation, when feelings arise, they should be observed as they are without any interpretation or thoughts of the

experience. In this way, nonjudgment is typically discussed in the context of nonjudgment towards self and experience. The way in which participants discussed how mindfulness includes being able to observe all of the information in a situation from a factual standpoint inferred that neutral attention is to be given to factors that are internal and external to the individual to subsequently determine action. Within that perspective, there is an evaluative nature to it, which is more in-line with the idea of objectivity as opposed to nonjudgment.

Another unique finding in this study is that these adolescent participants were also significantly oriented towards others. Peers are a very important and salient factor during the adolescent period (Rubin, Chen, Coplan, Buskirt, & Wojslawowicz, 2005). This is particularly true for adolescents diagnosed with chronic pain with multiple studies establishing peer relationships as either a risk factor or a protective factor for pediatric chronic pain (Forgeron et al., 2010). These studies suggest that patients often miss out on social activities, including school, due to chronic pain and physical limitations, which further perpetuates the experience of pain. However, social support from peers can provide patients with more positive outcomes. Therefore, peers may have a heightened level of importance for adolescents with chronic pain. Furthermore, patients have reported an increased ability for “dealing with problems” as compared to their peers, suggesting that perhaps the experience of having a chronic medical condition facilitates increased perspective taking (Eccleston, Wastell, Crombez, & Jordan, 2008). Taken together, this could account for this unique category of objectivity described as considering other points of view and respecting other individuals. This is an important contextual factor to consider in how adolescents with chronic pain conceptualize mindfulness versus how younger or older populations might conceptualize mindfulness.

The resulting theory was that mindfulness is composed of objective awareness of internal and external factors in a given situation to allow the individual to think through potential outcomes of a behavior prior to engaging in an action.

6.1.2 How can mindfulness be applied to chronic pain?

Participants talked at length about how mindfulness can be applied to chronic pain. Two different points of view emerged – Mindfulness as a contradiction of typically utilized coping strategies encouraging patients to ignore pain, and mindfulness as a potentially useful tool for identifying ways to attenuate or prevent exacerbating pain. This maps onto acceptability studies that have been conducted post-mindfulness interventions with pediatric chronic pain patients where participants disagreed on whether drawing attention to pain was favorable or not (Ruskin et al., 2017; Waelde et al., 2017). In this study, one participant stated,

“I don’t think it would make a lot of sense to be mindful of your pain...cause if you’re thinking about it you’re going to worry about it then you might end up feeling more pain. That’s what generally happens. Like, when we have the doctors ask where it hurts, I might come in not hurting but then it gets your attention like actually this does hurt, you know? [To cope with pain] I generally try to just like, I’ll watch a movie or I’ll eat ice cream or I’ll do something that makes me feel happy and content. Sometimes I take a nap. Whatever I can do to distraction myself from it.”

There are many potential reasons that underlie this divide in perspectives. Firstly, the treatment of pediatric chronic pain is not uniform across patients; in fact, it is often seen as a moving target due to heterogeneity of disease specific factors and individual factors (Coakley & Wihak, 2017). In addition, it may be that certain types or levels of pain call for different types of interventions, which has been observed even for distraction (Johnson, 2005). For coping

strategies to be effective, there must be a match between the stressor, or pain in this case, and the goals of the coping strategy (Liossi & Howard, 2016). So it is plausible that mindfulness could be an intervention that will not be well received or effective for all chronic pain patients.

However, this supports the importance of understanding how to best tailor the presentation and application of mindfulness to individuals to optimize outcomes.

Another explanation to consider is the readiness of adolescent chronic pain patients to approach their pain with objectivity, which appeared to account for the different perspectives on application of mindfulness for pain. Acute pain is evolutionarily adaptive and is meant to be an aversive experience so the individual is signaled to escape or avoid a potentially life-threatening situation (Loeser & Melzack, 1999). In acute pain, avoidance of the painful experience is beneficial and logical. However, in chronic pain, there is no real threat to life and avoiding the painful experience can potentially cause more harm in the form of functional disability and increased pain (Simons & Kaczynski, 2012). Therefore, using interventions that encourage approaching the pain experience may seem contradictory, but in fact serve a purpose in helping individuals reengage in daily activities despite pain. This concept is reinforced in Acceptance and Commitment Therapy, which encourages chronic pain patients to accept chronic pain and continue persevering in the face of aversive experiences (Pielech, Vowles, & Wicksell, 2017). Readiness to accept and approach pain may need to be fostered in order to truly view pain objectively and be mindful in the moment when experiencing pain. Pain acceptance was not assessed in this study but could account for the variation in responses.

