## CONCEPTUAL REFINEMENT OF THE PHENOMENON OF ADVERSE CHILDHOOD EXPERIENCES

by

### Lisa Maria Krinner

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Approved by:
Dr. Jan Warren-Findlow
Dr. Michele Issel
Dr. Jessamyn Bowling
Dr. Charlie Reeve

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### Abstract

LISA MARIA KRINNER. Conceptual Refinement of the Phenomenon of Adverse Childhood Experiences (Under the direction of DR. JAN WARREN-FINDLOW)

Adverse childhood experiences (ACEs) are stressful and/or traumatic events that happen during the first 18 years of a person's life. Researchers estimate that at least 50% of the U.S. adult population have experienced at least one ACE. Consequences of early traumatic experiences include higher rates of disease in adulthood. ACEs and their effect on later-life outcomes have gained considerable attention in the past 20 years; nevertheless, the research on ACEs lacks a clear conceptual structure. To advance a conceptual understanding of ACEs, this dissertation aimed to identify the role of different dimensions of ACEs, such as timing or frequency, and their relevance for research and practice.

In the first study, I reviewed quantitative, empirical journal articles on ACEs published after the groundbreaking ACE Study in 1998. The goal of this literature synthesis was to provide an overview of the conceptual landscape of ACEs related to different dimensions of adversity. I used a PRISMA methodology to identify articles that assessed at least two of the 10 original ACE domains and at least two ACE dimensions. A standardized data extraction spreadsheet was used to record basic article information and specifics on ACE domains and dimensions. I identified four primary dimensions used for most ACE domains: frequency, timing, perception, and the role of the perpetrator. Additionally, I found several secondary and domain-specific dimensions, which relate to the intensity of the adverse event.

The purpose of the second study was to develop a standardized measurement approach for five ACE dimensions identified in Study 1, related to the 10 original ACE domains. Sixteen

subject matter experts (SMEs) were asked to rate (1) the relative importance of dimensions for the 10 original ACE domains; (2) how dimension items and response options should be worded; (3) how dimension items should be anchored; and (4) how dimensions response options should be ranked based on their intensity. SMEs agreed that the five proposed dimensions are relevant for all except one ACE domain. The proposed wording of dimension items and response options was revised based on survey feedback. Most SMEs agreed that we should anchor participant responses on the adverse event most relevant to the participant. SMEs generally agreed on the ranking of response options in terms of the least to the most impactful response. Based on our results, a new instrument, the ACE dimensions questionnaire (ACE-DQ), was developed which has a minimum of 10 questions (the 10 original ACE domain items) if each domain stem question is answered with "no." If all original ACE domain stem questions are answered with "yes," the new ACE-DQ has a maximum of 48 items.

In the third study, I conducted a cross-sectional online survey using Amazon's MTurk to pilot test the ACE-DQ to determine its predictive validity and compare scoring approaches. I compared ACE exposure as assessed with the ACE index and the ACE-DQ, and their associations with depression outcomes. When using perception weighted ACE-DQ scores, participants had smaller, yet significant odds of reporting depression outcomes compared to the ACE index; thus suggesting that the original ACE index may overestimate the impact of ACEs and the effects of ACEs on depression outcomes. Further, the addition of the comprehensive set of conceptual dimensions to more fully weight participants' experience of adverse events might increase the accuracy of ACE measurement but would also increase participant burden considerably. I recommend including items to assess a person's perception of each adverse event for improved screening efforts and for research focused on cumulative adversity.

To Jan, who has been my mentor throughout my doctoral program and has always encouraged me to do my best, and to my Mom, who has supported me in my academic endeavors across borders and continents.

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### **Chapter 1: Introduction**

Adverse Childhood Experiences (ACEs) are defined as stressful or traumatic events that happen during the first 18 years of a person's life in the confines of a person's home environment or within close relationships (Chapman et al., 2004; Felitti et al., 1998). Researchers estimate, that at least 50% of the US adult population have experienced at least one ACE (Cronholm et al., 2015; Merrick, Ford, & Ports, 2019) meaning that more than half of the US population may be at an increased risk for stress, for developing health-risk behaviors, and for developing chronic physical and psychological health issues. Some researchers found prevalence rates for one or more ACEs as high as 72% (Cronholm et al., 2015).

ACEs seem to cluster, with most people who report one ACE having experienced at least one other ACE (Felitti et al., 1998; P. Nurius, S. Green, P. Logan-Greene, & S. Borja, 2015). In 2016, 46% of U.S. children had at least one ACE, 22% had at least two ACEs, and 10% had at least three ACEs. The 2015 results of the Behavioral Risk Factor Surveillance System (BRFSS) suggest that more than 15% of U.S. adults have four or more ACEs. Prevalence rates of ACEs differ by age, gender, race/ethnicity, and socioeconomic factors. The highest ACE rates were reported in children between the ages of 12 and 17 (56% compared to 46% in children of all ages), with girls reporting higher rates of sexual and emotional abuse (Bethell, Davis, Gombojav, Stumbo, & Powers, 2017). Children of different racial/ethnic groups do not experience ACEs equally. ACE prevalence also varies by state in the U.S., with Minnesota having the lowest and Arkansas having the highest ACE rates (Sacks & Murphey, 2018). Economic hardship and parental separation or divorce are the most common ACEs reported nationally, and in all states (Bethell, Davis, et al., 2017).

### **Consequences of Adverse Childhood Experiences**

A large body of research exists that connects childhood adversity to negative outcomes later in life (e.g. Kalmakis & Chandler, 2015). Experiencing childhood adversity can have physical, emotional, behavioral, socio-economical, cognitive, and epigenetic consequences among others (Berens, Jensen, & Nelson, 2017; Greenfield, 2010; Kalmakis & Chandler, 2015). Consequences of early traumatic experiences include severe mental health issues, low social mobility, social impairments, and higher rates of disease in adulthood (Chapman et al., 2004; Greenfield, 2010; Kessler et al., 2009). For example, those with ACEs are 2 times more likely to suffer from anxiety or depression and are more than twice as likely to rate their overall health as poor (Hughes et al., 2017). Other consequences are reaching a lower education level, and poor overall academic performance, and being more sensitive to everyday stress (Finkelhor, Shattuck, Turner, & Hamby, 2013). Many of these conditions overlap and negatively influence each other (Sheridan & McLaughlin, 2016; Wadsworth, 2015).

Research on ACEs has shown a graded dose-response relationship with various health outcomes – the more ACEs a person has experienced, the higher the number of ailments, the more severe the impact of a condition, the earlier the onset, and the faster the progression of a condition (Merrick et al., 2017; Zarse et al., 2019). Health outcomes that have been consistently related to ACEs in various populations are cardiometabolic disease (Friedman, Montez, Sheehan, Guenewald, & Seeman, 2015; Jakubowski, Cundiff, & Matthews, 2018) and anxiety and depression (Hughes et al., 2017; Kalmakis & Chandler, 2015). Other outcomes have shown a more complicated relationship with ACE, such as alcohol use behaviors (Mersky, Topitzes, & Reynolds, 2013) and physical inactivity (Hughes et al., 2017). A possible origin for the

ambiguity related to certain outcomes is the lack of nuanced details of ACEs assessed in many studies.

### Physical Health

ACEs can make a person more susceptible to various diseases and disorders including cardiovascular disease, diabetes, obesity, cancer, and lower self-rated health (Dimsdale, 2008; Kalmakis & Chandler, 2015; Monnat & Chandler, 2015; Mouton, Hargreaves, Liu, Fadeyi, & Blot, 2016; Yaribeygi, Panahi, Sahraei, Johnston, & Sahebkar, 2017). For example, persons with four or more ACEs have 60% increased odds to be severely obese (BMI ≥ 35) as compared to those with no ACEs (95% CI:1.2–2.1), and the risk for chronic bronchitis or emphysema is increased by nearly 400% (95% CI:2.6–5.8; Felitti et al., 1998). Friedman et al. (2015) suggest that the cardiovascular and the metabolic system might be particularly affected by early adverse experiences, especially those related to the child's environment. In a recent meta-analysis, ACEs were significantly related to cardiometabolic disease in all analyses with a cumulative odds ratio of 1.4 (95% CI:1.3–1.5) for all effects (Jakubowski et al., 2018). A higher number of ACEs is associated with higher rates of all-cause mortality (Elliot, Turiano, Infurna, Lachman, & Chapman, 2018). Those with an ACE score of 6 or higher are at risk of their lifespan being shortened by 20 years compared to those without ACEs (Brown et al., 2009).

### **Emotional Health**

Experiencing ACEs increases the risk for a large variety of mental and emotional disorders (Kalmakis & Chandler, 2015). For example, having four or more ACEs increases the risk for attempted suicide by 2900% (OR: 30.1, 95% CI:14.7–61.7; Hughes et al., 2017). Persons with ACEs have higher rates of depression and anxiety disorders, are more likely to have a negative affect, personality disorders, and substance use disorders (Herzog & Schmahl, 2018; Merrick et

al., 2017; E. Neumann, 2017; Raglan, Schmidt, & Schulkin, 2017). Persons who have experienced ACEs are more likely to be violent, or to be (re)victimized in later intimate relationships (Mair, Cunradi, & Todd, 2012; Taillieu, Davila, & Struck, 2020).

Behavioral/Psychological Health

# Persons who have experienced ACEs have higher rates of deleterious behaviors than persons without ACEs (Espeleta, Brett, Ridings, Leavens, & Mullins, 2018; Kalmakis & Chandler, 2015). Several researchers have shown a relationship between stress and health-related behavior (Nurius, Fleming, & Brindle, 2019; Park & Iacocca, 2014). Maladaptive behaviors such as smoking or substance use, but also social withdrawal and hostility, might be functionally adaptive and can be used to deal with stress and to survive and grow in adverse environments (Wadsworth, 2015). Persons with ACEs are more likely to engage in risky sex practices, substance use, physical inactivity, and an unhealthy diet (Hughes et al., 2017). For example, people with an ACE score of four are twice as likely to smoke (OR 2.2, 95% CI:1.7-2.9) and 7 times more likely to suffer from alcoholism (OR 7.4, 95% CI:5.4–10.2; Felitti et al., 1998). Those with four or more ACEs are almost 4 times as likely to initiate sexual activity early compared to those with no ACEs (OR 3.7, 95% CI:2.9-4.8), a factor that also explains more than 3 times higher odds for teenage pregnancy (OR 4.2, 95% CI:3.0–5.9; Hughes et al., 2017).

In addition to the directly deleterious behaviors, persons with ACEs are also less likely to engage in preventative health behaviors, such as getting screened for certain types of cancer (Mouton et al., 2016), or seeking help for personal and health-related issues (Karatekin, 2018), which puts them at higher risk for various health conditions in later life.

### Socio-economic Status

Persons who have experienced early adversity, especially in form of low childhood socio-economic status (SES), are at greater risk to have low SES in adulthood (McEwen & McEwen, 2017). ACEs decrease the chance to successfully complete higher education (Houtepen, Heron, Suderman, Fraser, & Howe, 2018), and increase the risk of unemployment later in life (Hardcastle et al., 2018). Persons with ACEs are likely to marry and be sexually active at an earlier age, which can lead to unwanted and early pregnancy (Hughes et al., 2017) and create further financial burdens. Similarly, persons with ACEs are likely to have fewer and poorer quality social relationships, less social support, and less social and economic resources in general (Chen, Brody, & Miller, 2017).

### Cognition

Certain ACEs are assumed to be related to aspects of brain development and cognitive functioning (Majer, Nater, Lin, Capuron, & Reeves, 2010; Short & Baram, 2019). For example, children who experience poverty or neglect often show deficits in language ability development (McLaughlin & Sheridan, 2016). This can lead to poor performance in school and affect their longer-term SES. Early-life adversity can also make people more susceptible to cognitive impairments in later life (Short & Baram, 2019). In a large Japanese study on older adults, those with three or more ACEs were almost twice as likely to develop dementia compared to those without ACEs (HR 1.8; 95% CI:1.1-2.7; Tani, Fujiwara, & Kondo, 2020).

### Epigenetic Mechanisms

Increasing attention is given to the effects of early adversity on gene expression. Early adversity can influence gene expression by turning certain genes on or off (Herzog & Schmahl, 2018; Mehta et al., 2013). Persons with ACEs generally have shorter telomeres than persons

without ACEs (Deighton, Neville, Pusch, & Dobson, 2018). Shorter telomere length can make the genes more susceptible to damage and can lead to harmful changes in the DNA (Deighton et al., 2018). Research also suggests that certain epigenetic changes can be transferred intergenerationally and can therefore increase a child's risks for premature morbidity and mortality even before birth (Bowers & Yehuda, 2016). Epigenetic researchers hypothesize that exposure to external risk factors such as ACEs in combination with a genetic predisposition may increase the odds for downstream adverse health outcomes (Schiele et al., 2016).

### Moderating and Mediating Factors for the Effects of ACEs on Health

Researchers have discussed possible intermediate factors on the pathway between ACEs and later-life health, such as coping, resilience, and posttraumatic growth (King et al., 2010; Lev-Wiesel, Amir, & Besser, 2004; Nahum-Shani, Hekler, & Spruijt-Metz, 2015; Veselska et al., 2009). A plethora of other indirectly influencing factors on the development of certain health-related behaviors in response to ACEs have been envisaged, such as social relationships (Umberson, Crosnoe, & Reczek, 2010), race/ethnicity and gender (Barkley, 2008), or different parent characteristics such as parents' social standing, mental health, and health behaviors (Felitti et al., 1998).

Researchers have found differential effects of ACEs in men and women (Friedman et al., 2015). For example, women report higher rates of contact sexual abuse (was touched by or forced to touch, or had intercourse with the perpetrator) than men (25% vs. 16%; Dube et al., 2005). Gender differences vary depending on the ACE domain and the population of interest (Friedman et al., 2015). ACE prevalence and risk factors also differ by race/ethnicity (Bethell, Davis, et al., 2017). Compared to White children, Black children in the U.S. have higher

prevalence rates of one ACE (64% vs. 41%; Bethell, Davis, et al., 2017). Rates are generally lower among Asian non-Hispanic children (Caballero, Johnson, Buchanan, & DeCamp, 2017). ACE prevalence also differs by childhood SES (Bethell, Davis, et al., 2017; Walsh, McCartney, Smith, & Armour, 2019). Children growing up in lower-income families have distinctly higher rates of having experienced one ACE than children of higher SES (62% vs. 26%; Bethell, Davis, et al., 2017). The effects of ACEs do not dwindle with age; for example, the odds for mental disorders are higher in older adults with ACEs compared to those with no ACEs (Raposo, Mackenzie, Henriksen, & Afifi, 2014).

Not everyone who experiences ACEs inevitably has poorer health outcomes later in life (Westermair et al., 2018). One branch of research has focused intently on childhood factors that might buffer the adverse effects of ACEs on health and later-life outcomes (Bethell, Jones, Gombojav, Linkenbach, & Sege, 2019; Crandall et al., 2019). We now understand that childhood adversity is a major social determinant of health (Greenfield, 2010) and that the health of Americans cannot improve until we learn how to prevent ACEs (Biglan, Van Ryzin, & Hawkins, 2017).

### The Conceptual Development of Adverse Childhood Experiences

Most early research related to ACEs focused on isolated experiences of sexual and physical abuse in childhood (Malinosky-Rummell & Hansen, 1993; D. A. Neumann, Houskamp, Pollock, & Briere, 1996; Zarse et al., 2019). Two decades ago, when Felitti and colleagues (1998) conducted the first large-scale study on ACEs, the understanding of childhood adversity shifted and the effects of a larger number of childhood events have gained considerable attention in research. ACEs were introduced into the medical world, and the concept was understood to

include a set of 10 adverse events (Felitti et al., 1998). In these early stages of ACE research, the concept of ACEs included experiences of abuse, neglect, violence, and household dysfunction (Felitti et al., 1998). Since then, the concept has been revised and expanded to include domains such as peer violence and the impact of community-level challenges (Cronholm et al., 2015). More recently, the concept has been further extended to cover more international and culturally inclusive domains such as forced marriage, or experiences of civil unrest or war (World Health Organization, 2020).

Definitions of ACEs vary considerably among studies, and many articles do not include a definition of the childhood adversity-related concept they used in their research. Instead, researchers often merely operationalize ACEs for their research without providing a definition (Centers for Disease Control and Prevention, 2019). The most commonly referred-to aspect of ACEs, if a definition is available, is the age-range ACEs occur in, such as "0-17 years of age" or "before the age of 18." Originally, the term "adverse childhood experiences" described the 10 original ACE-Study domains (Dube et al., 2001; Felitti et al., 1998), while the term "childhood adversity" includes all manner of adverse experiences in childhood. Because of the "concept creep" through which new domains are being added, the concept of ACEs has lost its clear boundaries (Levari et al., 2018). Despite the attempt to unify the language around the phenomenon of childhood adversity, researchers and practitioners use inconsistent terminology to describe potentially harmful experiences in childhood.

While ACEs are mostly operationalized as the experience of adverse events in childhood, several researchers define childhood adversity as the *perception* of these negative events. They emphasize that the child has no control over these events and that they potentially disrupt normal development and may cause harm (Burgermeister, 2007). Scientific disciplines such as

gerontology (Ferraro & Shippee, 2009) have incorporated insights gained from ACE research. However, the different disciplines often use diverse terminology to describe the same set of adverse experiences. Examples of different terms used to describe ACEs are maltreatment (Danese & McEwen, 2012), socioeconomic disadvantage in childhood (Chiang et al., 2016), or early life stress (Kuhlman et al., 2019). The inconsistent use of terminology complicates comparisons of ACE research across disciplines.

### **Assessment of Adverse Childhood Experiences**

The original ACE-Study Questionnaire (Dube et al., 2001; Felitti et al., 1998) assessed 10 single-item ACE domains - or types of adverse experiences, with binary response options (yes/no). These items are then scored creating an index by adding up the number of affirmative responses to determine the cumulative adversities experienced (range 0-10). Researchers have continued to develop the ACE-Study Questionnaire, and have added a number of domains, such as bullying and peer violence, community violence, or war (Cronholm et al., 2015; Finkelhor et al., 2013; World Health Organization, 2020). Other tools omit or revise conventional domains (Campbell, Walker, & Egede, 2016; Zarse et al., 2019), and assess other characteristics, or dimensions, of ACEs, such as the timing or frequency of adverse events (Cronholm et al., 2015; Finkelhor et al., 2013; Friedman et al., 2015; World Health Organization, 2020).