6.2 Mindfulness and Executive Function in Adolescents diagnosed with Chronic Pain

The relationship between mindfulness and executive function in this study generally indicated that participants who have stronger executive functioning skills spoke about

mindfulness at a more abstract level than participants with poorer executive functioning. A recent systematic review of mindfulness measures in adolescents similarly posited the role of working memory in differentiating the factor structure of mindfulness across age cohorts, such that with the development of executive functions, increased abstraction leads to a more sophisticated set of mindfulness skills (Pallozzi et al., 2017). Studies have found that dispositional mindfulness significantly accounts for the variance in executive function in early adolescence through self-judgment (Shin, Black, Shonkoff, Riggs, & Pentz, 2016). In addition, mindfulness interventions have been shown to improve aspects of executive function in adolescents by increasing body-mind awareness (Tang, Yang, Leve, & Harold, 2012).

It is apparent that mindfulness and executive function are related, though the exact nature of the relationship is unclear in regards to how these abilities influence each other. The results of this study suggest that the abstract nature of understanding and discussing mindfulness is best reflected in those youth with typical levels of executive function. It is likely that both share similar neurobiological correlates since the prefrontal cortex is indicated in both executive functioning and mindfulness (Diamond, 2002; Doll et al., 2016; Yuan & Raz, 2014). However, myelination of the prefrontal cortex is ongoing throughout adolescence, which means that there is considerable room for variability in prefrontal cortex dictated abilities. Given this, it may be of increased clinical utility to consider cognitive-developmental factors for appropriateness or content of mindfulness interventions instead of based purely on chronological age. Within the field, there is an increase in demand for formal investigations of cognitive-developmental factors using neurobiological methods in order to inform mindfulness interventions in younger populations (Sanger & Dorjee, 2015).

In regards to the relationship between mindfulness and executive function in pediatric chronic pain, one recent study indicated that patients might have subclinical levels of executive dysfunction in the domains of working memory or sustained attention (Weiss et al., 2018). In a review, researchers have argued from evolutionary and behavioral perspectives that pain significantly interferes with attention (Eccleston & Crombez, 1999). It is also possible that because pain interferes with neural connectivity (Simons, Elman, & Borsook, 2014), executive function may subsequently be impacted. Perhaps this would interfere with acquisition or application of mindfulness skills or mindfulness skills could serve as a negative feedback loop to reengage executive function during the pain experience. Another consideration is that common comorbidities of chronic pain could also contribute to executive dysfunction. Specifically, sleep disruption (Harrison, Wilson, & Munafo, 2014; Valrie, Bromberg, Palermo, & Schanberg, 2013) and mood concerns (Knook et al., 2011) are prevalent in pediatric chronic pain. Coincidentally, these variables can also interfere with executive functioning (Cox, Ebesutani, Olatunji, 2016). The relationship amongst these variables warrants further investigation in the quest to understand how mindfulness is understood in adolescents diagnosed with chronic pain in order to inform future interventions.

6.3 Implications

These results support the need for an endogenous conceptualization of mindfulness in adolescent populations and especially populations that are likely to be encouraged to turn to mindfulness as an intervention. Unique features of mindfulness emerged from the qualitative aims of this study and important considerations for intervention development were revealed. Specifically, a multidimensional conceptualization of mindfulness emerged from this study, suggesting that different adolescents may understand mindfulness differently. Contextual

factors that are unique to the adolescent period emerged, such as orientation to others and a focus on outcomes.

Participants also conveyed confusion between using mindfulness for pain and using distraction for pain because these coping strategies appear to be in conflict. Thus, this conflict in messages should be considered in intervention development and directly addressed to avoid confusion. Additionally, mindfulness may be better suited for adolescents who have well-developed executive functioning capabilities. Alternatively, mindfulness may be differentially explained to adolescents with greater executive dysfunction by using more concrete examples and simple language. Should this modification be made, it will be important to empirically investigate how this alteration impacts acceptability and effectiveness.