Most research is still focused mainly on the types of ACEs, without considering other aspects of the adverse experiences. (e.g. Hughes et al., 2017). However, the effects that different domains can elicit in a person may depend on a variety of other specific factors, also called dimensions, including the frequency and timing of events, or a person's perception of the event. A few researchers have previously pointed towards the importance of different dimensions of

ACEs (Friedman et al., 2015; McLaughlin & Sheridan, 2016; Ruffell et al., 2016), but no conceptual shift has been proposed and no rigorous efforts have been made to include conceptual dimension in the measurement of ACEs.

Because the assessment of ACEs differs for different populations (e.g., children vs. adults, different cultures) a vast number of assessment tools for ACEs have been developed. Many of these tools are targeted at children (for a detailed review, see Eklund et al. (2018)). In children, the assessment of childhood adversity is intended to prevent negative outcomes of identified ACEs by early implementation of targeted prevention efforts (Bethell, Carle, et al., 2017). (Ferraro & Kelley-Moore, 2003). Childhood adversity assessment in adults aims to promote healing and improve the quality of life for adults with ACEs (Bethell, Carle, et al., 2017; Bryan, 2019) and to further prevent premature mortality which may be due to these manifested effects of childhood adversity. No recent review of available ACE measurement tools for adults exists at this point.

### **Variations Among Adverse Childhood Experiences Assessment Tools**

At this point, a variety of measurement tools for childhood adversity exists. These are for example the Traumatic Experiences Questionnaire (TEQ; Nijenhuis, Van der Hart, & Kruger, 2002) or the Childhood Trauma Questionnaire (CTQ; Bernstein, Ahluvalia, Pogge, & Handelsman, 1997). The ACE-Study Questionnaire (Felitti et al., 1998) is the one measure that most consistently detected a dose-response relationship between ACEs and health outcomes in different populations (Zarse et al., 2019). Despite the various ways in which ACEs are measured, virtually all researchers have found that ACEs adversely affect later-life outcomes in various aspects of a person's life – physically, mentally, and socially. And yet, effects on specific

outcomes differ depending on the assessment tool used in the study. Even though many tools use an unweighted ACE index (i.e., a simple summary score of domains) to determine cumulative adversity, the use of different ACE tools with a varying number of ACE domains makes it difficult to compare research results.

Some researchers have compared different ACE assessment tools in the same population. For example, when assessing a larger number of adverse experiences than in the ACE-Study Questionnaire, ACEs had stronger and more significant correlations with anxiety, depression, somatization, and hostility symptoms (Teicher & Parigger, 2015). In samples of young U.S. adults, different ACE measurement tools resulted in different associations between ACEs and a health outcome. For example, using the ACE Study Questionnaire, (Felitti et al., 1998) found that persons with 4 or more ACEs had 60% increased odds of having diabetes as compared to those with no ACEs (OR 1.6, 95% CI: 1.0-2.5). Using the BRFSS ACE module, a slightly modified version of the ACE-Study Questionnaire omitting physical neglect and including two additional questions on sexual abuse, Bellis et al. (2015) found increased odds of having diabetes by almost three times in persons with four or more ACEs (OR 2.99; 95% CI: 1.90–4.72). Differences in results may have occurred because of variations in the study populations, because of different approaches to measure outcomes, or because of differences in the administration of ACE assessment (survey vs. interview).

Some researchers have used ACE measurement tools which include the assessment of a single dimension, such as age at first occurrence or the relationship to the perpetrator (Kallstrom-Fuqua, Weston, & Marshall, 2004; Loeb, Gaines, Wyatt, Zhang, & Liu, 2011). Such measures are for example the Adverse Childhood Experiences – International Questionnaire (ACE-IQ) which assesses the frequency of most ACE domains (World Health Organization, 2020) or the

Midlife in the United States (MIDUS) stressful life events questionnaire which assesses a person's perception of the impact of adverse events in childhood (Elliot et al., 2018).

### Research Gaps

More than 20 years after the groundbreaking ACE study (Felitti et al., 1998), myriad research studies exist that connect childhood adversity to negative outcomes later in life (Kalmakis & Chandler, 2015). The concept of ACEs has been subject to extensive research; however, conceptualization and operationalization issues persist. There is low agreement on how the concept of ACEs should be defined and hence measured.

To date, ACEs are mostly weighted equally in research with no distinction between different ACE domains. The use of an overall ACE index cannot reflect the impact of individual experiences and "can lead to significant underestimation or overestimation of actual risk" (Anda, Porter, & Brown, 2020, p. 293). Various researchers have examined differences in the effects of certain ACE domains on later-life outcomes (Ajnakina et al., 2018; Friedman et al., 2015; Schilling et al., 2016), and found that certain types of stressors might overall have greater effects on certain mental health outcomes than others (Zarse et al., 2019). Researchers voice their concerns about using a simple equally weighted ACE index for research and practice and call for the development and use of more advanced ACE measurement tools to be able to distinguish between the effects of different ACEs (Anda et al., 2020; Zarse et al., 2019). Westermair et al. (2018) point out, that not all adverse experiences have the same effects on everybody. It is currently unclear, which adverse experiences have the most severe effects on later-life outcomes within the context of cumulative disadvantage and adversity, in which circumstances, and why.

The effects different domains can elicit in a person may also depend on a variety of other specific factors/dimensions, including frequency of event(s), the age of occurrence, and a person's perception/appraisal of the event (see Figure 1). Different theories suggest the need to learn more about the characteristics of adverse experiences. However, theory is rarely used for the development of ACE assessment tools. Simple ACE tools likely overestimate the effects of ACEs because of the way they are constructed and scored (Anda et al., 2020). The assessment of conceptual ACE dimensions provides more information about the characteristics and circumstances of an adverse experience. Yet, no comprehensive effort has been made to review and systematically delineate the full range of dimensions within and across the established ACE domains. No standardized measurement has been developed to assess a larger number of conceptual ACE dimensions in relation to different ACE domains.

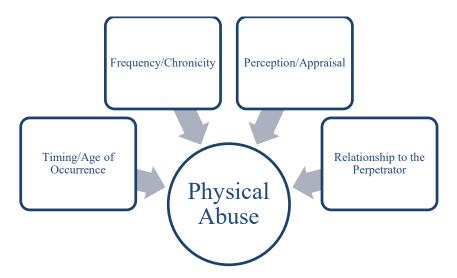


Figure 1.1. Example of Possible ACE dimensions for the ACE domain "Physical Abuse"

### **Theoretical Foundation for Conceptual ACE Dimensions**

Researchers have theorized on the various ways in which ACEs can influence later-life opportunities and health: bio-physiological, socio-psychological, economic, and ecological

(Ferraro & Shippee, 2009). Any of these pathways has the potential to negatively influence later life, and factors from different pathways can occur simultaneously and influence each other (Ferraro, Shippee, & Schafer, 2009). Several theoretical approaches have been used to describe different aspects of the association between childhood adversity and health. To have a better understanding of theoretical mechanisms we need to know more about the characteristics of ACE experiences. Thus, adding items to assess these characteristics, or dimensions, can inform theory development and refinement. Such theories are, for example, the Theory of Cumulative Inequality (Ferraro et al., 2009), which relates to the frequency of events; developmental and life-course frameworks (Ben-Shlomo & Kuh, 2002; P. S. Nurius, S. Green, P. Logan-Greene, & S. Borja, 2015), which relate to the timing of events; the Theory of Stress and Coping (Folkman & Lazarus, 1984), which relates to the perception of events; and Betrayal Trauma (Freyd, 2008) and Attachment Theory (Kwako, Noll, Putnam, & Trickett, 2010), which relate to the role of the perpetrator.

### **Measurement Theory for Scale Development**

In this dissertation project, measurement theory lays the foundation to develop a new, refined measure for ACEs. Scale development is a complex and iterative process (Morgado, Meireles, Neves, Amaral, & Ferreira, 2017). It is imperative to use the appropriate method to measure a construct depending on the nature of the construct so that the measure reflects its true value (Bandalos, 2018). Certain phenomena can be observed and measured directly, while other phenomena require the use of a measurement scale "to attribute scores in some numerical dimension to phenomena" (Morgado et al., 2017, p. 1). The types of ACEs, or ACE domains, are observable, as are some ACE dimensions, such as the timing or frequency of events; they can be

observed or reported directly with more or less effort (Tay & Jebb, 2017). Other ACE dimensions, such as the perception or appraisal of an event, or the closeness to the perpetrator, are unobservable and cannot be measured directly and need to be assessed with a scale (Tay & Jebb, 2017). Developing such a scale can be done by either using a deductive approach to scale development which is based on pre-existing literature or scales, or an inductive approach, based on a collection of qualitative information and opinions (Morgado et al., 2017). The addition of an inductive approach is advised when there is ambiguity in the definition or dimensionality of the construct, as is the case for ACEs (Tay & Jebb, 2017). For this dissertation project, I used a combination of both approaches to develop ACE dimension items for the 10 conventional ACE domains (Dube et al., 2001; Felitti et al., 1998; Morgado et al., 2017). I first performed a research review to determine the state of the literature surrounding the dimensionality of ACEs and to create an initial pool of dimensions items (deductive). Second, I conducted a Delphi study with subject matter experts (SMEs) in the field of ACE research and practice to determine dimension items as an extension to the conventional ACE-Study Questionnaire (inductive).

### **Significance**

This research fills a gap in the literature by examining the value of assessing different conceptual dimensions in the measurement of childhood adversity and its relationship with later-life outcomes, specifically mental health. To advance a conceptual understanding of ACEs, we need to identify the role of different dimensions of ACEs and their importance regarding different ACE domains. The inclusion of ACE dimensions contributes directly to our understanding of various theories that underlie the relationship between ACEs and health

outcomes. Insights gained from this dissertation project are relevant for scientific and practice efforts alike.

### **Concept Dimensionality**

Three studies are used to fill the research gaps identified above. The first study provides an overview of the conceptual dimensions that have been used in ACE research so far. This review lays the foundation for the development (Study 2) and pilot testing (Study 3) of a standardized measurement tool to assess ACE dimensions.

Study 1 fills a gap in the literature by reviewing the use of dimensions in the measurement of childhood adversity. As our theoretical understanding of how ACEs may influence health has evolved, a simple index that measures the different types of ACE experiences is insufficient. A few researchers have pointed towards the importance of different dimensions of ACEs (Friedman et al., 2015; McLaughlin & Sheridan, 2016; Ruffell et al., 2016), but no effort has been made to develop standardized ACE dimensions assessment. Further, it is currently unclear, which dimensions of ACEs are relevant for research and practice. More research on the dimensionality of ACEs is needed to confirm theory and support theory refinement.

Study 2 contributes to the field by developing standardized items to assess different ACE dimensions based on the literature review in Study 1. Including dimensions in measurement will help increase the accuracy of ACE assessment tools to inform decision-making about public health resource allocation. At the same time, it is important to acknowledge that adding items and requesting additional details about adverse experiences may increase participant burden and re-traumatization.

In Study 3, I pilot tested the newly developed dimension items and their relationship with the mental health outcome of depression. This study contributes to the field by examining the predictive value of adding conceptual ACE dimensions. The addition of dimensions to ACE measurement has the potential to increase the scoring complexity of a scale. An increase in accuracy and predictive validity by including dimensions might be offset by the decreased usefulness in the field. In Study 3, I take into consideration the different possible applications of a new ACE dimensions questionnaire – in research and practice – and provide recommendations for the addition of ACE dimensions for different assessment purposes.

### Screening Accuracy

In addition to addressing the theoretical concept ambiguity of ACEs, this study contributes to the psychometric refinement of ACE assessment tools which will eventually lead to greater screening accuracy. Since 2009, nearly all U.S. states have included ACE measures in the BRFSS survey (Centers for Disease Control and Prevention, 2020). Many agencies use the ACE-Study Questionnaire as a convenient screening tool to calculate an ACE score (sum of all ACE domains indicated with "yes") that can predict disease (Anda et al., 2020). As that, most ACE screening tools score the presence of different ACEs based on a dichotomous response (e.g., Felitti et al., 1998) or based on a higher frequency of events (e.g., Bernstein et al., 1997; World Health Organization, 2020) and create an equally weighted index by adding up all affirmative responses. The tools used for statewide screening have low sensitivity and specificity to determine who is or will be affected by the consequences of ACEs and to what extent. Many researchers use this index of cumulative adversity to predict outcomes without considering the potentially different effects of different types of adversity. Even within the same ACE score, individual experiences can vary widely from one person to another (Anda et al., 2020). For example, a person with an ACE score of 1 could have experienced the divorce of their parents, or could have experienced frequent sexual abuse over multiple years by multiple perpetrators. In

addition, while a person might have experienced a certain ACE, they might not consider the effect as negative. An example would be the incarceration of a violent or abusive household member, which would remove a negative influence from a child's life.

With an ACE index, we are merely measuring the average effect of each type of adversity. An unweighted cumulative ACE score cannot speak to the actual effect an adverse experience could have on a person and could influence their later-life outcomes. The authors of the ACE-Study Questionnaire are concerned that the use of the ACE-Study Questionnaire as a screening or diagnostic tool leads to skewed results and an incorrect picture of the people at risk because of the shortcomings of equally-weighted domains (Anda et al., 2020). Screening for ACEs can provide insights into who might have experienced which ACEs and who might be at increased risk for health consequences but does not provide sufficient information to determine who might need interventions most to prevent the consequences of ACEs. The ACE-Study Questionnaire, however, does not distinguish between ACE domains and does not measure factors such as timing, severity, or duration of the adverse events (Zarse et al., 2019). Effects of ACEs on a person's health can differ greatly by the type of ACE experienced, but also depending on the frequency and severity of the experience (e.g., Felitti et al., 1998), and how the person appraises a certain experience. Anda et al. (2020) also point out, that a simple screening tool such as the ACE-Study Questionnaire is not appropriate for use in research.

For persons at risk of having adverse downstream outcomes because of ACEs, it is crucial to further assess details about their experiences and how they affect their life so we can allocate resources in a meaningful way and tailor treatment to specific resources. At this point, only limited casual evidence can be established using screening tools to assess the association between ACEs and health outcomes (Hill, 1965; Trevethan, 2017). More detailed measures are

needed to determine nuances in the effects of ACEs on health. Because of limited public health resources, we need to improve our screening measures so that we can deploy interventions and treatments depending on the dosage of adversity experienced.

### **Study Overview**

It is currently unclear, which dimensions of ACEs are relevant for research and practice and how they can be measured in a meaningful way. The purpose of this dissertation project was to provide a refinement of the concept of adverse childhood experiences and develop and pilot test standardized measurement for a set of five ACE dimensions.

The goal of Study 1 was to provide insight into the relative importance of conceptual ACE dimensions for research and practice. I conducted a scoping review of empirical journal articles on ACEs published after the original ACE-Study in 1998 to summarize the use of dimensions for the 10 original ACE domains. I explored (1) which dimensions have been assessed in relation to the 10 original ACE domains and (2) how these dimensions have been operationalized, measured, and analyzed in health outcomes research. I searched two scientific databases (PubMed and PsycINFO). Of 15,417 articles in our initial search, 61 articles met all selection criteria for this review. I used a standardized data extraction spreadsheet to keep record of the article information. Extracted data include specifics on ACE domains and the dimensions discussed and measured in the final sample of articles. In addition to the ACE-related information, I recorded the article type, the sample and setting, the outcome of interest, and other basic article information.

In <u>Study 2</u>, I aimed to develop a standardized set of dimension items that can be added to the 10-item ACE-Study Questionnaire, as a foundation for future research in the field. I used a

Delphi method to establish face validity regarding five different conceptual ACE dimensions identified in Study 1. I collected data via 2 rounds of Qualtrics survey. Subject matter experts (SMEs) in the field of ACEs were asked to determine (1) the relative importance of dimensions for the 10 original ACE domains; (2) how dimension items and response options should be worded; (3) how dimension items should be anchored; and (4) how dimensions response options should be ranked based on their intensity.

Lastly, the goal of <u>Study 3</u> was to pilot test the newly developed dimension items with regards to their predictive value for different depression outcomes. I conducted a cross-sectional online survey using Amazon's MTurk to collect data on the ACE-Study Questionnaire and the newly developed ACE dimension items, mental health outcomes, health behaviors, and demographics. I explored the characteristics of four different scoring approaches for the ACE dimension items. Finally, I compared the predictive value of ACE measurement with and without the inclusion of conceptual dimensions and their association with depression outcomes. I conclude by providing recommendations for the inclusion of conceptual dimensions in the assessment of ACEs for research and practice.

# Chapter 2: The Dimensionality of Adverse Childhood Experiences: An Analysis of ACE Dimensions Measurement

**Objective.** Adverse childhood experiences (ACEs) have been subject to extensive research. However, the concept of ACEs is not fully developed and there is low agreement on how the concept is defined, and hence measured. The purpose of this study is to identify the different dimensions of ACEs, such as timing or frequency, determine the frequency of assessment and analysis of these dimensions, and summarize how they have been operationalized to this point, to further advance the conceptual understanding of ACEs.

**Methods.** We conducted a scoping review of empirical journal articles on ACEs published after the original ACE Study in 1998 to provide an overview of the use of dimensions for the 10 conventional ACE domains. We used a PRISMA methodology to identify articles assessing at least 2 of the 10 conventional ACE domains and at least 2 ACE dimensions. A standardized data extraction spreadsheet was used to record basic article information as well as specifics on ACE domains and dimensions. **Results.** Of 15,417 articles in our initial search, 61 articles met all selection criteria for this review. We identified four primary dimensions used for most ACE domains: frequency, timing, perception, and the

role of the perpetrator. Additionally, we found a number of secondary and domain-specific dimensions, which relate to the severity of the adverse event.

Discussion. Research on ACEs has increased drastically in the last two decades. We identified the most

common dimensions but these lack standardized phrasing and response options. Future research should

use consensus development techniques to develop standardized measurements for ACE dimensions.

Additionally, more research in form of meta-analyses is needed to determine the predictive value of ACE dimensions for later-life consequences of childhood adversity and to inform theory development and

refinement.

### Introduction

Adverse Childhood Experiences (ACEs) are defined as stressful or traumatic events that happen during the first 18 years of a person's life in the confines of a person's home environment or within close relationships (Chapman et al., 2004; Felitti et al., 1998). In recent analyses, 61% of US adults had one or more ACEs (Centers for Disease Control and Prevention, 2019); thus, more than half of the US population may be at increased risk for stress, developing health-risk behaviors, and developing chronic physical and psychological health issues as a consequence of ACEs. A plethora of other indirectly influencing factors on the development of certain health-related behaviors in response to ACEs have been envisaged, such as social relationships (Umberson, Crosnoe, & Reczek, 2010), race/ethnicity and gender (Barkley, 2008), or different parent characteristics such as parents' social standing, mental health, and health behaviors (Felitti et al., 1998). Another explanation for different outcomes in response to ACEs might be how nuanced ACE characteristics - or dimensions - such as the frequency, duration, or severity of the experienced event, are assessed for analyses. In the literature, the dimensions of ACEs are sometimes referred to as "characteristics" or "aspects" of ACEs (Heidinger & Willson, 2019). ACE dimensions like the duration of the experience and the relationship to the perpetrator have been shown to moderate outcomes of sexual abuse, and are a critical component for later sexual adjustment (Browne & Finkelhor, 1986; Felsher, Derevensky, & Gupta, 2010). Only a few researchers have discussed the importance of different dimensions of ACE (Friedman, Montez, Sheehan, Guenewald, & Seeman, 2015). Research has been conducted on single ACE domains regarding their dimensions, such as age at first occurrence or the relationship to the perpetrator (Kallstrom-Fuqua, Weston, & Marshall, 2004; Loeb, Gaines, Wyatt, Zhang, & Liu,

2011), but no comprehensive effort has been made to review dimensions of established ACE domains.

### Type and Accumulation of Adversity: Status Quo of ACE Measurement

The majority of ACE research focuses on the aggregation of different adverse experiences (Hughes et al., 2017), also called "additive adversity" (Heidinger & Willson, 2019). Most ACE research uses different measurement tools to assess a varying number of ACE domains and then sums experiences for an accumulation index. Researchers either use this index as a continuous score (Friedman et al., 2015), or categorized it to examine a non-linear relationship (Krinner, Warren-Findlow, & Bowling, 2020a, 2020b). Regardless of which assessment and analytical approach is used, many researchers find dose-response patterns between the number of ACEs and negative later-life outcomes (Friedman et al., 2015).

Because of the different number and types of ACEs assessed in research, comparing results from studies is extremely difficult (Hughes et al., 2017). In recent years, researchers have attempted to minimize limitations of established ACE scales by developing new scales or extensions to existing scales to add or rephrase domains or redistribute scoring (Cronholm et al., 2015; Teicher & Parigger, 2015; Turner, Finkelhor, Mitchell, Jones, & Henly, 2020). A different approach to improving the assessment of ACEs is to add concept dimensions to established ACE assessment tools.

### The Theory Behind ACE Dimensions

A number of theoretical approaches have been used to describe different aspects of the association between childhood adversity and health: bio-physiological, socio-psychological,

economic, and ecological (Ferraro & Shippee, 2009). For example, the Theory of Stress and Coping by Lazarus and Folkman (1966) describes an individual's behavioral efforts to deal with stress and adversity. It emphasizes the role of a person's perception of a stressful event and appraisal of available coping resources (Biggs, Brough, & Drummond, 2017). Thus, it is not the stress that affects our health, but our perception and reaction to it (Selye, 1950). Similarly, the Theory of Cumulative Advantage and Disadvantage (CAD), later refined within gerontology as the Theory of Cumulative Inequality (CI; Dannefer, 2003; Ferraro, Shippee, & Schafer, 2009) considers the frequency or chronicity of an adverse event as contributing to the accumulation of disadvantage and inequality (Ferraro & Shippee, 2009). Other coping and resilience theories, on the contrary, suggest the possibility of functional adaptation, if certain events happen to a child repeatedly (Wadsworth, 2015).

### **Problem Statement**

Adverse childhood experiences have gained considerable research attention over the past 20 years. The concept of ACEs, however, is not fully developed and there are various issues with low agreement on how the concept is defined, and hence measured (Aftanas, 1988). Researchers have not established a widely accepted, comprehensive conceptualization of the different dimensions of ACEs. Consequently, there is no widely accepted approach to operationalize ACE dimensions. As our theoretical understanding of how ACEs may influence health has evolved, a simple index of ACE experiences is insufficient, which calls for the inclusion of dimensions.

Furthermore, it is currently unclear, which dimensions of ACEs are relevant for research and practice. It is crucial to develop an understanding of the different dimensions of ACEs and

how they are being assessed and used. These insights will be relevant for the interpretation of research as well as for ACE screening efforts.

### **Significance**

This study will fill a gap in the literature by reviewing the use of different dimensions in the measurement of childhood adversity. Despite the abundance of ACE research conducted in the past 20 years, researchers have not established a widely accepted conceptualization of the different ACE dimensions. A few researchers have previously pointed towards the importance of different dimensions of ACEs, such as frequency, severity, or timing (Friedman et al., 2015; McLaughlin & Sheridan, 2016; Ruffell et al., 2016), but no conceptual shift has been proposed. More research on the dimensionality is needed to confirm theory and support theory refinement. No conclusion can be drawn about the relative impact of different ACE domains without potentially considering these and other concept dimensions.

To advance a conceptual understanding of ACEs, we need to identify the role of different dimensions of ACEs and their importance regarding different ACE domains, contexts, and populations. This study will provide more insight into the relevance of specific dimensions of ACEs on health outcomes by providing an approach to assess more details about the experienced adversity. To our knowledge, no attempt has been to synthesize the knowledge base related to the dimensionality of ACEs, and to advance the conceptual understanding by integrating concept dimensions.

In addition to addressing the theoretical concept ambiguity of ACEs, this study will contribute to the potential psychometric refinement of ACE assessment tools which will eventually lead to greater screening accuracy. For persons at risk of having adverse downstream

outcomes because of ACEs, it is crucial to assess details about their experiences and how they affect their life so we can allocate intervention and treatment resources in a meaningful way.

### **Aims and Objectives**

The goals of this study were to conduct a scoping review to provide an overview of the conceptual landscape of adverse childhood experiences. Specifically, we examined the various dimensions of ACEs and how these are operationalized, to provide insight into the relative importance of these dimensions for research and practice.

### **Research Questions**

By conducting this research synthesis, we aimed to answer the following questions:

- 1. Which dimensions of ACEs have been discussed in research so far for the 10 conventional ACE domains?
- 2. Which and how many of these dimensions have been assessed and analyzed in health research?
- 3. How are these dimensions measured?

### Methods

We used the scoping review approach developed by Arksey and O'Malley (2005) which includes the following five steps: (1) identify the research question(s), (2) identify relevant studies, (3) study selection, (4) charting the data, and (5) collating, summarizing, and reporting the results. Scoping reviews are useful for synthesizing the literature on complex concepts that have no clear boundaries; they are particularly useful "when a body of literature has not yet been comprehensively reviewed" (Peters et al., 2015, p. 141), as is the case with ACE dimensions.

To be included for data extraction, articles had to 1) include one or more quantitative

assessment tools including <u>at least two</u> of the 10-item conventional ACE domains of the participant (as opposed to parents' rating of their abusive behavior towards their children) and 2) discuss the implications of <u>at least two</u> conceptual dimensions to enable us to evaluate the effects of ACEs beyond a simple index of ACE domains. These five steps are described in detail below.

## (1) Identifying the Research Questions

Several empirical articles point out gaps in the literature and laid the foundation for developing the problem statement of the present study (e.g., Friedman et al., 2015). Prior research on ACEs (Krinner et al., 2020a, 2020b) and the consulting of several literature reviews on ACEs have informed the development of our research questions.

## (2) Identifying Relevant Studies

We used a PRISMA methodology for the article review and selection process (http://www.prisma-statement.org/). Two scientific databases (PubMed and PsycINFO) were used to search for articles using a combination of the search terms "adverse childhood experiences," "child," "abuse," and "dimensions" with variations. We applied a-priori exclusion criteria to filter results for English language, peer-reviewed, empirical journal articles on adults. The concept of ACEs has been introduced in 1998 to describe and examine the effects of multiple adverse events during childhood. We limited our search to articles published after 1998 and focused on the 10 conventional ACE domains by Felitti et al. (1998).

## (3) Study Selection

EndNote X9 (The EndNote Team, 2013) was used as a data repository. The first author extracted the resulting articles from both databases into a combined EndNote library and screened the results for duplicates (automatically and manually). She reviewed the titles, abstracts, and article information provided in EndNote for the remaining articles to exclude those

articles that do not fit the inclusion criteria. Articles were excluded based on the following criteria (in order):

- research on populations outside the continental U.S. or Canada: the understanding of ACEs
  is context and culture-bound. Therefore, we focused on reviewing studies from the U.S.
  and Canada only;
- 2) review articles or meta-analyses;
- 3) documents other than journal articles;
- 4) qualitative and/or mixed-method studies;
- 5) research not related to the 10 conventional ACEs, or articles that included no ACE assessment (for example, research on bullying, elderly abuse, or hemispheric neglect after stroke);
- 6) research on under-18 populations;
- 7) other research related to ACEs but not relevant for this review (for example, studies that do not include retrospective ACE assessment, research on single ACE domains or other aspects of ACEs).

After the title/abstract review, the first author retrieved and reviewed the full texts of the remaining articles to determine the final sample of articles for data extraction. If not enough information was available in the article, source/referenced articles were consulted.

For ACE domains represented in less than 5 articles and those that were not represented in the final data extraction sample, we conducted additional searches by using the same search strategy as described under (2). None of these search strategies identified relevant studies that fit inclusion criteria.

To increase the rigor of the article selection process, a second reviewer verified the article exclusion at the title/abstract and the full-text review stage based on a 1% and 2% random sample of excluded articles, respectively. We calculated percent agreement, all articles with disagreements were discussed between the two reviewers until full consensus was reached.

## (4) Charting the Data

We used a standardized data extraction spreadsheet to keep record of the article information. Extracted data include specifics on ACE domains and the dimensions discussed and measured in the final sample of articles. In addition to the ACE-related information, we recorded the article type, the sample and setting, the outcome of interest and other basic article information.

## (5) Collating, Summarizing, and Reporting the Results

We provide information on basic article information including sample size distribution, gender distribution, and outcomes of interest. To answer the research questions, we synthesized the extracted data to summarize how ACE dimensions are defined and measured in the literature. For each of the 10 conventional ACE domains, we analyzed how many and which dimensions were assessed. Further, we compared how dimensions were assessed and analyzed across domains and across articles. We provide recommendations for the inclusion of certain dimensions in future ACE measurement based on evidence found in this review. Finally, we discuss the implications of certain ACE dimensions for health research and practice.

#### Results

# **Identification and Selection of Articles**

We used a PRISMA methodology for the review and selection process, see Figure 1 for a PRISMA diagram. To be ultimately included for data extraction, articles had to include the assessment of at least 2 ACE domains and at least 2 ACE dimensions. Our initial database search yielded 15,417 articles (PubMed: 8,984; PsycINFO: 6,433); 3,411 of these articles were duplicates and were removed.

*Title/abstract review*. Abstracts, titles, and EndNote article information of the remaining 12,006 articles were screened. We excluded 91.6% of articles (10,994 articles) based on the exclusion criteria described above.

Title/abstract exclusion verification. A random 1% sample of title/abstract excluded articles (n=110) was confirmed by a second researcher to determine if the articles should be "definitely included," "definitely excluded," or "not sure." We reached 99.1% agreement in the title/abstract exclusion verification of 110 articles. Five articles marked as "not sure" by the second reviewer were discussed and excluded after inspecting the full-text article. One initially excluded article was added back to the sample, yielding a total of 1,013 articles for full-text review.

*Full-text review*. Of these 1,013 articles, 91% (922 articles) were excluded based on the exclusion criteria. Of these, 47% (433 articles) articles mention the assessment of only one dimension (391 frequency, 28 timing, 5 severity, 8 perception, 1 perpetrator).

Full-text exclusion verification. A random 2% sample of full-text excluded articles (n=23) was confirmed by a second researcher to determine if the articles should be "definitely included," "definitely excluded," or "not sure." We reached 100% agreement on the full-text exclusion.

Data extraction. Of the 91 remaining articles, we excluded 21 references due to insufficient information about the assessment of ACE domains or dimensions in the article or source articles. Nine more articles were scale development or validation studies where no data on an outcome was collected, leaving a final sample of 61 articles for data collection.

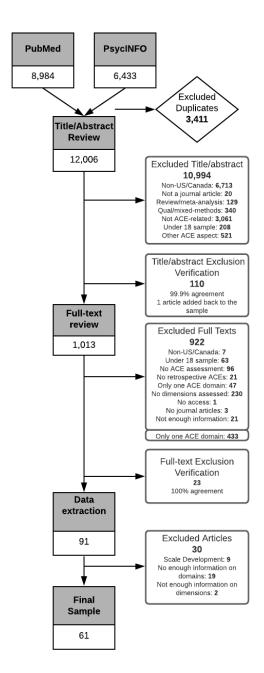


Figure 2.1. PRISMA Diagram for the Selection of Empirical Research Articles on Adverse Childhood Experiences

Dimensions

# **Basic Article Description**

Of the 61 articles, 44% (27 articles) had all-female and 18% (11 articles) had mostly female samples; only 1 article had an all-male sample (Clancy et al., 2006). Other articles were

more-or-less balanced or had slightly more male participants. Three-fourths (47 articles) used original or adapted scales to assess ACEs, while 28% (18 articles) used independent ACE items or combined a limited number of items taken from different scales. Sample sizes ranged from 36 to 68,505 participants, with more than half of the articles (56%; 34) having between 100 and 1,000 participants.

Most studies (79%; 48) recorded results in the expected direction (with varying significance levels), with a higher number of reported ACEs leading to higher levels of impairment in adulthood. Seven articles (11%) had diverging results; only 2 articles had results that indicated no association between ACEs and the outcome of interest (Mason, Prescott, Tworoger, De Vivo, & Rich-Edwards, 2015; Sokol et al., 2019). These articles assessed 2 and 3 dimensions, respectively. Other articles were exploratory in nature or had no unidirectional hypotheses.

The majority of articles (61%; 37) assessed the effects of ACEs on a psychological outcome, such as symptoms of depression (B. E. Carlson, McNutt, & Choi, 2003; Dunn, McLaughlin, Slopen, Rosand, & Smoller, 2013; Wise, Zierler, Krieger, & Harlow, 2001) or post-traumatic stress (Ogle, Rubin, Berntsen, & Siegler, 2013; Ogle, Rubin, & Siegler, 2014) (DeTore, Gottlieb, & Mueser, 2019). One-fifth (13 articles) assessed physical health outcomes, such as preterm birth (Selk, Rich-Edwards, Koenen, & Kubzansky, 2016), or urologic symptoms (Link, Lutfey, Steers, & McKinlay, 2007; Schrepf et al., 2018). Thirteen percent (8 articles) assessed biological correlates of ACEs, such as serotonin and cortisol indices (Orta et al., 2020; Steiger et al., 2004; Steiger et al., 2001) or leukocyte telomere length (Mason et al., 2015; Mayer et al., 2019). Other articles assessed behavioral (8%; 5) and cognitive (3%; 2) outcomes. Four articles (6%) assessed more than one outcome type (Evans, Steel, Watkins, & DiLillo, 2014;

McNutt, Carlson, Persaud, & Postmus, 2002; O'Rinn, Lishak, Muller, & Classen, 2013; Plichta & Falik, 2001).

## **ACE Domains**

In the following section, we summarized findings for each of the 10 conventional ACE domains using the order they are assessed in the ACE Study Questionnaire (Felitti et al., 1998). Articles included in our data analysis assessed 2 to 6 conventional ACE domains (mean (SD) = 3.0 (1.2)). The most commonly assessed domain was physical abuse (61 articles), followed by sexual abuse (55 articles; Figure 2).

In additional searches of online databases for domains represented in less than 5 articles (parental separation/divorce and household substance use) and those domains that were not included in our final sample (household substance use and household member incarceration), we did not identify relevant articles which met our selection criteria.

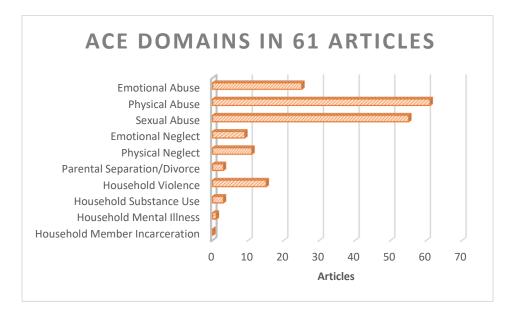


Figure 2.2. ACE Domains Assessed in the Final Sample of 61 Articles

Table 1 presents the proportion of articles assessing each domain as well as the dimensions assessed and analyzed for each domain. Based on the dimensions we identified for each domain across articles, we categorized dimensions into three groups: primary dimensions, secondary dimensions, and domain-specific dimensions (described in detail below). Primary dimensions are those assessed most consistently across domains (8 of 10 domains). Secondary dimensions (assessed for 3-5 domains) are disclosure, duration/chronicity, if an injury resulted from the abuse, and author-rated severity. Other dimensions are domain-specific and mostly relate to nuances of the severity of the traumatic experience. Across domains, the dimensions frequency and timing were assessed most frequently.

Domains used in % of articles (n)	Emotional Abuse 41% (25)	Physical Abuse 100% (61)	Sexual Abuse 90% (55)	Emotional Neglect 15% (9)	Physical Neglect 18% (11)	Parental Separation/ Divorce 5% (3)	Hhld* Violence 23% (14)	Hhld* Substance Use 5% (3)	Dimension assessed across n Domains
Dimensions			% as	sessed, % anal	vzed of thos	e assessed			
Primary Dimensions Frequency Timing Perception Perpetrator Secondary Dimensions Disclosure Duration Injury Severity (author-	88, 81 56, 50 28, 57 36, 89 12, 67 20, 100	77, 70 67, 68 28, 65 36, 59 6, 50 11, 57 2, 100 28, 100	73, 75 74, 63 27, 67 38, 67 5, 33 14, 63 2, 0 29, 100	89, 88 33, 67 22, 50 33, 67	73, 88 45, 60 18, 50 27, 67 9, 100 9, 100	33, 0 100, 33 100, 33	64, 78 57, 63 36, 100 36, 100 14, 100 7, 100 14, 100	33, 0 33, 0 33, 0	8 8 7 7 7 3 5 3 5
rated)  Domain-specific Dimensions Location of the abuse Medical attention was sought Number of times medical attention was received Penetration happened Use of force		2, 100 3, 100 2, 100	5, 100 7, 25				7, 100 7, 100		2 2 1 1
Dimensions assessed per Domain	6	11	10	4	6	4	9	3	

<sup>\*</sup>Hhld=Household; no dimensions were assessed for the domains of Household Mental Illness and Household Member Incarceration

Table 2.1. Total Number of Dimensions Assessed and Analyzed per Domain in the Final Data Extraction Sample of 61 Articles

Domains with the highest number of dimensions assessed across all articles were physical abuse (11 dimensions), sexual abuse (10 dimensions), and witnessing household violence (9 dimensions). While dimensions were described in their respective articles, it was not always clear if or how the dimensions were used in analyses.