6.4 Study Limitations and Future Directions

These findings are informative both for research and clinical avenues; however, there are limitations in the current study that might be addressed in future projects. First, all participants were recruited from the same outpatient pain relief clinic located within one hospital. Therefore, these findings may not generalize to patients in inpatient settings or patients treated in other hospitals. For example, there might be comprehensive approaches to teaching pediatric patients about mindfulness in some settings. Second, this study was exploratory in scope and should be further verified through larger studies that include additional quantitative and qualitative lines of inquiry. This would include quantitative studies to explore and confirm the components of mindfulness found in this study. To extend these findings, it would also be helpful to conduct similar inductive studies in other populations, including other medical cohorts, clinical populations, and “healthy” adolescents. There was also variability amongst participants in type and extent of previous exposure to mindfulness concepts. Although this was beneficial in

providing a breadth of perspectives, it may be useful to investigate these questions in more depth based on prior experiences with mindfulness.

Although not necessarily examined in this study, in the future it may also be beneficial to conduct qualitative studies pre- and post-mindfulness intervention to measure change in perception and understanding of both the construct and its application. Pre-intervention interviews may also help determine suitability or needed modifications for the intervention. Studies that have utilized qualitative approaches have typically done so post-intervention, which is informative but could also limit understanding of baseline factors. The relationship between executive function and mindfulness should be further investigated through longitudinal neurocognitive endeavors to understand if there are common underlying neural mechanisms to consider. It may also be of benefit to utilize multi-method assessment of executive functioning and to include measures of variables that commonly impact executive functioning, such as mood and sleep.

7 CONCLUSION

Within the field of psychological research, operationally defining constructs and subsequently developing informed measurements are fundamental steps to implementing interventions and understanding intervention results. This certainly applies to mindfulness research and the present study explored how adolescents diagnosed with chronic pain understand mindfulness, the applicability of mindfulness for pain, and the relationship between understanding mindfulness at an abstract level and executive function. The result was a multidimensional theory of mindfulness that is composed of objective awareness of internal and external factors in a given situation to allow the individual to think through potential outcomes of a behavior prior to engaging in an action. However, participants differed in perspectives on the

utility of mindfulness for chronic pain. Disagreement over the applicability of mindfulness for chronic pain reflects the need to better understand for whom mindfulness would be an appropriate intervention. It is likely that for those adolescents who do not think mindfulness would be applicable for pain are those who perceive mindfulness more concretely and exhibit more diffuse executive dysfunction. As such, to maximize future intervention development, a ground-up approach that considers individual factors, including cognitive development, should be pursued. Adolescents who demonstrate well-developed executive functioning may be predisposed to understanding mindfulness at a more abstract level and could be inclined to utilize and readily apply mindfulness interventions.

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APPENDICES

Appendix A: Semi-structured Interview

Thank you so much for agreeing to participate in this research! This study will help us understand what we can do to help teens with chronic pain feel better. I'm going to ask you a few questions about having chronic pain and how you manage any difficulties with chronic pain. There are no right or wrong answers; just try your best to answer the questions honestly and please give as much detail as possible. Your thoughts and point of view are very important to us! We want to make sure we hear everything you say correctly so I have a tape recorder to catch anything I might miss. We will chat for around 30 minutes. Feel free to stop me at any time if a question or word is unclear. Do you have any questions? Are you ready to start?

Warm Up

- What is your name?
- How old are you today?

Chronic Pain Experience

- When and how did your chronic pain start?
- Can you tell me how you feel about having chronic pain?
- What are some of the positive things about having chronic pain?
- What are some of the toughest things about having chronic pain?
 - Which of those do you think is the hardest?
 - How often does ____ happen?
 - What are some thoughts you have when ____ happens?
 - How do you deal with _____?
 - Do you do anything to make yourself feel better when _____ happens?
 - How well does _____ work to make you feel better?

Mindfulness Facets

Acting with Awareness

- What is the first thing that pops into your head when I say, "bring your awareness to the present moment?"
- Do you ever do that?
 - If YES: Tell me more.
 - If NO, move on.
- When ____ happens, do you ever bring your awareness to it?
 - If YES: Tell me more about that
 - How often do you think you bring your awareness to ____?
 - Is anyone around?
 - When you're doing this, does your mind ever wander off?
 - Are you able to bring your awareness back to what is happening?
 - How long do you do this for?

- When does this happen the most?
- If NO: Do you think you would be able to do that?
 - Why or why not?

Observing

- What is the first thing that you think of when I say, “notice your own thoughts, feelings, and bodily sensations?”
- Is that something you do?
 - If YES: What is it like?
 - Are you able to let the thoughts/feelings/bodily sensations go? Or do you think about your thoughts/feelings/bodily sensations a lot?
 - How often?
 - If NO, move on.
- When ____ happens, do you ever notice any thoughts/feelings/bodily sensations that come up?
 - If YES: Tell me more about that
 - How often do you think you notice your thoughts/feelings/bodily sensations____?
 - Is anyone around?
 - How long do you do this for?
 - When does this happen the most?
 - If NO: Do you think you would be able to do that?
 - Why or why not?

Non-Judgment of Experience

- What is the first thing that comes to mind when I say, “be nonjudgmental of your own experiences?”
- When you have ____, what thoughts and feelings do you have?
- Do you ever label those thoughts as good or bad?
 - If YES: Tell me more about that
 - How often do you label your thoughts?
 - Is anyone around?
 - When does this happen the most?
 - If NO: Do you do anything instead?
 - How often?

Non-Reactivity

- When I say “not being reactive to your own experiences,” what does that mean to you?
- What about when _____ happens, do you usually react?
 - If YES: Do you think you would be able to accept it when ____ happens?
 - What does that mean to you?
 - Why or why not?
 - If NO: Tell me more. Are you able to accept it?
 - What does that mean to you?
 - Is it hard or easy to do?
 - How often?

Describe

- What is the first thing that comes to mind when I say “describe your experience?”
- When you have _____, what thoughts and feelings do you have?
- Do you ever describe your thoughts and feelings?
 - If YES: Tell me more about that
 - How often do you describe your thoughts and feelings?
 - Is anyone around?
 - When does this happen the most?
 - If NO: Do you do anything instead?
 - How often?

Mindfulness Overall

- The next time _____ happens, do you think you would be able to bring your awareness to it, notice thoughts as they come to your mind, let them go, and accept what is happening without labeling yourself, your thoughts, or the situation as good or bad?
 - If YES: Do all parts sound equally doable?
 - Do you think you would be able to do this every time _____ happens?
 - What about in other tough situations?
 - Can you give me some examples?
 - Can you think of anything that would make it hard to do?
 - If NO: What part of that makes you say no?
 - What part sounds the hardest?
 - What part sounds the easiest?
 - Would you be able to do any part of it?
- Have you heard of “mindfulness?”
 - If YES: What do you think it means?
 - What does it mean to you?
 - Do you ever practice it?
 - If NO: What do you think it means?

General Probes

- Can you tell me more?
- How so?

Closing

That is all of the questions I have for you today! Thank you so much for chatting with me. Do you have any questions about anything we just went over?

Appendix B: Semi-structured Interview

Thank you so much for agreeing to participate in this research! This study will help us understand what we can do to help teens with chronic pain feel better. I'm going to ask you a few questions about having chronic pain and how you manage your diagnosis. There are no right or wrong answers just try your best to answer the questions honestly and please give as much detail as possible. Your thoughts and point of view are very important to us! We want to make sure we hear everything you say correctly so I have a tape recorder to catch anything I might miss. We will chat for around 30 minutes. Feel free to stop me at any time if a question or word is unclear. Do you have any questions? Are you ready to start?

Chronic Pain Experience

- When did you first learn about your chronic pain diagnosis?
- Can you tell me how you feel about having chronic pain?
- What are the positive things about having chronic pain? Tell me about those.
- What are the tough things about having chronic pain? Tell me about those.
 - **PROMPTS**
 - Which of those do you think is the hardest?
 - How often does ____ happen?
 - What are some thoughts you have when ____ happens?
 - How do you deal with _____?
 - What do you do to make yourself feel better when _____ happens?
 - How well does _____ work to make you feel better?