## **Dimensions within Domains**

- 1. Emotional Abuse. Twenty-five articles assessed emotional abuse. We found 6 different dimensions assessed, see first column Table 1. Frequency was most commonly used, and duration was the least used. Author-rated severity was used in analyses 100% of the time, followed by frequency and perpetrator. Timing was least frequently used in analyses.
- 2. *Physical Abuse*. Moving to the second column, in the 61 articles that assessed physical abuse, we found 11 different dimensions assessed. Frequency was most commonly assessed. Only one article each assessed the number of times medical attention was sought (B. E. Carlson et al., 2003), the location of the participant at the time of the abuse (Evans et al., 2014), and whether an injury has occurred as an effect of childhood physical abuse (Evans et al., 2014). Author-rated severity, and the domain-specific dimensions were used in analyses 100% of the time. The remaining 7 dimensions were used in analyses between 50 and 70% of the time.
- 3. Sexual Abuse. In the 55 articles that assessed sexual abuse, we found 10 different dimensions assessed. Only 1 article assessed if an injury occurred as a result of childhood sexual abuse (Alvy, Hughes, Kristjanson, & Wilsnack, 2013). Author-rated severity and whether penetration happened was used in analyses 100% of the time, followed by frequency. Injury was not used in analyses.

- 4. Emotional Neglect. Across the 9 articles, we identified 4 dimensions assessed for emotional neglect, see Table 1, fourth column. Frequency was assessed most, and perception was assessed the least. Frequency was used in analyses 89% of the time. The perception of the abuse was assessed in only 2 articles; only 1 article used it in analyses (LaNoue, Graeber, Helitzer, & Fawcett, 2013).
- 5. Physical Neglect. In 11 articles assessing physical neglect, we found 6 dimensions assessed. The dimension analyzed most often is frequency. Duration and severity were assessed in only 1 article (Simeon, Guralnik, Schmeidler, Sirof, & Knutelska, 2001); both dimensions were used in analyses 100% of the time. Perception was used in analyses least frequently.
- 6. Parental Separation/Divorce. Parental separation/divorce is one of the most common adverse childhood events (Jackson, Rogers, & Sartor, 2016). Nevertheless, only 3 articles included the domain of parental separation or divorce. We found 4 dimensions assessed. Timing and perception were assessed in all three articles, and were used in analyses 33% of the time. Frequency and disclosure were assessed in only 1 article; it was not clear if the dimensions were used in analyses.
- 7. Household Violence. In the 14 articles assessing household violence, 9 different dimensions were assessed, see Table 1, column 7. Most commonly assessed was frequency; injury was least commonly assessed. Seven of these dimensions were analyzed 100% of the time; timing was analyzed least frequently.
- 8. Household Substance Use. Only 3 articles included household substance use. We found 3 different dimensions assessed: frequency, timing, and perception. None of these dimensions has clearly been used in analyses (Elliot, Turiano, Infurna, Lachman, & Chapman, 2018).

## **ACE Dimension Characteristics**

When we synthesized ACE dimensions across the domains, we saw some patterns related to use and measurement. Across the 61 articles in our analytical sample, between 2 and 7 ACE dimensions (mean (SD) = 2.9 (1.2)) were assessed. Table 2 provides an overview of the ACE dimension response option formats we found.

Dimensions	Response Option Format
Primary Dimensions	
Frequency	Likert-type scale
Timing	Continuous (age in years) or age categories
Perception	Likert-type scale or categories
Perpetrator	Relationship to survivor or # of perpetrators
Secondary Dimensions	
Disclosure	Dichotomous yes/no
Duration	Continuous (# of years) or dichotomous (acute vs. chronic)
Injury	Likert-type scale
Severity (author-rated)	Subjective rating or calculation
Domain-specific Dimensions	
Location of the abuse	No information
Medical attention was sought	Likert-type scale
Number of times medical attention was received	Continuous
Penetration happened	Dichotomous yes/no
Use of force	Dichotomous yes/no

Table 2.2. ACE Dimension Response Option Formats in the Final Data Extraction Sample of 61 Articles

## **Primary Dimensions**

Frequency was generally assessed on a Likert-type scale, for example as "1 = never true" to "5 = very often true (Berenbaum, Valera, & Kerns, 2003)" or "this never happened," "1 time," to "more than 10 times" (Karmakar, Elhai, Amialchuk, & Tietjen, 2018). A sample item stem wording is "Before your 18th birthday, how often did a parent or other adult caregiver..." (Karmakar et al., 2018). Different scoring approaches were used, such as dichotomous (never versus once or more), categorical (e.g., never, low, moderate, or high frequency), or continuous scoring.

*Timing* was assessed in two ways: (1) by either asking the participant for their age at the time of the event and then dichotomizing for childhood vs. adulthood (Mugavero et al., 2007;

Slopen, McLaughlin, Dunn, & Koenen, 2013) or categorizing as childhood vs. adolescence vs. adulthood (Boynton-Jarrett, Rich-Edwards, Jun, Hibert, & Wright, 2011); or (2) by assessing age categories directly (Bremner, Vermetten, & Mazure, 2000). A sample item wording is "How old were you the first time you experienced…?" (Clarke, Stein, Sobota, Marisi, & Hanna, 1999).

The *perception* of an adverse event, also described as perceived impact or perceived stressfulness (Mayer et al., 2019), was assessed using different approaches across the studies. In one case, by asking the participant how they rate the perceived stressfulness/impact on a scale from 1 (not at all traumatic) to 7 (extremely traumatic; Greenberg, Baron-Cohen, Rosenberg, Fonagy, & Rentfrow, 2018). Perception was also assessed by asking if the event has evoked feelings of intense fear, helplessness, or horror (DSM-IV Criterion A2 for PTSD), for example with the Traumatic Life Experiences Questionnaire (TLEQ; Clancy et al., 2006; Dedert et al., 2009; DeTore et al., 2019). McCaslin et al. (2006) asked their participants to rate how upsetting the event was at the time it happened, and how upsetting the event would have been perceived by an average person. We also found questions about the impact of ACEs during (1) childhood, (2) adulthood, or (3) during the past year (LaNoue et al., 2013; McCaslin et al., 2006), or to what extent participants have experienced abuse (not at all (1), a little (2), some (3), and a lot (4); Kong & Martire, 2019).

Adverse experiences were assessed for different *perpetrators*, e.g., separately for mother and father (Fréchette, Zoratti, & Romano, 2015; Viana & Stevens, 2016) or parental vs. non-parental figures (O'Rinn et al., 2013). For analyses, abuse scores were either summed (Folger & Wright, 2013; Fréchette et al., 2015) or averaged for different perpetrators (Viana & Stevens, 2016). One article asked about the number of perpetrators but not about the relationship with the

perpetrator; the number of perpetrators for any given ACE domain was used to construct a continuous variable (Simoni & Ng, 2000).

## **Secondary Dimensions**

Disclosure of the abuse was assessed related to the domains of physical abuse, sexual abuse, and parental separation/divorce; authors assessed disclosure to medical or legal authorities (B. E. Carlson et al., 2003; McNutt et al., 2002; Schrepf et al., 2018; Soloff, Lynch, & Kelly, 2002) or to anyone else (Loper, Mahmoodzadegan, & Warren, 2008). In two studies, the dimension was incorporated into an overall score, but no details were provided (B. E. Carlson et al., 2003; McNutt et al., 2002). Reasons for non-disclosure are fear from perpetrator threats or further violence (Loper et al., 2008). Generally, only a small number of disclosed cases are followed up by police or social services (Loper et al., 2008).

Several articles included *duration* in their assessment. Duration was either assessed as the number of years over which the ACE occurred (range 0-18; Simeon et al., 2001), calculated as the time between the first and last occurrence of an event (Mayer et al., 2019; Soloff et al., 2002), or assessed as acute (present for a day or two) versus chronic (present for at least one month) events (Mayer et al., 2019). Other authors did not specify how they assessed duration (B. E. Carlson et al., 2003; E. B. Carlson et al., 2001). Simeon et al. (2001) incorporated duration into an overall domain score by multiplying scores for duration, frequency, and severity for each perpetrator. Mayer et al. (2019) compared rates for acute versus chronic stressors lifetime stressors but did not separately analyze acute versus chronic childhood stressors.

*Injuries* were assessed for the domains physical abuse, sexual abuse, and household violence (Alvy et al., 2013; Evans et al., 2014). Alvy et al. (2013) asked participants whether they experienced physical consequences such as pain, cuts/bruises or broken bones compares

following sexual abuse. In analyses, they stratified sexual abuse experiences based on injuries involved (Alvy et al., 2013). Evans et al. (2014) assessed if physical abuse has resulted in "bruises, bloody nose or lip, cuts or scratches," "broken or fractured bones, burns," or "internal injuries, paralysis" (DiLillo et al., 2010, p. 309). This dimension was then incorporated with all other dimensions into "a weighted score reflecting abuse severity" (Evans et al., 2014, p. 5).

In the included articles, the term *severity* either referred to the severity as (1) rated by the authors, such as types of physical abuse in increasing severity from being pushed to being beaten unconscious (e.g., Berenbaum et al., 2003); (2) a score obtained through calculation or factor analysis (Evans et al., 2014); or to the severity of the abuse (3) as perceived by the participant (Mayer et al., 2019; Schrepf et al., 2018). We referred to the latter option as perception/appraisal of the abuse, rather than severity, which was discussed above.

# **Domain-specific Dimensions**

One study assessed the *location of participants* during the act for the domains of physical abuse and household violence (Evans et al., 2014). No further information is provided on the wording, response options, or scoring of this dimension. The original article of the scale used by (Evans et al., 2014) does not include this dimension (DiLillo et al., 2010).

Two articles assessed whether *medical attention was sought* (Evans et al., 2014; McNutt et al., 2002) after physical abuse, sexual abuse, and after household violence. In Evans et al. (2014), this dimension has the response options "no medical attention but had cuts or bruises," "no medical attention but had a black eye or bloody nose," or "received medical attention or had broken bones, internal injuries, or burns" (DiLillo et al., 2010, p. 309). No further details were provided by McNutt et al. (2002).

One article assessed the *number of times medical attention was received* after physical abuse (B. E. Carlson et al., 2003) using items from the Child Maltreatment Interview Schedule (CMIS; Briere, 1992). The question was incorporated into an overall score, but no further information is provided.

Three articles assessed if *penetration* happened during sexual abuse (B. E. Carlson et al., 2003; McNutt et al., 2002; O'Rinn et al., 2013). Sample item wording approaches for the binary assessment are: "Before you were age 17, did an adult ever touch your body in a sexual way or make you touch their sexual parts?" (B. E. Carlson et al., 2003; McNutt et al., 2002), or "Before age, 18, did anyone ever have oral, anal, or vaginal intercourse with you, or insert a finger or object in your anus or vagina when you did not want them to?" (O'Rinn et al., 2013). Two authors incorporated this dimension into an overall score, but neither provides further information as to how (B. E. Carlson et al., 2003; McNutt et al., 2002). Others considered only experiences involving penetration as sexual abuse for their analyses (O'Rinn et al., 2013).

Also related to sexual abuse, 4 articles assessed the *use of force* during the event (Alexander, 2009; Alvy et al., 2013; Berenbaum et al., 2003; O'Rinn et al., 2013). Alexander (2009) considered only experiences involving the use of force (or if the perpetrator was at least 5 years older than the victim) as sexual abuse for analyses. Two authors compared prevalence rates of sexual abuse events in which force had been used versus not, but did not include the dimension in further analyses (Alvy et al., 2013; O'Rinn et al., 2013). Berenbaum et al. (2003) used the information of whether force was used during the abuse to rate the severity of sexual abuse experiences, but do not further specify as to how.

#### **Discussion**

In this scoping literature review, we synthesized the assessment and analysis of conceptual ACE dimensions in empirical ACE literature published after 1998. We found 4 primary dimensions that were used in most ACE domains – frequency, timing, perception, and the role of the perpetrator. These primary dimensions support theories that have been used to discuss ACEs, such as the Theory of Cumulative Inequality (Ferraro et al., 2009), developmental and life-course frameworks (Ben-Shlomo & Kuh, 2002; Nurius, Green, Logan-Greene, & Borja, 2015), the Theory of Stress and Coping (McEwen, 1998), and Attachment Theory (Kwako, Noll, Putnam, & Trickett, 2010). Additionally, we found a number of secondary and domain-specific dimensions, which generally seem to relate to the severity of traumatic events. More research on severity-related dimensions is needed to inform the development of a comprehensive ACE theory.

Articles included in our data extraction sample assessed between 2 and 6 domains; the most commonly assessed domains were physical and sexual abuse. Our search strategy did not reveal sufficient research to examine the domains of parental separation/divorce, household substance use, household mental illness, and household member incarceration, and their dimensions. Independent research has discussed the nuanced effects of e.g. parental separation/divorce (Bohman, Låftman, Päären, & Jonsson, 2017) or household member incarceration (Mowen & Visher, 2016; Wildeman, Goldman, & Turney, 2018) on later-life outcomes. These dimensional insights should be incorporated in future ACE research.

Articles included in our data extraction sample assessed between 2 and 7 ACE dimensions; most frequently assessed were the frequency and timing of adverse events. In a large number of articles, dimensions were assessed but were not used in analyses (e.g., Folger &

Wright, 2013). Several authors stated that they included ACE dimensions in their analyses, but did not explain in detail how the dimensions were incorporated, or how they were used to create an overall score (e.g., Berenbaum et al., 2003; B. E. Carlson et al., 2003). Future research should aim to develop a clearly articulated, standardized approach to assessing and analyzing ACE dimensions.

The operationalization of ACE dimensions varied distinctly between articles. Many authors used Likert-type scales to assess dimensions, which can enhance the reliability of a scale and maximize its statistical power (Majer, Nater, Lin, Capuron, & Reeves, 2010). However, in most articles, the wording of questions and response options differed slightly. Many authors did not provide details on how they operationalized and worded questions on ACE dimensions (e.g., B. E. Carlson et al., 2003). The lack of information and the low consistency in terminology, as was particularly apparent for the dimensions of severity and perception, complicates the psychometric evaluation of ACE domains and dimensions. Costa (2015) points out that it is not necessary to create one generally accepted definition of a certain concept, as long as researchers are clear about what they are researching, and therefore the assessment can be conducted with precision. It is critical, however, that theory is consulted for the conceptualization of all aspects of the phenomenon of childhood adversity. When conducting research on ACEs, researchers should match their terminology and study aims with the theory that is being used to allow for the accurate interpretation of study results.

## **Implications and Future Directions**

Four dimensions seem particularly relevant for the measurement of ACEs: frequency, timing, perception, and the role of the perpetrator. In addition, secondary and domain-specific

dimensions mostly represent nuances of the severity of abuse. We recommend the inclusion of primary as well as severity-related dimensions for every domain. Future research should consider consensus development techniques using subject matter experts in the field of ACE research to develop and validate dimension items for inclusion in ACE measures.

Adding dimensions to the assessment and analysis of ACEs has the potential to improve the predictive validity of ACE measurement. However, further research in form of meta-analyses needs to be conducted to compare the effects of ACEs assessed with and without dimensions. We found several articles that included many dimensions but had small sample sizes (under 100 participants). Future research should aim to use a larger number of ACE dimensions with larger sample sizes to examine the nuanced effects of ACE dimensions on later-life outcomes. The understanding of ACEs is context and culture-bound; hence, we focused on reviewing studies from the U.S. and Canada only. Future research should review the dimensionality of ACEs in other cultures or specific populations.

## **Strengths and Limitations**

This study has several strengths. In this review, we focused on the 10 conventional ACE domains. These domains are the basis for many ACE measurement tools and are widely used in research and practice. With the search terms used to identify relevant literature, we included a wide variety of articles discussing the phenomenon of ACEs. Articles were included from various disciplines. We did not limit our search to specific outcomes; hence, we were able to synthesize literature from a broad knowledge base.

We also note some caveats to this study. We limited our literature search to two databases and to articles published after the original ACE study. A comprehensive review of all literature

related to every ACE domain was beyond the scope of this review. We limited our review to the 10 conventional ACE domains; future research should include a more comprehensive list of ACE domains.

Many authors did not provide sufficient information on the specific items, psychometric details of the measures and/or analytic approaches used in their studies. The low consistency in the use of established scales and the sparse description of study methods make the psychometric evaluation of ACE domains and dimensions nearly impossible. None of the articles in our sample assessed the whole ACE set; our sample mainly focused on physical and sexual abuse, which might skew our results. Lastly, we found only two articles that recorded no association between ACE and their outcome of interest. Publication bias towards positive results might skew the results of this review.

## Conclusion

This study is the first attempt to review a comprehensive list of ACE dimensions for a cumulative measure of childhood adversity. Our findings illustrate the lack of standardization in terminology and measurement of ACE dimensions. More research on the dimensionality of ACEs is needed including a more inclusive list of ACE domains to inform theory development and refinement. Future ACE research should aim to apply a theoretical foundation to the use of terminology. Simultaneously, researchers should match the study aims to theory in order to allow for the accurate interpretation of study results.