Mindfulness General

- Have you heard of “mindfulness?”
- If YES: What do you think it means?
 - **PROMPT:** Do you ever try to be mindful in your daily life?
- If NO: What do you think it means?
- Can you think of a time you were mindful?
 - **PROMPTS:**
 - Describe what happened.
 - Tell me your thoughts and feelings when you experienced mindfulness.

Mindfulness Application

- What would it look like to be mindful in your life?
- If mindfulness is [provide description from participant's response to above], how would you use mindfulness for pain?
- What would be easy about that?
- What would be hard about that?

Closing

- Is there anything else you would like to add to what you know about mindfulness?

That is all of the questions I have for you today! Thank you so much for chatting with me. Do you have any questions about anything we just went over?

General Probes

- Can you tell me more?
- How so?

Appendix C: The Behavior Rating Inventory of Executive Function-Self-Report (BRIEF-SR)

Over the past 6 months, how often has each of the following behaviors been a problem?

1. I have trouble sitting still
2. I have trouble accepting a different way to solve a problem with schoolwork, friends, tasks, etc.
3. When I am given three things to do, I remember only the first or last
4. I start projects (such as homework, recipe) without the right materials
5. I overreact to small problems
6. My desk/workspace is a mess
7. I am not aware of how my behavior affects or bothers others
8. I have problems finishing long-term projects (such as papers, book reports)
9. I get upset by a change in plans
10. I get in other peoples' faces
11. I try the same approach to a problem over and over even when it does not work (I get stuck)
12. I have a short attention span
13. I don't plan ahead for future activities
14. I have angry outbursts
15. I lose things (such as keys, money, wallet, homework, etc.)
16. I don't notice when my behavior causes negative reactions until it is too late
17. I have difficulty finishing a task on my own
18. I get disturbed by an unexpected change (such as teacher, daily activity)
19. I have problems waiting my turn
20. I am slower than others when completing my work
21. I forget to hand in my homework, even when it's completed
22. I have trouble getting ready for the day (such as school, work, etc.)
23. I become tearful easily
24. I forget to bring home from school what I need (such as homework, assignments, books, materials, etc.)
25. I am unaware of my behavior when I am in a group
26. I have problems completing my work
27. It bothers me when I have to deal with changes (routines, foods, places)
28. I interrupt others
29. I am not creative in solving a problem
30. I have trouble with jobs or tasks that have more than one step
31. I don't plan ahead for school assignments
32. I have outburst for little reason
33. My backpack/schoolbag is disorganized
34. I have a poor understanding of my own strengths and weaknesses (I try things that are too difficult or too easy for me)
35. I have many unfinished projects
36. I have trouble getting used to new situations (such as classes, groups, friends)
37. I am impulsive

38. I test poorly even when I know the correct answers
39. I forget what I am doing in the middle of things
40. I have problems organizing my written work
41. My eyes fill with tears quickly over little things
42. I am late for many activities (such as school, appointments, meals)
43. I don't know when my actions bother others
44. I have good ideas but do not get the job done (I lack follow-through)
45. I have trouble changing from one activity to another
46. I get out my seat at the wrong times
47. I get caught up in details and miss the main idea
48. When I am sent to get something, I forget what I am supposed to get
49. I don't think ahead about possible problems
50. I react more strongly to situations than my friends
51. I have difficulty finding my clothes, glasses, shoes, books, pencils, etc.
52. I make careless errors
53. I have trouble finishing tasks (such as chores, homework)
54. I get out of control more than my friends
55. I have difficulty coming up with different ways of solving a problem
56. I have trouble staying on the same topic when talking
57. I have trouble carrying out the things that are needed to reach a goal (such as saving money for special items, studying to get good grades, etc.)
58. I get upset easily
59. My work is sloppy
60. I don't check my work for mistakes
61. I blurt things out
62. I get stuck on one topic or activity
63. I have trouble remembering things, even for a few minutes (such as directions, phone numbers, etc.)
64. I have problems getting started on my own
65. I get upset over small events
66. I talk too loudly
67. I have trouble thinking of a different way to solve a problem when I get stuck
68. I change topics in the middle of a conversation
69. I have trouble prioritizing my activities
70. I overreact
71. I act too wild or "out of control"
72. I have problems showing what I know during tests
73. I forget instructions easily
74. I have problems balancing school, work, and other activities
75. I am easily overwhelmed
76. I think or talk out loud when working
77. It takes me longer to complete my work
78. I am absentminded
79. I talk at the wrong time
80. I don't think of consequences before acting

Appendix D: The Behavior Rating Inventory of Executive Function-Parent Form

We would like to know if your child has had problems with these behaviors over the past 6 months.