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**Appendix 2-A**. Supplement Table 2.1. Article References for the Final Data Extraction Sample of 61 Articles

	nains erences	Emotional Abuse	Physical Abuse	Sexual Abuse	Emotional Neglect	Physical Neglect	Parental Separation/ Divorce	Hhld* Violence	Hhld* Substance Use	Hhld* Mental Illness	Hhld* Member Incarceration	Total
1.	Alexander (2009)	<del>i</del>	х	х	İ		21.0100	x			incur cer ation	3
2.	Alvy, Hughes, Kristjanson, and Wilsnack (2013)		x	x								2
3.	Anderson, Edwards, Silver, and Johnson (2018)		х	Х								2
4.	Babcock Fenerci, Chu, and DePrince (2016)		х	х								2
5.	Babcock and DePrince (2012)	x	х	Х				х				4
6.	Berenbaum, Valera, and Kerns (2003)	х	Х	х	Х	Х						5
7.	Boynton-Jarrett, Rich-Edwards, Jun, Hibert, and Wright (2011)	х	х	х								3
8.	Boynton-Jarrett, Rosenberg, Palmer, Boggs, and Wise (2012)		X	х								2
9.	Boynton-Jarrett et al. (2013)	x	Х	Х								3
10.	Briere, Runtz, Eadie, Bigras, and Godbout (2019)	X	х	Х	Х							4
11.	E. B. Carlson et al. (2001)		х	х		х		x	х	x		6
12.	B. E. Carlson, McNutt, and Choi (2003)		х	х								2
13.	Clancy et al. (2006)		х	х				x				3
14.	Clarke, Stein, Sobota, Marisi, and Hanna (1999)		х	х								2
15.	Dedert et al. (2009)		X	X				X				3
16.	DeTore, Gottlieb, and Mueser (2019)		X	X				x				3
17.	Dunn et al. (2016)		X	х								2
18.	Dunn, McLaughlin, Slopen, Rosand, and Smoller (2013)		х	х								2
19.	Dunn, Nishimi, Powers, and Bradley (2017)	х	х	х				х				4
20.	Dunn, Nishimi, Gomez, Powers, and Bradley (2018)	х	х	х				х				4
21.	Elliot, Turiano, Infurna, Lachman, and Chapman (2018)	x	х				x		х			4
22.	3Eubanks, Kenkel, and Gardner (2006)	х	Х	Х								3
23.	Evans, Steel, Watkins, and DiLillo (2014)		х					х				2
24.	Folger and Wright (2013)	х	Х	Х	Х	Х						5
25.	Fréchette, Zoratti, and Romano (2015)	X	х									2
26.	Grant, Cannistraci, Hollon, Gore, and Shelton (2011)	х	х	Х	Х	х						5
27.	Cohen, Rosenberg, Fonagy, and Rentfrow (2018)		х	х			x					3
28.	Groleau et al. (2014)		Х	х								2
29.	Groleau, Steiger, Bruce, et al. (2012)	X	х	х								3
30.	Groleau, Steiger, Joober, et al. (2012)	х	х	Х								3
31.	Heyman and Slep (2002)		х					x				2

	nains	Emotional Abuse	Physical Abuse	Sexual Abuse	Emotional Neglect	Physical Neglect	Parental Separation/	Hhld* Violence	Hhld* Substance	Hhld* Mental	Hhld* Member	Total
	erences						Divorce		Use	Illness	Incarceration	
32.	Hyun, Friedman, and Dunner (2000)		x	X								2
33.	Karmakar, Elhai, Amialchuk, and Tietjen (2018)		х	х		х						3
34.		х	х	х	х	х		х				6
35.		х	х	х								3
36.		Х	х	х								3
37.	Tworoger, De Vivo, and Rich- Edwards (2015)		х	х								2
38.	Mayer et al. (2019)	X	x	X								3
39. 40.	McCaslin et al. (2006) McNutt, Carlson,	X	x x	x x	x	х						5
	Persaud, and Postmus (2002)			^								
41.	Miller-Perrin, Perrin, and Kocur (2009)	х	х									2
42.	Mugavero et al. (2007)		х	х								2
43.	Nugent, Koenen, and Bradley (2012)	х	Х	х								3
44.	Muller, and Classen (2013)	X	х	х								3
45.	Berntsen, and Siegler (2013)		х	х				х				3
46.	Siegler (2014)		x					х				2
47.	Orta et al. (2020)		x	X								2
48.	Plichta and Falik (2001)		х	х								2
49.	Schaefer, Howell, Schwartz, Bottomley, and Crossnine (2018)		х	х								2
50.	Schrepf et al. (2018)		x	X			X					3
51.	Selk, Rich- Edwards, Koenen, and Kubzansky (2016)	х	х	х	х	х						5
52.	Simeon, Guralnik, Schmeidler, Sirof, and Knutelska (2001)	Х	х	х		х		х				5
53.	Simoni and Ng (2000)		x	х								2
54.	Slopen, McLaughlin, Dunn, and Koenen (2013)		х	х								2
55.	Sokol et al. (2019)		X	X		X						3
56.	Kelly (2002)		х	X								2
	Steiger et al. (2004)	х	X	X								3
58.	(2001)		X	X								2
59.	Rosenberg (2013)		x	X								2
60.	Krieger, and Harlow (2001)		х	Х								2
61.	and Del Castillo (2009)	X	х	Х	Х	х			Х			6
ψT T1. 1	Total Article n d=Household	25	61	55	9	11	3	14	3	1	0	

# Chapter 3: Reimagining the Measurement of Adverse Childhood Experiences: A Delphi Study to Develop Standardized ACE Dimension Items

The latest research on adverse childhood experiences (ACE) has identified a number of conceptual dimensions that have been used in relation to ACEs, such as the timing or frequency of adverse events. However, there is little consistency in the way ACE dimensions are worded, assessed, and analyzed. The purpose of this study was to develop a standardized measurement approach for five common ACE dimensions related to the 10 original ACE domains. We used a Delphi method to establish face validity regarding five different conceptual ACE dimensions identified in previous ACE research. We collected data via 2 rounds of Qualtrics survey. Sixteen subject matter experts (SMEs) were asked to determine (1) the relative importance of dimensions for the 10 original ACE domains; (2) how dimension items and response options should be worded; (3) how dimension items should be anchored; and (4) how dimensions response options should be ranked based on their intensity. Responses to each survey round were aggregated and a summary was sent to the SMEs for feedback. SMEs agreed that the five proposed dimensions are relevant for all except one ACE domain. We revised the proposed wording of dimension items and response options based on survey feedback. Most SMEs agreed that we should anchor participant responses on the adverse event most relevant to the participants. SMEs generally agreed on the ranking of response options in terms of the least impactful to the most impactful response. Rankings of moderate impact response options were less consistent, and some response options within a dimension were rated to have a similar impact on later-life consequences of ACEs. The field of ACEs is complex and not clearly defined. SMEs had a wide variety of opinions regarding ACE dimensions and how they should be measured. More research is needed to quantitatively evaluate different dimension scoring approaches and to develop an overall ACE

dimensions score. Researchers might consider using a similar Delphi approach focused on individual ACE domains to develop a more specific dimension assessment approach.

#### Introduction

Well over half of the US adult population has experienced childhood adversity (Cronholm et al., 2015; Merrick, Ford, & Ports, 2019). Adverse childhood experiences (ACEs) are a significant contributor to various negative health outcomes in later life (e.g. Kalmakis & Chandler, 2015) including cardiometabolic disease (Friedman, Montez, Sheehan, Guenewald, & Seeman, 2015; Jakubowski, Cundiff, & Matthews, 2018), and anxiety and depression (Hughes et al., 2017; Kalmakis & Chandler, 2015). In a recent meta-analysis, ACEs were significantly related to cardiometabolic disease in all analyses with a cumulative odds ratio of 1.4 (95% CI:1.3–1.5) for all effects (Jakubowski et al., 2018). Having four or more ACEs increases the risk for attempted suicide by 2900% (OR: 30.1, 95% CI:14.7-61.7; Hughes et al., 2017). Research shows a graded dose-response relationship of ACEs with various health outcomes – the more types of ACEs a person has experienced, the higher the number of ailments, the more severe the impact of a condition, the earlier the onset, and the faster the progression of a condition (Merrick et al., 2017; Zarse et al., 2019). However, some outcomes have shown a more complicated relationship with ACE, such as alcohol use behaviors (Mersky, Topitzes, & Reynolds, 2013) and physical inactivity (Hughes et al., 2017).

## **Assessment of Adverse Childhood Experiences**

The original ACE-Study questionnaire (Felitti et al., 1998) assesses 10 types of ACEs, or ACE domains (e.g., physical abuse, household violence) with binary response options (yes/no); an ACE index is created by adding up the number of affirmative responses to determine the cumulative number of adversities experienced. Researchers have continued to develop the concept of ACEs, and revised original domains (Campbell, Walker, & Egede, 2016; Zarse et al.,

2019) or added new domains, such as bullying and peer violence, community violence, or war (Cronholm et al., 2015; Finkelhor, Shattuck, Turner, & Hamby, 2013; World Health Organization, 2020). A simple index of binary ACE exposures is particularly convenient for screening purposes. Screening for ACEs can provide insights into who might have experienced which ACEs and who might be at increased risk for health consequences. It does not, however, provide sufficient information to determine who might have the highest need for treatment and intervention to prevent the longer-term consequences of ACEs. Anda, Porter, and Brown (2020) also point out, that a simple screening tool such as the ACE-Study questionnaire is not appropriate for use in research.

Effects of ACEs on a person's health can differ greatly by the type of adversity experienced, but also depending on other factors such as the frequency and severity of the experience (e.g., Felitti et al., 1998), or how the person appraises a certain experience. The ACE index does not provide information about these nuances of adverse experiences. For example, a person who has experienced repeated severe child sexual abuse through multiple perpetrators is categorized as having 1 ACE, and would therefore fall into a "low trauma" category (Monnat & Chandler, 2015), when in reality this person has experienced severe childhood adversity. We need to assess more details about adverse experiences to determine the extent of adversity experienced (Zarse et al., 2019). This can be achieved by assessing ACE dimensions, such as the frequency or timing of an adverse event.

## **Refining the Assessment of ACEs**

In recent years, researchers have voiced their concerns about the simplistic assessment of ACEs using the existing index measure (Anda et al., 2020). An ACE index measure weighs each

type of experience equally and does not allow for meaningful interpretation of the effect of the experience, nor does it take into account other aspects of the experience.

Because of limited public health resources, we need to improve our ACE assessment tools so that we can deploy interventions and treatments to those most in need, which depends on the intensity and effect of adversity experienced. Including the exposure dimensions of ACEs will be helpful in increasing the accuracy of ACE assessment tools to inform decision-making about public health resource allocation, and to increase the understanding of the downstream effects of experiencing childhood adversity. At the same time, it is important to acknowledge that adding items and requesting additional details about adverse experiences may increase participant burden and trauma.

#### **Problem Statement**

A recent scoping review of ACE dimensions (Krinner Dissertation Paper 1) identified 4 primary dimensions discussed for at least 8 of the 10 original ACE domains – frequency, timing, perception, and the role of the perpetrator. Additionally, a number of secondary and domain-specific dimensions were found, which generally relate to the intensity of traumatic events (Krinner Dissertation Paper 1). However, there was little consistency in the way ACE dimensions were worded, assessed, and analyzed. Many authors did not provide details on how they operationalized and worded questions on ACE dimensions. The lack of information and the high variability in terminology complicates the psychometric evaluation of ACE domains and dimensions.

## **Aims and Objectives**

It is currently unclear, which dimensions of ACEs are relevant for research and practice, and how they can be measured in a meaningful way. The goal of this study was to develop a set of dimension items that can be added to the 10-item ACE-Study questionnaire, as a foundation for future research in the field.

In this study, we addressed the following research questions:

- 1. What is the relative importance of different conceptual dimensions for each of the 10 original ACE domains?
- 2. How should these dimensions be operationalized and worded?
- 3. Should we anchor participants to a specific adverse event (first/most severe/most meaningful), or should we assess all adverse events?
- 4. How should the dimension response options be ranked based on their intensity and impact on later-life outcomes?

## **Measurement Theory for Scale Development**

Scale development is a complex and iterative process (Morgado, Meireles, Neves, Amaral, & Ferreira, 2017). Not all phenomena can be observed and measured directly (Morgado et al., 2017). While many types of adversity are directly observable, we cannot directly observe and measure certain ACE dimensions, such as the perception or appraisal of an event, or the relationship to the perpetrator (Tay & Jebb, 2017). It is imperative to use the appropriate method to measure a phenomenon based on its observability so that the measure reflects the phenomenon's true value (Bandalos, 2018). This can be done by either using a deductive approach to scale development, which is based on pre-existing literature or scales, or an

inductive approach, based on the collection of qualitative information and opinions (Morgado et al., 2017). The combination of both approaches is advised when there is ambiguity in the definition or dimensionality of the construct, as is the case for ACEs (Tay & Jebb, 2017). With this study, we build on previous research that determined the state of the literature surrounding the dimensionality of ACEs as a deductive approach to identifying existing ACE dimensions used in research (Krinner Dissertation Paper 1). We conducted a Delphi study with subject matter experts (SMEs) in the field of ACE research and practice as an inductive approach to develop a standardized measurement approach for ACE dimensions as an extension to the original ACE-Study questionnaire.

#### **Methods**

# Delphi Approach

We used a Delphi study to develop dimension items for the 10 original ACE domains (Felitti et al., 1998). A Delphi method is ideal to establish face validity in cases where no solid knowledge about a topic exists yet (Avella, 2016; Morgado et al., 2017). Since this specific area of research related to ACEs is rather new, a Delphi approach was most flexible and accommodated the complexity of the new topic. A Delphi method is an iterative process; several rounds of questionnaires are sent out to a group of SMEs. Responses to the questionnaires are synthesized and presented back to the experts for further evaluation with the goal to reach a consensus on a specific topic (RAND Corporation, 2020). SMEs can equally provide their educated opinion to find a solution for a specific problem (Avella, 2016). The final result of this present Delphi study is meant to be a true consensus of the group of SMEs about how the domains and their dimensions should be assessed and ranked for practice and research. The

Delphi method has been adapted and used previously in content validation and scale development (Aazami & Mozafari, 2015; Bauer, Fusté, Andrés, & Saldaña, 2019; Thomas et al., 2020).

#### Recruitment

Initial contact emails with basic study information were sent to 98 SMEs in the field of ACEs. We used the following sampling frames to identify researchers and practitioners: (1) author lists of relevant journal articles and editorial board members from key journals, and (2) the directory of participants in the 2019 American Psychological Association Committee on Children, Youth, & Families Summit "Adverse Childhood Experiences (ACEs): Translation to Action." A follow-up recruitment email was sent out a few days after the initial contact.

We aimed to include experts who either have specific knowledge on a certain ACE domain or who have expertise related to the overall concept of ACEs and surrounding research. Our goal was to include at least one expert with specific knowledge of each of the 10 original ACE domains. Because of language and time restrictions, we limited our search to English-speaking experts. In accordance with Ludwig (1997), who points out that neither a too small nor too large sample is advantageous for the Delphi process, we aimed for a sample of 15 to 20 experts.

# **Data Collection**

We collected two rounds of anonymous questionnaires over the course of three months.

Before the start of data collection, SMEs were asked to sign a non-disclosure agreement via

DocuSign (DocuSign.com). A Qualtrics survey (Qualtrics.com) was generated for each round of

data collection. Participating SMEs received a link to the Qualtrics survey for each round via email with a brief description of the content of the survey and an estimate for how long it will take them to complete the survey. We provided an online consent form on the first page of survey 1. SMEs had the opportunity to provide comments and suggestions regarding each question in both survey rounds, as well as to the survey results summaries. The dimensions, phrasing of the dimension items, and possible dimension response options emerged from a recent scoping review of empirical literature on ACE dimensions published after 1998 (Krinner Dissertation Paper1). SMEs who agreed to participate initially had ten days to complete the survey in each round. We sent out a reminder email after seven days. This study was approved by the university's Institutional Review Board (protocol # 21-0040).

## Round 1 Data Collection

In the first round, we asked three things from the SMEs: (1) which dimensions are relevant for which ACE domain; (2) their level of agreement with the way the dimension items are phrased; and (3) their level of agreement on the dimension response options.

For example, to determine the relevance of the dimension *frequency*, we asked:

The first part of this question relates to the relevance of frequency for each ACE domain with regards to the impact on the individual's later-life outcomes. Please indicate for which domains you consider frequency to be relevant in the table below.

Response options range from "Very irrelevant" to "Very relevant" on a 5-point Likert scale.

To gain feedback on the item wording for the dimension frequency we asked:

Do you agree with the way this question is worded: "How often did the event occur?" Response options range from "strongly disagree" to "strongly agree" on a 5-point

Likert scale. SMEs had the opportunity to provide comments or suggestions on how to rewrite this item.

A sample item related to the wording of response options related to the dimension *perception* is:

In our literature review, we identified two common sets of response options for the frequency of an adverse event. Please indicate which of the two options you think is the superior one, or provide an alternative assessment approach:

- 1) "Never, Once, More Than Once, Frequently, Almost all the time,"
- 2) "this never happened, this happened 1 time, this happened more than once, this happened more than 10 times, this happened more than 20 times," or
- 3) "If neither of the two, please indicate an alternative assessment approach."

  SMEs had the opportunity to provide comments or suggestions on how to rewrite the response options. At the end of survey 1, SMEs provided their demographic information and scientific background.

#### Round 2 Data Collection

In survey round 2, we asked SMEs (1) how we should anchor the dimension items so that participants focus on a specific adverse event, and (2) how we should rank the dimensions response options developed in round 1.

(1) For participants who experienced multiple instances of a given type of ACE, it is necessary to anchor their memory to a specific adverse event within each ACE domain. For example, regarding the dimension of timing, a participant could have experienced physical abuse

at age 4, age 7, and age 16. To facilitate consistent assessment, we asked SMEs' opinions about which specific adverse event a participant should focus on. SMEs were asked:

How should we proceed if a participant would select multiple responses to the dimension questions?

#### Ask them to indicate:

- the FIRST occurrence of the event
- the most SEVERE occurrence of the event
- the most RELEVANT occurrence of the event to them
- the most FREQUENT occurrence of the event or
- ALL occurrences of the event.
- (2) Next, we asked the SMEs to rank the dimension response options for each ACE domain based on their negative impact on later-life outcomes relative to each other. We assessed the ranking of response options for the dimensions of frequency and perception once for all 10 ACE domains, as the ranking likely is the same across all domains. For the dimensions of timing, perpetrator, and intensity, we assessed the ranking of dimension response options individually for each ACE domain. A sample item related to the impact ranking of dimension response options is:

For the dimension of *timing*, please indicate how you would rank the impact of *Emotional Abuse* on later-life outcomes for these age groups on a scale from 1 (*lowest impact*) to 5 (*highest impact*): "0-2yrs, 3-5yrs (*Preschool*), 6-9yrs (*Elementary School*), 10-13yrs (*Middle School*), 14-17yrs (*High School*)."

## **Data Analysis**

We synthesized the quantitative survey responses and the comments to both survey rounds and presented an aggregate summary to SMEs seven days after we closed the surveys. SMEs had ten days to provide comments. We used comments to the survey Round 1 summary to further inform questions in survey 2, and comments on the survey Round 2 summary to inform the development of a scoring approach for the dimension response options.

#### **Results**

#### **Subject Matter Experts**

We invited 98 SMEs from a wide variety of geographic locations in the US and Canada and scientific backgrounds to participate. Sixteen agreed, nineteen declined participation, sixty-three did not respond to our emails. SMEs were between 34 and 80 years old (mean 53 years) and were mostly female (73%). Except for one SME who preferred not to answer, all SMEs indicated that they were White/European American. All SMEs had a PhD (80%) or another terminal degree (JD or MD). Seven SMEs (47%) indicated Psychology as their main field of employment, while others reported Medicine, Public Health, Education, or Nursing. Most SMEs were involved in research (87%) either as a primary occupation or in an academic environment. In addition to general expertise related to ACE, SMEs had specific knowledge on child development, child behavior, child maltreatment, emotional neglect, parental separation/divorce, and parental incarceration.

## **Delphi Round 1 Survey Results**

The Delphi Round 1 focused on (1) which dimensions are relevant for which ACE domain; (2) the level of agreement with the way the dimension items were phrased; and (3) the level of agreement on the dimension response options. Fifteen SMEs responded to the Round 1 survey.

#### Relevance of ACE Dimensions for the 10 Original ACE Domains

In general, there was strong agreement among the SMEs about the relevance of most dimensions for the 10 original ACE domains (see Table 1). One SME commented that "[adding concept dimensions] gets at dosage effect more directly per item than simply adding single category types up." For the dimensions of *frequency* and *perpetrator* within the domain Parental Separation/Divorce, 50% or fewer SMEs selected "*relevant*" or "*very relevant*." We excluded these dimensions from that domain in future surveys, and they do not appear in the final proposed ACE dimensions measure. All other dimensions were identified as "*relevant*" or "*very relevant*" for the remaining domains by a majority of Delphi SME participants (64-100%).

Example SME comments related to the relevance of the dimension of timing are: "[ACEs are] likely to have profound effects if they occurred during the major periods of neurobiological development since all of the emotion and behavioral regulations systems are at maximum organization at the time and provide set points for emergence of psychopathology" and "Infancy/early childhood and early adolescence, periods of heightened neural plasticity, may be especially important."

Dimensions	Frequency	Timing	Perpetrator	Intensity	Perception		
Domains	% S	% SMEs who selected "relevant" or "very relevant"*					
1. Emotional Abuse	92.9	91.7	92.3	100	90.0		
2. Physical Abuse	83.8	91.7	92.3	92.8	90.0		
3. Sexual Abuse	84.6	91.7	92.3	92.9	90.0		
4. Emotional Neglect	85.8	91.7	92.8	92.8	90.0		
5. Physical Neglect	85.7	91.7	84.7	85.7	90.0		
6. Parental Separation/ Divorce	50.0	83.3	38.5	85.7	90.0		
7. Household Violence	92.3	100	84.6	92.9	100		
8. Household Substance Use	100	91.7	88.8	85.8	90.0		
9. Household Mental Illness	91.6	91.7	75.0	92.9	80.0		
10. Household Member Incarceration	83.4	100	84.7	69.3	100		

<sup>\*</sup>only valid responses included

Table 3.1. Agreement on the Relevance of ACE Dimensions for the 10 Original ACE Domains

## **Dimension Item Wording**

The proposed item wording and revised item wording for all dimensions are shown in Table 2. An overall comment by two SMEs related to the wording of items and response options was that we should adjust the wording to a lower literacy level (5-6<sup>th</sup> grade). There was low agreement on the item wording we proposed for each dimension (Table 2). We used SME comments to revise our items. For example, regarding the dimension of perpetrator, one SME commented that "perpetrator assumes they have a pejorative view of the person. You might consider just asking "who did this?"" Another SME pointed out, that "the word perpetrator does not work for all categories [domains] (e.g., incarceration, mental illness, divorce)." Based on these and other comments, we revised the item wording for the dimension of perpetrator from the proposed wording "Who was the perpetrator?" to "Who did this to you?" for the domains Emotional, Physical, and, Emotional Abuse, and Emotional and Physical Neglect, and "Which household member was this?" for the domains Household Violence, Household Substance Use, Household Mental Illness, and Household Member Incarceration. SMEs also pointed out that

with the increased level of detail assessed with our dimensions scale, it is important to frame questions in a way that maintains the power balance between researcher and participant.

	Item Wording					
Dimension	Delphi Round 1 Proposed Item Wording	Agreement*	Revised Item Wording			
Frequency	How often did the event occur?	57.1%	How often did this happen to you?			
Timing	When did the event occur?	50.0%	How old were you when this happened to you?			
Perpetrator	Who was the perpetrator?	35.7%	Who did this to you? (EA <sup>‡</sup> , PA, SA, EN, PN) Which household member was this? (HV <sup>‡</sup> , HSU, HMI, HInc)			
Intensity	How would you rate the severity of the adverse event?	61.5%	Which of these answers best reflects the intensity of the event?			
Perception	How would you rate the perceived stressfulness/impact of the event?	46.2%	Looking back at the event now, what impact did this event have on you?			

<sup>\* %</sup> of SMEs who selected "agree" or "strongly agree" regarding the wording of the item

Table 3.2. Proposed and Revised Wording of ACE Dimension Items

## Wording of Dimension Response Options

In addition to the wording of dimension items, we asked SMEs to provide feedback on the dimension response options we proposed in survey round 1. Response options were the same for all domains for the dimensions of frequency, timing, perpetrator, and perception; response options for the dimension intensity were domain specific. We used SME comments to revise the dimension response options. All proposed and revised response options are presented in Supplement Table 1.

For example, regarding the dimension of timing, most SMEs opted for response options indicating age in a categorical format: 0-2years, 3-5years, 6-9years, 10-13years, 14-17 years.

One SME commented that "you might also consider using anchors like adding which age people tend to be in which [school] grade." Based on this feedback, we revised the response options to

<sup>&</sup>lt;sup>‡</sup>EA=emotional abuse, PA=physical abuse, SA=sexual abuse, EN=emotional neglect, PN=physical neglect, PSD=parental separation/divorce, HV=household violence, HSU=household substance use, HMI=household mental illness. HInc=household member incarceration

read 0-2yrs, 3-5yrs (Preschool), 6-9yrs (Elementary School), 10-13yrs (Middle School), 14-17yrs (High School). Final response options for all dimensions are shown in Table 3.

#### **Round 2 Survey Results**

In Round 2, we asked the SMEs (1) how we should anchor the dimension items so that participants focus on a specific adverse event, and (2) to rank the response options for each dimension based on their intensity relative to each other. Ten SMEs responded to the Round 2 survey.

#### Anchoring of Adverse Events

When asked if we should anchor participants to the first, most relevant, most severe, or most frequent event related to each type of adversity, most SMEs (62.5%) indicated that we should assess the most relevant event. Some proposed the term "meaningful" instead of "relevant." One SME pointed out that assessing the most meaningful adverse event might reduce participants' recall bias: "[...] most relevant makes sense because it's what is most meaningful to the individual. It may also be the one they remember most accurately."

#### Item Ranking Based on Negative Impact on Later-life Health Consequences

We asked SMEs to rank the dimensions response options for each ACE domain based on their intensity relative to each other. Results of the response option rankings are presented in Table 3. SMEs generally agreed on the ranking of response options in terms of the least impactful to the most impactful response. For example, for the dimension of *perpetrator* within the domain Physical Abuse, SMEs rated the response option "A Stranger" as having the lowest

negative impact, and "*Mother/Stepmother*" as having the highest negative impact on later-life consequences of ACEs. Rankings of moderate impact response options were less consistent, and some response options within a dimension were rated to have a similar impact. For example, for the dimension of timing within the domain Physical Abuse, the response options "*0-2 years*," "*6-9yrs (Elementary School)*," and "*10-13yrs (Middle School)*" were rated to have a similar impact on later-life consequences of ACEs.

Domains	Dimension	Item Wording	Lowest Impact	Moderate Impact	Highest Impact
Emotional Abuse	Frequency	How often did this happen to you?	Once	More than once/Sometimes, Frequently	Almost all the time
	Timing	Thinking about your most meaningful experience of this, how old were you when this happened to you?	14-17yrs (High School)	0-2yrs, 3-5yrs (Preschool), 6-9yrs (Elementary School)	10-13yrs (Middle School)
	Perpetrator	Thinking about your most meaningful experience of this, who did this to you?	A Stranger	Father/Stepfather, Other Family Member, Other Adult you knew (babysitter, teacher, family friend etc.)	Mother/Stepmother
	Intensity	Thinking about your most meaningful experience of this, how intense was this event?	Put you down/ humiliated you	Insulted you, called you things like "ugly," "lazy," or "stupid"; Threatened to leave you; Threatened to physically hurt you	Said they hated you or they wish you had never been born
	Perception	Looking back at your most meaningful experience of this, what impact did this event have on you?	Very positive	Positive, Neither positive nor negative, Both negative and positive, Negative	Very Negative
Physical Abuse	Frequency	How often did this happen to you?	Once	More than once/Sometimes, Frequently	Almost all the time
	Timing	Thinking about your most meaningful experience of this, how old were you when this happened to you?	14-17yrs (High School)	0-2yrs, 6-9yrs (Elementary School), 10-13yrs (Middle School)	3-5yrs (Preschool)
	Perpetrator	Thinking about your most meaningful experience of this, who did this to you?	A Stranger	Father/Stepfather, Other Family Member, Other Adult you knew (babysitter, teacher, family friend etc.)	Mother/Stepmother
	Intensity	Thinking about your most meaningful experience of this, how intense was this event?	Grabbed, shook, slapped, pinched, spanked you on bottom with/without object - no injury	Grabbed, shook, slapped, pinched, spanked you on bottom with/without object - minor injury, left me with bruises or marks; Punched, kicked, knocked you down, threw a hard object at you - minor injury, left me with bruises or marks; Punched, kicked, knocked you down, threw a hard object at you - major injury, had to see a doctor or go to the hospital	Hit you with a hard object, choked, beat, burned you, or threatened you with a weapon - major injury, had to see a doctor or go to the hospital
	Perception	Looking back at your most meaningful experience of this, what impact did this event have on you?	Very positive	Positive, Neither positive nor negative, Both negative and positive, Negative	Very Negative

Sexual Abuse	Frequency	How often did this happen to you?	Once	More than once/Sometimes, Frequently	Almost all the time
	Timing	Thinking about your most meaningful experience of this, how old were you when this happened to you?	0-2yrs	3-5yrs (Preschool), 6-9yrs (Elementary School), 14-17yrs (High School)	10-13yrs (Middle School)
	Perpetrator	Thinking about your most meaningful experience of this, who did this to you?	A Stranger	Mother/Stepmother, Other Family Member, Other Adult you knew (babysitter, teacher, family friend etc.)	Father/Stepfather
	Intensity	Thinking about your most meaningful experience of this, how intense was this event?	Exposed your private parts or their private parts to you against your will	Forced you to watch others engaged in sexual acts; Fondled or touched private parts of your body or made you touch theirs against your wishes; Threatened to hurt you or tell lies about you unless you did something sexual with them; Forced oral, anal, or vaginal penetration on you with their fingers or genitals	Forced anal or vaginal penetration on you with objects
	Perception	Looking back at your most meaningful experience of this, what impact did this event have on you?	Very positive	Positive, Neither positive nor negative, Both negative and positive, Negative	Very Negative
Emotional Neglect	Frequency	How often did this happen to you?	Once	More than once/Sometimes, Frequently	Almost all the time
Ü	Timing	Thinking about your most meaningful experience of this, how old were you when this happened to you?	14-17yrs (High School)	0-2yrs, 6-9yrs (Elementary School), 10-13yrs (Middle School)	3-5yrs (Preschool)
	Perpetrator	Thinking about your most meaningful experience of this, who did this to you?	A Stranger	Father/Stepfather, Other Family Member, Other Adult you knew (babysitter, teacher, family friend etc.)	Mother/ Stepmother
	Intensity	Thinking about your most meaningful experience of this, how intense was this event?	Your parents/guardians did not know what you were doing with your free time when you were not at school or work	People in your family did not care about your emotional needs; People in your family did not look out for each other; Your parents/guardians did not understand your problems and worries	You did not feel loved by your family members
	Perception	Looking back at your most meaningful experience of this, what impact did this event have on you?	Very positive	Positive, Neither positive nor negative, Both negative and positive, Negative	Very Negative
Physical Neglect	Frequency	How often did this happen to you?	Once	More than once/Sometimes, Frequently	Almost all the time
- 105000	Timing	Thinking about your most meaningful experience of this, how old were you when this happened to you?	14-17yrs (High School)	0-2yrs, 6-9yrs (Elementary School), 10-13yrs (Middle School)	3-5yrs (Preschool)
	Perpetrator	Thinking about your most meaningful experience of this, who did this to you?	A Stranger	Father/Stepfather, Other Family Member, Other Adult you knew (babysitter, teacher, family friend etc.)	Mother/Stepmother

	Intensity	Thinking about your most meaningful experience of this, how intense was this event?	You did not have enough clothes to wear to keep you warm or protected from the weather and There was nobody to take you to the doctor if you needed it	You had nobody to take care of you and protect you, You did not have enough clothes to wear to keep you warm or protected from the weather, There was nobody to take you to the doctor if you needed it	Your parents/guardians did not give you enough food even when they could easily have done so and Your parents/guardians were too drunk or intoxicated by drugs to
	Perception	Looking back at your most meaningful experience of this, what impact did this event have on you?	Very positive	Positive, Neither positive nor negative, Both negative and positive, Negative	take care of you  Very Negative
Parental Separation/ Divorce	Timing	Thinking about your most meaningful experience of this, how old were you when this happened to you?	0-2yrs	3-5yrs (Preschool), 6-9yrs (Elementary School), 14-17yrs (High School)	10-13yrs (Middle School)
	Intensity	Thinking about your most meaningful experience of this, how intense was this event?	Your parents/guardians separated peacefully and harmoniously	Your standard of living decreased significantly after the separation/divorce of your parents/guardians, Your parents/guardians said bad things about each other and tried to get you on their side, You had to talk to a lawyer or judge during your parents/ guardians' separation/divorce	You lost contact with one parent/guardian after the separation/divorce
	Perception	Looking back at your most meaningful experience of this, what impact did this event have on you?	Very positive	Positive, Neither positive nor negative, Both negative and positive, Negative	Very Negative
Hhld Violence	Frequency	How often did this happen to you?	Once	More than once/Sometimes, Frequently	Almost all the time
, inches	Timing	Thinking about your most meaningful experience of this, how old were you when this happened to you?	0-2yrs <b>and</b> 14-17yrs (High School)	3-5yrs (Preschool), 6-9yrs (Elementary School)	10-13yrs (Middle School)
	Perpetrator	Thinking about your most meaningful experience of this, which household member was this?	Other Family Member	Mother/Stepmother, Other Adult living in your household (e.g., mother's boyfriend, a family friend etc.)	Father/Stepfather
	Intensity	Thinking about your most meaningful experience of this, how intense was this event?	Being called names or having something thrown at - no injury	Being grabbed, pushed, shook, pulled - minor injury; Being slapped, bit, hit with a minor object, threw something, punched, kicked with injury; Being choked, hit with a major object, burned, threatened with a weapon, or misused - major injury	Being killed by another family member
	Perception	Looking back at your most meaningful experience of this, what impact did this event have on you?	Very positive	Positive, Neither positive nor negative, Both negative and positive, Negative	Very Negative
Hhld Substance Use	Frequency	How often did this happen to you?	Once	More than once/Sometimes, Frequently	Almost all the time

	Timing	Thinking about your most meaningful experience of this, how old were you when this happened to you?	0-2yrs	3-5yrs (Preschool), 6-9yrs (Elementary School), 14-17yrs (High School)	10-13yrs (Middle School)
	Perpetrator	Thinking about your most meaningful experience of this, which household member was this?	Other Family Member	Father/Stepfather, Other Adult living in your household (e.g., mother's boyfriend, a family friend etc.)	Mother/Stepmother
	Intensity	Thinking about your most meaningful experience of this, how intense was this event?	A household member was hospitalized/ institutionalized because of substance use	You did not have your daily needs fulfilled because of a household member's substance use (e.g., you did not have enough food), You had to take on additional responsibilities because of a family member's substance use (e.g., you had to take care of your siblings), The substance use of a household member negatively influenced your education	A household member died because of substance use
	Perception	Looking back at your most meaningful experience of this, what impact did this event have on you?	Very positive	Positive, Neither positive nor negative, Both negative and positive, Negative	Very Negative
Hhld Mental Illness	Frequency	How often did this happen to you?	Once	More than once/Sometimes, Frequently	Almost all the time
	Timing	Thinking about your most meaningful experience of this, how old were you when this happened to you?	0-2yrs <b>and</b> 14-17yrs (High School)	3-5yrs (Preschool), 6-9yrs (Elementary School)	10-13yrs (Middle School)
	Perpetrator	Thinking about your most meaningful experience of this, which household member was this?	Other Family Member	Father/Stepfather, Other Adult living in your household (e.g., mother's boyfriend, a family friend etc.)	Mother/Stepmother
	Intensity	Thinking about your most meaningful experience of this, how intense was this event?	Took medication and/or received treatment for mental illness	Attempted suicide, Was institutionalized because of mental illness, Had a mental illness that negatively influenced your education and daily needs, Had a mental illness and did not receive treatment for it	Blamed you for their mental illness
	Perception	Looking back at your most meaningful experience of this, what impact did this event have on you?	Very positive	Positive, Neither positive nor negative, Both negative and positive, Negative	Very Negative
Hhld Member	Frequency	How often did this happen to you?	Once	More than once/Sometimes, Frequently	Almost all the time
Incarceration	Timing	Thinking about your most meaningful experience of this, how old were you when this happened to you?	0-2yrs	3-5yrs (Preschool), 6-9yrs (Elementary School), 14-17yrs (High School)	10-13yrs (Middle School)
	Perpetrator	Thinking about your most meaningful experience of this, which household member was this?	Other Family Member and Other Adult living in your household (e.g., mother's boyfriend, a family friend etc.)	Father/Stepfather	Mother/ Stepmother

Intensity	Thinking about your most meaningful experience of this, how intense was this event?	You experienced any additional adversity you have not experienced before the incarceration of a household member	You witnessed a household member's arrest, You had to move or live with somebody else because a household member was incarcerated, Your standard of living decreased significantly because a household member was incarcerated, Your education was impacted because a household member was incarcerated	You were not able to stay in contact with a household member after they were incarcerated
Perception	Looking back at your most meaningful experience of this, what impact did this event have on you?	Very positive	Positive, Neither positive nor negative, Both negative and positive, Negative	Very Negative

<sup>\*</sup>Hhld=Household

Table 3.3. Final ACE Dimension Item and Response Options Wording and Ranking of Response Options Impact

#### **Establishing ACE Dimension Values**

The ultimate goal of this study is to develop a scale that can be used to evaluate details of ACE exposure by assessing ACE dimensions. We will use the SME rankings of dimension response options to develop a scoring approach for the dimension responses. An example for the response option rating results for the dimension of timing within the domain Physical Abuse is shown in Table 4. SMEs ranked the relative impact of each response option (in this case age category) on a scale from 1 (*lowest impact*) to 5 (*highest impact*). We calculated a weighted average of the proportion of SMEs who selected each impact value for each age category. An example for the response option *0-2 years* is: (.2\*1)+(.2\*3)+(.2\*4)+(.4\*5)=3.6. We used this weighted average to determine dimension response option values for scoring. Supplement Table 2 lists the response options values for all dimensions within each domain.