1. Overreacts to small problems
2. When given three things to do, remembers only the first or last
3. Is not a self-starter
4. Leaves playroom a mess
5. Resists or has trouble accepting a different way to solve a problem with schoolwork, friends, chores, etc.
6. Becomes upset with new situations
7. Has explosive, angry outburst
8. Tries the same approach to a problem over and over even when it does not work
9. Has a short attention span
10. Needs to be told to begin a task even when willing
11. Does not bring home homework, assignment sheets, materials, etc.
12. Acts upset by a change in plans
13. Is disturbed by change of teacher or class
14. Does not check work for mistakes
15. Has good ideas but cannot get them on paper
16. Has trouble coming up with ideas for what to do in play or free time
17. Has trouble concentrating on chores, schoolwork, etc.
18. Does not connect doing tonight's homework with grades
19. Is easily distracted by noises, activity, sights, etc.
20. Becomes tearful easily
21. Makes careless errors
22. Forgets to hand in homework, even when completed
23. Resists change of routine, foods, places, etc.
24. Has trouble with chores or tasks that have more than one step
25. Has outbursts for little reason
26. Mood changes frequently
27. Needs help from an adult to stay on task
28. Gets caught up in details and misses the big picture
29. Keeps room messy
30. Has trouble getting used to new situations (classes, groups, friends)
31. Has poor handwriting
32. Forgets what he/she was doing
33. When sent to get something, forgets what he/she is supposed to get
34. Is unaware of how his/her behavior affects or bothers others
35. Has good ideas but does not get job done (lacks follow-through)
36. Becomes overwhelmed by large assignments
37. Has trouble finishing tasks (chores, homework)
38. Acts wilder or sillier than others in groups (birthday parties, recess)
39. Thinks too much about the same topic
40. Underestimates time needed to finish tasks
41. Interrupts others

42. Does not notice when his/her behavior causes negative reactions
43. Gets out of seat at the wrong time
44. Gets out of control more than friends
45. Reacts more strongly to situations than other children
46. Starts assignments or chores at the last minute
47. Has trouble getting started on homework or chores
48. Has trouble organizing activities with friends
49. Blurts things out
50. Mood is easily influenced by the situation
51. Does not plan ahead for school assignments
52. Has poor understanding of own strengths and weaknesses
53. Written work is poorly organized
54. Acts too wild or "out of control"
55. Has trouble putting the brakes on his/her actions
56. Gets in trouble if not supervised by an adult
57. Has trouble remembering things, even for a few minutes
58. Has trouble carrying out the actions needed to reach goals (saving money for special item, studying to get a good grade)
59. Becomes too silly
60. Work is sloppy
61. Does not take initiative
62. Angry or tearful outbursts are intense but end suddenly
63. Does not realize that certain actions bother others
64. Small events trigger big reactions
65. Talks at the wrong time
66. Complains there is nothing to do
67. Cannot find things in room or school desk
68. Leaves a trail of belongings wherever he/she goes
69. Leaves messes that others have to clean up
70. Becomes upset too easily
71. Lies around the house a lot ("couch potato")
72. Has a messy closet
73. Has trouble waiting for turn
74. Loses lunch box, lunch money, permission slips, homework, etc.
75. Cannot find clothes, glasses, shoes, toys, books, pencils, etc.
76. Test poorly even when knows correct answers
77. Does not finish long-term projects
78. Has to be closely supervised
79. Does not think before doing
80. Has trouble moving from one activity to another
81. Is fidgety
82. Is impulsive
83. Cannot stay on the same topic when talking
84. Gets stuck on one topic or activity
85. Says the same thing over and over
86. Has trouble getting through morning routine in getting ready for school