Relative Impact  Age Categories	1 % of	2 SMEs wh	3 no selecte	<b>4</b> each ra	5 nking	Weighted Average Rankings	Possible Dimension Values
0-2yrs	20		20	20	40	3.6	4
3-5yrs (Preschool)				40	60	4.6	5
6-9yrs (Elementary School)			60	40		3.4	3
10-13yrs (Middle School)		80	20			2.2	2
14-17yrs (High School)	80	20				1.2	1

Table 3.4. Response Options Ranking Results for the Dimension of Timing within the Domain Physical Neglect from 1 (Lowest Impact) to 5 (Highest Impact)

Dimension response option values can then be used to calculate a domain score as well as an overall ACE score. Possible approaches to calculate a domain score are to (1) sum all dimension values within a domain; (2) use a mean dimension value for each domain; or (3) calculate the mean of the dimension values for frequency, timing, perpetrator, and intensity and then multiply it by the participant's perception rating to "weight" it by perception.

We will use psychometric analyses to evaluate these scoring approaches quantitatively in a later study using cross-sectional data. To arrive at an overall ACE dimensions score, we will have to determine if the 10 ACE domain subscores should be added up to a simple sum, or if we should use domain weighting for analyses.

Based on our results, the new ACE dimensions questionnaire (ACE-DQ) has a minimum of 10 questions (the 10 original ACE domain items) if each domain stem question is answered with "no." If all original ACE domain stem questions are answered with "yes," the new ACE dimensions questionnaire has a maximum of 48 items.

#### **Discussion**

The purpose of this Delphi Study was to develop a standardized measurement approach for the five ACE dimensions of frequency, timing, perpetrator, intensity, and perception. We asked SMEs to (1) evaluate the relevance of ACE dimensions for each of the 10 original ACE domains; (2) provide their opinion on how dimension items and response options should be worded; (3) how dimension items should be anchored; and (4) how dimension response options should be ranked based on their negative impact on later-life health outcomes.

## **Research Questions**

Relevance of ACE Dimension: SMEs considered most conceptual dimensions relevant for all 10 original ACE domains. These results of this study support our research objective.

Wording of Dimension Items and Response Options: SME provided feedback on the wording of dimension items, and we revised the items accordingly. For some dimensions, e.g., for the dimension of perpetrator, we created two different item versions for certain domains. This feedback highlights the difference between different dimensions within different domains and supports our goal to design a targeted assessment approach for dimensions within different domains.

Anchoring of Adverse Events: Most SMEs agreed that we should ask participants to focus on the adverse event most meaningful to them. While anchoring can introduce bias in decision-making processes (e.g., Saposnik, Redelmeier, Ruff, & Tobler, 2016), SMEs suggest that asking participants to focus on a specific event will reduce recall bias and ensure consistent answers across dimensions within a domain.

Item Ranking Based on Negative Impact on Later-life Health Consequences: SMEs generally agreed on the ranking of response options for the dimensions of frequency, perpetrator, and perception, and for most intensity items. However, we noticed great variability in the interpretation of the intensity of the negative effects on later-life outcomes of other dimension

response options. These results again support our goal to develop targeted assessment for different dimensions within the domains, as opposed to using a uniform assessment approach for dimensions within each domain.

#### The Complexity of Adverse Childhood Experiences

ACEs are a complex phenomenon including a variety of distinct experiences. The high variability in SME survey responses suggests the difficulty in finding experts familiar with all forms of childhood adversity. We purposefully recruited SMEs to ensure expert knowledge on each of the 10 original ACE domains. As a result, SMEs generally had specialized knowledge on individual domains and had difficulty speaking to the concept of ACEs as a whole.

Based on comments we received on e.g. the association between the time of occurrence of an adverse event, or the role of the perpetrator, it may seem that there is a disconnect between ACE measurement and theory. Concept dimensions such as the relationships between the time of occurrence or the role of the perpetrator and adverse outcomes are directly derived from theory. Theories underlying conceptual ACE dimensions are for example, the Theory of Cumulative Inequality (Ferraro, Shippee, & Schafer, 2009), which relates to the frequency of events; developmental and life-course frameworks (Ben-Shlomo & Kuh, 2002; Dunn, Nishimi, Gomez, Powers, & Bradley, 2018; Nurius, Green, Logan-Greene, & Borja, 2015), which relate to the timing of events; the Theory of Stress and Coping (Folkman & Lazarus, 1984), which relates to the perception of events; and Betrayal Trauma (Freyd, 2008) and Attachment Theory (Kwako, Noll, Putnam, & Trickett, 2010), which relate to the role of the perpetrator. Our results suggest a need to return to the theoretical foundations of ACE dimensions to inform scale development and to conceptually refine ACEs.

## **Implications for Future ACE Research**

Feedback from our SMEs supports our aspiration to include conceptual dimensions in the measurement of ACEs and develop standardized measurement for ACE dimensions. Follow-up research should quantitatively evaluate the scoring of the newly developed ACE-DQ and test its predictive validity against different health outcomes.

As evidence emerges for the relevance of other adverse events in childhood, such as bullying and poverty, we need to review and develop a standardized measurement approach for ACE dimensions for a wider variety of ACE domains. Researchers might consider using a similar Delphi approach focused on individual ACE domains to develop a more specific dimension assessment approach. As we add dimensions to each domain, the scoring will increase in complexity. Moving forward, we will have to consider if any improvement in the scale's predictive validity is going to be offset by decreased usefulness in the field.

#### **Limitations and Strengths**

This Delphi study has a few shortcomings. We were not able to recruit SMEs with specific knowledge of each of the 10 ACE domains. The dimension items we developed in this study are based on North American culture and might not be applicable in other cultures and countries. Based on the variance of specialized SME expertise, we were not able to reach a complete consensus related to all research questions.

This study also has several strengths. A Delphi method is ideal to establish face validity in cases where no solid knowledge about a topic exists yet. Since this specific area of research related to ACEs is rather new, a Delphi approach was most flexible and accommodated the complexity of the new topic. Lastly, we included SMEs from a broad range of disciplines, who

were able to contribute their unique knowledge to this study. Except for one, all SMEs described 4 or more years of experience in the field of ACEs.

#### **Conclusion**

Adverse childhood experiences are a complex phenomenon with low agreement on how they should be defined and hence measured. This Delphi study endorses the relevance of conceptual dimensions for the assessment of ACEs. The lack of consensus on the ranking of dimension details points towards a greater need to return to theory for the conceptual refinement of ACEs. In the present study, we developed a set of dimension items that can be added to the 10-item ACE-Study Questionnaire. Future research is needed to pilot test the new measure and evaluate different scoring approaches for these dimension items.

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**Appendix 3-A:** Supplement Table 3.1. *ACE Dimension Item and Response Options Wording Pre and Post Survey Round 1* 

Dimension		Response Option W	ording
	Domain	Survey Round 1 Proposed Response Options	Revised Response Option Wording
Frequency		(1) Never; Once, More Than Once; Frequently; Almost all the time (2) this never happened; this happened 1 time; this happened more than once; this happened more than 10 times; this happened more than 20 times (3) If neither of the two, please indicate an alternative assessment approach:	Never; Once; Sometimes (EN*, PN, HSU, HMI)/More than once (EA*, PA, SA, PSD, HV, HInc); Frequently; Almost all the time
Timing		(1) Indicate age in years (2) Indicate age category: 0-2yrs; 3-5yrs; 6-9yrs; 10-13yrs; 14-17yrs (3) Other (please specify):	0-2yrs; 3-5yrs (Preschool); 6-9yrs (Elementary School); 10-13yrs (Middle School); 14-17yrs (High School)
Perpetrator		(1) Mother/Stepmother; Father/Stepfather; Other (2) Mother/Stepmother, Father/Stepfather, Other Family Member, an Acquaintance (babysitter, teacher, friend etc.), a Stranger (3) Other (please specify):	Mother/Stepmother; Father/Stepfather; Other Family Member; Other Adult you knew (babysitter, teacher, family friend etc.); A Stranger (EA*, PA, EN, PN)  Mother/Stepmother; Father/Stepfather; Other Family Member; Other Adult living in your home (e.g., mother's boyfriend, a family friend etc.) (HV*, HSU, HMI, HInc)
Intensity	Emotional Abuse	When you were growing up, somebody: Swore at you; Insulted you, called you things like "ugly," "lazy," or "stupid"; Put you down/humiliated you; Said they hated you; Said they wish you had never been born; Threatened to physically hurt you	When you were growing up, somebody: Insulted you, called you things like "ugly," "lazy," or "stupid"; Put you down/humiliated you; Said they hated you or they wish you had never been born; Threatened to leave you; Threatened to physically hurt you
	Physical Abuse	When you were growing up, somebody: Grabbed, shook, slapped, pinched, spanked on bottom with/without object - no injury; Grabbed, shook, slapped, pinched, spanked on bottom with/without object - minor injury, left me with bruises or marks; Punched, kicked, knocked down, hard object thrown - minor injury, left me with bruises or marks; Punched, kicked, knocked down, hard object thrown - major injury, had to see a doctor or go to the hospital; Hit with hard object, choked, beaten, burned, threatened with weapon - major injury, had to see a doctor or go to the hospital	When you were growing up, somebody: Grabbed, shook, slapped, pinched, spanked you on bottom with/without object - no injury; Grabbed, shook, slapped, pinched, spanked you on bottom with/without object - minor injury, left me with bruises or marks; Punched, kicked, knocked you down, threw a hard object at you - minor injury, left me with bruises or marks; Punched, kicked, knocked you down, threw a hard object at you - major injury, had to see a doctor or go to the hospital; Hit you with a hard object, choked, beat, burned you, or threatened you with a weapon - major injury, had to see a doctor or go to the hospital
	Sexual Abuse	When you were growing up, somebody: Exposed their private parts to you or your private parts against your will; Fondled or touched private parts of your body or make you touch theirs against your wishes or when you were asleep; Threatened to hurt you or tell lies about you unless you did something sexual with them; Forced anal or vaginal penetration on you with objects; Forced oral, anal or vaginal penetration on you with their fingers or genitals	When you were growing up, somebody: Exposed your private parts or their private parts to you against your will; Forced you to watch others engaged in sexual acts; Fondled or touched private parts of your body or made you touch theirs against your wishes; Threatened to hurt you or tell lies about you unless you did something sexual with them; Forced anal or vaginal penetration on you with objects; Forced oral, anal or vaginal penetration on you with their fingers or genitals
	Emotional Neglect	When you were growing up: You did not feel loved; You did not feel close to your family members; People in your family did not look out for each other; Your parents/guardians did not know what you were doing with your free time when you were not at school or work; Your parents/guardians did not understand your problems and worries; Your family did not serve as a source of strength and support	When you were growing up: You did not feel loved by your family members; People in your family did not care about your emotional needs; People in your family did not look out for each other; Your parents/guardians did not know what you were doing with your free time when you were not at school or work; Your parents/guardians did not understand your problems and worries
	Physical Neglect	When you were growing up: You had nobody to take care of you and protect you; You had to wear dirty or unfitting clothes;	When you were growing up: You had nobody to take care of you and protect you; You did not have enough clothes to wear to keep you

you enough food even when they could easily have done so; Your parents/guardians were too drunk or intoxicated by drugs to take care of you. There was nobody to take you to the doctor if you needed it when they could easily have done so; Your parents work of whom you were growing up: Your parents separated peacefully and Parmoniously; Your standard of living decreased significantly after the separation/divorce of your parents; Your standard of living decreased significantly after the separation/divorce of your parents; Your standard of living decreased significantly after the separation/divorce of your parents; Your standard of living decreased significantly after the separation/divorce of your parents; Your standard of living decreased significantly after the separation/divorce of your parents; Your standard of living decreased significantly after the separation/divorce of your parents; Your standard of living decreased significantly after the separation/divorce of your parents; Your standard of living decreased significantly after the separation/divorce of your parents; Your standard of living decreased significantly after the separation/divorce of your parents; Your standard of living decreased significantly after the separation/divorce of your parents; Your standard of living decreased significantly after the separation/divorce of your parents; Your standard of living decreased significantly after the separation/divorce of your parents; Your standard of living decreased significantly after the separation/divorce of your parents; Your standard of living decreased significantly after the separation/divorce of your parents; Your standard of living decreased significantly after the separation divorce of your parents; Your standard of living decreased significantly because of a household member; Your characteristic that the parents of the parents of the your standard of living decreased significantly after the separation of your decreation, A household member was incarcerated. Your standard of living decreased s		-		
Divorce  harmoniously; Your standard of living decreased significantly hearthe separation/divorce of your parents; significantly hearth set hearth of the significantly hearth set hearth of the significantly hearth set of household court to separate/get divorced; You had to testify in court/take sides during your parents' separation/divorce of your parents' guardians sid bad things about each other and to talk to a lawyer or judge during your parents' guardians' separation/divorce. When you saw a family member. Having something from at -no injury; Being grabbed, pushed, shook, pulled -minor injury; Being grabbed, pushed, shook,			done so; Your parents/guardians were too drunk or intoxicated by drugs to take care of you; There was nobody to take you to the doctor if you needed it  When you were growing up:	when they could easily have done so; Your parents/guardians were too drunk or intoxicated by drugs to take care of you; There was nobody to take you to the doctor if you needed it  When you were growing up:
When you were growing up:  Household Substance Use  Household Mental Illness Having something thrown at - no injury; Being grabbed, pushed, shook, pulled - minor injury; Being slapped, bit, hit with minor object, therew something, punched, kicked with injury; Being choked, hit with major object, threw object, threw something, punched, kicked with injury; Being slabed, pushed, shook, pulled - minor injury.  Household Substance Use  Household When you were growing up:  Household Mental Illness  Household Member Incarcerated  When you were growing up, a household member: Took medication for mental illness; Hata mental illness that interfered with your daily schedule; Had a mental illness that interfered with your daily schedule; Had a mental illness that interfered with your daily schedule; Had a mental illness that interfered with your daily schedule; Had a mental illness that interfered with your daily schedule; Had a mental illness that negatively influenced your education and daily needs; Had a mental illness that negatively influenced your education and daily needs; Had a mental illness; Had a mental illness; Had a mental illness; Had a mental illness that negatively influenced your education and daily needs; Had a mental illness that incererated; You were not able to visit your family member in you for their mental and versity you have not experienced hefore the incarcerated; You experienced any additional adversity you have not experienced before the incarcerated; You experienced any additional adversity you have not experienced before the incarcerated.  When you were growing up: You were growing up: You were growing up: You were ort able to visit your family member in you were growing up: You wer	Div	vorce	harmoniously; Your standard of living decreased significantly after the separation/divorce of your parents; Your parents used lawyers and/or went to court to separate/get divorced; You had to testify in court/take sides during your parents' separation/divorce	harmoniously; Your standard of living decreased significantly after the separation/divorce of your parents/guardians; Your parents/guardians said bad things about each other and tried to get you on their side; You lost contact with one parent/guardian after the separation/divorce; You had to talk to a lawyer or judge during your parents'/guardians' separation/divorce
A household member was hospitalized because of a substance use; The substance use of a household member negatively influenced your education; The substance use of a household member interfered with your daily schedule  Household Mental Illness  When you were growing up, a household member: Took medication for mental illness; Attempted suicle; Was institutionalized because of a household member negatively influenced your education; A household member: Took medication for mental illness; Had a mental illness; Blamed you for their mental illness; Had a mental illness that interfered with your daily schedule; Had a mental illness that negatively influenced your education and daily needs; Had a mental illness that negatively influenced your education and daily needs; Had a mental illness and did not receive treatment for metal illness and incarcerated; You standard of living decreased significantly because a household member was incarcerated; You experienced any additional adversity you have not experienced before the incarceration of a household member; Your education was impacted because a household member was incarcerated.	Vic	olence	member: Having something thrown at - no injury; Being grabbed, pushed, shook, pulled - no injury; Being grabbed, pushed, shook, pulled - minor injury; Being slapped, bit, hit with minor object, threw something, punched, kicked with injury; Being choked, hit with major object, burned, threatened with weapon, used weapon, sexual assault - major injury	member: Being called names or having something thrown at - no injury; Being grabbed, pushed, shook, pulled - minor injury; Being slapped, bit, hit with minor object, threw something, punched, kicked with injury; Being choked, hit with major object, burned, threatened with weapon, or misused - major injury; Being killed by another family member
Mental Illness  Took medication for mental illness; Attempted suicide; Was institutionalized because of mental illness; Blamed you for their mental illness; Had a mental illness that interfered with your daily schedule; Had a mental illness that negatively influenced your education  Household Member Incarceration  When you were growing up: You were not able to visit your family member in prison; You had to move or live with somebody else because a household member was incarcerated; You experienced any additional adversity you have not experienced before the incarceration was impacted because a household member; Your education was impacted because a household member was incarcerated; Your education was impacted because a household member; Your education was impacted because a household member was incarcerated.	Sub	bstance	A household member was hospitalized because of substance use; The substance use of a household member negatively influenced your education; The substance use of a household member interfered	A household member was hospitalized/institutionalized because of substance use; You did not have your daily needs fulfilled because of a household member's substance use (for example: you did not have enough food); You had to take on additional responsibilities because of a family member's substance use (for example: you had to take care of your siblings); The substance use of a household member negatively influenced your education; A household member
Member Incarceration  You were not able to visit your family member in prison; You had to move or live with somebody else because a household member was incarcerated; Your standard of living decreased significantly because a household member was incarcerated; You experienced any additional adversity you have not experienced before the incarceration of a household member; Your education was impacted because a household member was incarcerated  You were not able to stay in contact with a household member after they were incarcerated; You witnessed a household member's arrest; You had to move or live with somebody else because a household member was incarcerated; You experienced any additional adversity you have not experienced before the incarcerated was impacted because a household member was incarcerated the incarceration of a household member; Your education was impacted because a household member was incarcerated because a household member was incarcerated; You experienced any additional adversity you have not experienced before the incarceration of a household member; Your education was impacted because a household member was incarcerated before the incarcerated was incarcerated was incarcerated because a household member was incarcerated; You experienced any additional adversity you have not experienced before the incarceration of a household member; Your education was impacted because a household member was incarcerated; You experienced any additional adversity you have not experienced before the incarceration of a household member was incarcerated; You experienced any additional adversity you have not experienced before the incarceration of a household member was incarcerated; You experienced any additional adversity you have not experienced any additional adversity you have not experienced before the incarcerated.			Took medication for mental illness; Attempted suicide; Was institutionalized because of mental illness; Blamed you for their mental illness; Had a mental illness that interfered with your daily schedule; Had a mental illness that negatively	Took medication and/or received treatment for mental illness; Attempted suicide; Was institutionalized because of mental illness; Blamed you for their mental illness; Had a mental illness that negatively influenced your education and daily needs; Had a mental illness and did not receive
Percention   Not at all transmatic, a little transmatic; somewhat   Very negative; Negative; Neighter positive nor	Me Inc	ember	You were not able to visit your family member in prison; You had to move or live with somebody else because a household member was incarcerated; Your standard of living decreased significantly because a household member was incarcerated; You experienced any additional adversity you have not experienced before the incarceration of a household member; Your education was impacted because a household member was incarcerated	You were not able to stay in contact with a household member after they were incarcerated; You witnessed a household member's arrest; You had to move or live with somebody else because a household member was incarcerated; Your standard of living decreased significantly because a household member was incarcerated; You experienced any additional adversity you have not experienced before the incarceration of a household member; Your education was impacted because a household member was incarcerated
traumatic, traumatic, very traumatic, extremely traumatic traumatic, very traumatic, extremely traumatic traumatic traumatic, extremely traumatic traumatic, extremely negative; Both negative and positive; Very positive	Perception			

<sup>\*</sup>EA=emotional abuse, PA=physical abuse, SA=sexual abuse, EN=emotional neglect, PN=physical neglect, PSD=parental separation/divorce, HV=household violence, HSU=household substance use, HMI=household mental illness, HInc=household member incarceration

Appendix 3-B: Supplement Table 3.2. ACE Dimension Response Option Values for Scoring

Dimension	Response Options	Scori	ng Value
All Domains		· ·	-0
Frequency (not for	Once	1	
Parental	More than once/Sometimes	2.33	
Separation/Divorce)	Frequently	3.66	
Separation Bivorce)	Almost all the time	5	
Perception	Very positive	-2	1/3*
1 creeption	very positive	-2	1/3
	Positive	-1	1/2
	Neither positive nor negative	0	1
	Both negative and positive	0	1
	Negative Negative	1	2
	Very negative	2	3
<b>Emotional Abuse</b>	Very negative	2	J
		1 2	
Timing	0-2yrs	3	
	3-5yrs (Preschool)	3	
	6-9yrs (Elementary School)	3	
	10-13yrs (Middle School)		
<b>D</b>	14-17yrs (High School)	1	
Perpetrator	Mother/Stepmother	5	
	Father/Stepfather	4	
	Other Family Member	3	
	Other Adult you knew (babysitter, teacher, family friend etc.)	2	
	A Stranger	1	
Intensity	Insulted you, called you things like "ugly," "lazy," or "stupid"	3	
	Put you down/humiliated you	1	
	Said they hated you or they wish you had never been born	4	
	Threatened to leave you	3	
	Threatened to physically hurt you	3	
Physical Abuse			
Timing	0-2yrs	3	
	3-5yrs (Preschool)	5	
	6-9yrs (Elementary School)	3	
	10-13yrs (Middle School)	3	
	14-17yrs (High School)	1	
Perpetrator	Mother/Stepmother	5	
	Father/Stepfather	4	
	Other Family Member	3	
	Other Adult you knew (babysitter, teacher, family friend etc.)	2	
	A Stranger	1	
Intensity	Grabbed, shook, slapped, pinched, spanked you on bottom with/without	1	
•	object - no injury		
	Grabbed, shook, slapped, pinched, spanked you on bottom with/without	2	
	object - minor injury, left me with bruises or marks		
	Punched, kicked, knocked you down, threw a hard object at you - minor	3	
	injury, left me with bruises or marks		
	Punched, kicked, knocked you down, threw a hard object at you - major	4	
	injury, had to see a doctor or go to the hospital		
	Hit you with a hard object, choked, beat, burned you, or threatened you	5	
	with a weapon - major injury, had to see a doctor or go to the hospital		
Sexual Abuse			

Timina	0.25	1
Timing	0-2yrs 3-5yrs (Preschool)	3
	6-9yrs (Elementary School)	3
	10-13yrs (Middle School)	4
7	14-17yrs (High School)	3
Perpetrator	Mother/Stepmother	4
	Father/Stepfather	5
	Other Family Member	3
	Other Adult you knew (babysitter, teacher, family friend etc.)	2
	A Stranger	1
Intensity	Exposed your private parts or their private parts to you against your will	1
	Forced you to watch others engaged in sexual acts	2
	Fondled or touched private parts of your body or made you touch theirs	2
	against your wishes	
	Threatened to hurt you or tell lies about you unless you did something	4
	sexual with them	
	Forced anal or vaginal penetration on you with objects	5
	Forced oral, anal, or vaginal penetration on you with their fingers or	5
	genitals	
<b>Emotional Neglect</b>		
Timing	0-2yrs	4
C	3-5yrs (Preschool)	4
	6-9yrs (Elementary School)	3
	10-13yrs (Middle School)	2
	14-17yrs (High School)	2
Perpetrator	Mother/Stepmother	5
. r	Father/Stepfather	4
	Other Family Member	3
	Other Adult you knew (babysitter, teacher, family friend etc.)	2
	A Stranger	1
Intensity	You did not feel loved by your family members	5
intensity	People in your family did not care about your emotional needs	4
	People in your family did not look out for each other	2
	Your parents/guardians did not know what you were doing with your	2
	free time when you were not at school or work	
	Your parents/guardians did not understand your problems and worries	2
Physical Neglect	Tour parents, gautotains are not anteristante your problems and wornes	1 2
Timing	0-2yrs	4
Tilling	3-5yrs (Preschool)	5
	6-9yrs (Elementary School)	3
	10-13yrs (Middle School)	2
	14-17yrs (High School)	1
Darnatrator		5
Perpetrator	Mother/Stepmother  Eather/Stepfother	
	Father/Stepfather	4
	Other Family Member	3
	Other Adult you knew (babysitter, teacher, family friend etc.)	2
Turkensite	A Stranger	1
Intensity	You had nobody to take care of you and protect you	3
	You did not have enough clothes to wear to keep you warm or protected	2
	from the weather	4
	Your parents/guardians did not give you enough food even when they	4
	could easily have done so	

	Your parents/guardians were too drunk or intoxicated by drugs to take	4
	care of you	
	There was nobody to take you to the doctor if you needed it	2
Parental Separa		T
Timing	0-2yrs	1
	3-5yrs (Preschool)	2
	6-9yrs (Elementary School)	4
	10-13yrs (Middle School)	5
	14-17yrs (High School)	3
Intensity	Your parents/guardians separated peacefully and harmoniously	1
	Your standard of living decreased significantly after the	3
	separation/divorce of your parents/guardians	
	Your parents/guardians said bad things about each other and tried to get you on their side	4
	You lost contact with one parent/guardian after the separation/divorce	5
	You had to talk to a lawyer or judge during your parents'/guardians'	3
** 1 11 *** 1	separation/divorce	
Household Viole		Та
Timing	0-2yrs	2
	3-5yrs (Preschool)	3
	6-9yrs (Elementary School)	3
	10-13yrs (Middle School)	4
	14-17yrs (High School)	2
Perpetrator	Mother/Stepmother	3.66
	Father/Stepfather	5
	Other Family Member	1
	Other Adult living in your household (e.g., mother's boyfriend, a family	2.33
	friend etc.)	
Intensity	A household member was hospitalized/institutionalized because of substance use	1
		2
	You did not have your daily needs fulfilled because of a household	2
	member's substance use (e.g., you did not have enough food)	3
	You had to take on additional responsibilities because of a family	3
	member's substance use (e.g., you had to take care of your siblings)	4
	The substance use of a household member negatively influenced your education	4
	A household member died because of substance use	5
Household Subst		
Timing	0-2yrs	2
1 mmg	3-5yrs (Preschool)	2
	6-9yrs (Elementary School)	4
		4
	10-13yrs (Middle School)	3
Damatustan	14-17yrs (High School)	5
Perpetrator	Mother/Stepmother  Fother/Step fother	
	Father/Stepfather Other Family Member	3.66
	Other Family Member	•
	Other Adult living in your household (e.g., mother's boyfriend, a family friend etc.)	2.33
Intensity	A household member was hospitalized/institutionalized because of	2
inclisity	substance use	
	You did not have your daily needs fulfilled because of a household	4
	member's substance use (e.g., you did not have enough food)	
	You had to take on additional responsibilities because of a family	3
	member's substance use (e.g., you had to take care of your siblings)	

	The substance use of a household member negatively influenced your	3
	education	
	A household member died because of substance use	5
Household Ment		
Timing	0-2yrs	2
C	3-5yrs (Preschool)	3
	6-9yrs (Elementary School)	3
	10-13yrs (Middle School)	4
	14-17yrs (High School)	2
Perpetrator	Mother/Stepmother	5
1	Father/Stepfather	3.66
	Other Family Member	1
	Other Adult living in your household (e.g., mother's boyfriend, a family	2.33
	friend etc.)	
Intensity	Took medication and/or received treatment for mental illness	1
·	Attempted suicide	5
	Was institutionalized because of mental illness	3
	Blamed you for their mental illness	5
	Had a mental illness that negatively influenced your education and daily	4
	needs	
	Had a mental illness and did not receive treatment for it	4
Household Mem	ber Incarceration	
Timing	0-2yrs	1
	3-5yrs (Preschool)	3
	6-9yrs (Elementary School)	4
	10-13yrs (Middle School)	5
	14-17yrs (High School)	3
Perpetrator	Mother/Stepmother	5
•	Father/Stepfather	3.66
	Other Family Member	2.33
	Other Adult living in your household (e.g., mother's boyfriend, a family friend etc.)	2.33
Intensity	You were not able to stay in contact with a household member after they were incarcerated	4
	You witnessed a household member's arrest	4
	You had to move or live with somebody else because a household	4
	member was incarcerated	'
	Your standard of living decreased significantly because a household	3
	member was incarcerated You experienced any additional adversity you have not experienced	3
	before the incarceration of a household member Your education was impacted because a household member was	3
	incarcerated	

<sup>\*</sup>scoring values for perception weighted domain scores

## **Appendix 3-C.** IRB Approval Letter



OFFICE OF RESEARCH COMPLIANCE 9201 University City Boulevard 319 Cameron Hall Charlotte NC 28223-0001 (704)-687-1871 Web site: http://research.uncc.edu/ Federalwide Assurance (FWA) #00000649

To: Lisa Krinner Graduate School

From: Office of Research Protections and Integrity

Date: 10/07/2020

RE: Notice of Approval of Exemption with No End Date Exemption Category: 2. Survey, interview, public observation

Study #: 21-0040

Study Title: Adverse Childhood Experiences Dimensions Content Validity Delphi

This submission has been reviewed by the Office of Research Protections and Integrity (ORPI) and was determined to meet the Exempt category cited above under 45 CFR 46.104(d). This determination has no expiration or end date and is not subject to an annual continuing review. However, you are required to obtain IRB approval for all changes to any aspect of this study before they can be implemented.

#### Important Information :

- Human Subjects Research (HSR) activities that can be conducted virtually/remotely should be conducted virtually/remotely. Protocol Modifications are required to adjust data collection procedures to remote data collection (e.g., phone, online or virtual).
- The operational status of the research/study location where HSR activities will occur will guide whether the activities should occur.
- Off-campus HSR activities may occur if the organization, institution, agency, business, etc. is operational and is willing to support the researcher to conduct the research.
  - Researchers will be representing the University and therefore, regardless of the organization's standards, researchers must adhere to University, local, and state requirements regarding the use of face coverings, physical distancing standards, group size limitations, etc.
- Conducting HSR activities on-campus (Main campus, Center City campus, and other locations that may be
  extensions of the University) is subject to the operational status of the University.
  - Researchers must adhere to all University, local, and state public health and safety requirements including wearing face coverings whenever indoors and maintaining physical distancing.
  - Researchers must adhere to the Niner Nation Cares requirements including the 6 Ws (Wash, Wear, Wait, Wipe, Watch, and Wave) and limitations on the size of gatherings.
- 5. Should the operational status of off-campus study locations change, the University's operational status change, Mecklenburg County and/or the state of North Carolina impose higher restrictions (stay-at-home orders), researchers must comply with these requirements and therefore HSR activities, regardless of whether the activities are off-campus or on-campus may need to halt.

#### Study Description:

For this study, we will invite subject matter experts to participate in a consensus development study using a Delphi approach. The study will be about characteristics of adverse childhood experiences (ACE) such as timing, frequency, or perception of the adverse event. Our goal is to design a set of items as addition to the 10 conventional ACE domains (Felitti et al., 1998).

Your approved consent forms (if applicable) and other documents are available online at http://uncc.myresearchonline.org/irb/index.cfm?event=home.dashboard.irbStudyManagement&irb\_id=21-0040.

The Investigator Responsibilities listed below apply to this study. Carefully review the Investigator

#### Responsibilities.

#### Investigator's Responsibilities:

The above-cited determination has no expiration or end date and is not subject to annual continuing review.

However, the Principal Investigator needs to comply with the following responsibilities:

- Modifications must be submitted for review and approval before implementing the modification. This includes changes to study procedures, study materials, personnel, etc.
- Data security procedures must follow procedures as approved in the protocol and in accordance with ITS <u>Guidelines for Data Handling</u>.
- Promptly notify the IRB (uncc-irb@uncc.edu) of any adverse events or unanticipated risks to participants or others.
- Complete the Closure eform via IRBIS once the study is complete.
- Be aware that this study is now included in the Office of Research Protections and Integrity
   (ORPI) Post-Approval Monitoring program and may be selected for post-review monitoring at some point in
   the future.
- Reply to ORPI post-review monitoring and administrative check-ins that will be conducted periodically to update ORPI as to the status of the study.
- Three years (3) following this Exemption determination, ORPI will request a study status update (active/not active).

Please be aware that approval may still be required from other relevant authorities or "gatekeepers" (e.g., school principals, facility directors, custodians of records).

Appendix 3-D. Subject Matter Expert Recruitment Emails for Delphi Study

SUBJECT LINE: Invitation to Participate as a Subject Matter Expert on Adverse Childhood Experiences

Dear [name],

My name is Lisa Maria Krinner. I am a Doctoral Candidate in the Department of Public Health Sciences at the University of North Carolina at Charlotte. My dissertation chair is Dr. Jan Warren-Findlow at the Department of Public Health Sciences at the University of North Carolina at Charlotte. I am conducting my dissertation research in the field of Adverse Childhood Experiences (ACEs).

Within the scope of my dissertation, I am performing a Delphi study to develop items for ACE dimensions, such as timing, frequency, or perception of the adverse event. The goal of my dissertation research is to conceptually refine ACEs and their measurement.

I am inviting you to participate in my study as a subject matter expert. Participation involves the completion of 2-3 rounds of short online surveys. Each survey will be administered online using the Qualtrics platform. There will be approximately 3 weeks between surveys. The surveys will require about 15-20 minutes to complete via computer, tablet, or smartphone. You will have the opportunity to provide comments and suggestions regarding each item in the survey.

In preparation for this Delphi study, I conducted a scoping review of empirical journal articles on ACEs published after the original ACE Study in 1998 to provide an overview of the conceptual landscape of ACEs, a comprehensive understanding of the different dimensions of ACEs and how these dimensions have been operationalized in research to this point. We used a PRISMA methodology to identify articles assessing at least 2 of the 10 conventional ACE domains as well as 2 ACE dimensions.

Of 15,417 unique articles in our initial search, 61 articles met all selection criteria for this review. We identified four primary dimensions used for most ACE domains: frequency, timing, perception, and the role of the perpetrator. Additionally, we found a number of secondary and domain-specific dimensions, which mostly relate to nuances of the severity of the traumatic experience.

Our review illustrates the lack of standardized terminology and measurement of ACE dimensions. Hence, with this Delphi study, we are aiming to develop items for a standardized measurement approach of these dimensions.

#### Based on our literature review, our research questions for this first round are:

- 1. What is the relative importance of different conceptual dimensions for each of the 10 conventional ACE domains?
- 2. How should these dimensions be operationalized and assessed?

Please find attached for your reference the 10-item ACE-Study questionnaire.

Adverse Childhood Experience Finding your ACE Sco	
While you were growing up, during your first 18 years of life	i
Did a parent or other adult in the household often	
Swear at you, insult you, put you down, or humiliate you	0
or	
Act in a way that made you afraid that you might be phy	sically hurt?
Yes No	If yes enter 1
Did a parent or other adult in the household often     Push, grab, slap, or throw something at you?	
or	
Ever hit you so hard that you had marks or were injured	7
Yes No	If yes enter 1
<ol> <li>Did an adult or person at least 5 years older than you ever Touch or fondle you or have you touch their body in a se or</li> </ol>	caual way?
Try to or actually have oral, anal, or vaginal sex with you	
Yes No	If yes enter 1
4. Did you often feel that	
No one in your family loved you or thought you were in	sportant or special?
Your family didn't look out for each other, feel close to Yes No	each other, or support each other?  If yes enter I
5. Did you often feel that	
You didn't have enough to eat, had to wear dirty clothes	, and lud no one to protect you?
or	
Your parents were too drunk or high to take care of you	
Yes No	If yes enter I
6. Were your purests ever separated or divorced?	
Yes No	If yes enter I
7. Was your mother or stepmother:	
Often pushed, grabbed, slapped, or had something thros	on at bor?
OF	with a second law to 188
Sometimes or often kicked, bitten, hit with a fist, or hit	wan something hard?
Ever repeatedly hit over at least a few minutes or threate	ened with a run or knife?
Yes No	If yes enter 1
<ol> <li>Did you live with anyone who was a problem drinker or alcohing.</li> <li>Yes No</li> </ol>	olic or who used street drugs?  If yes enter 1
9. Was a household member depressed or mentally ill or did a bo	susehold member attempt suicide?
Yes No	If yes enter 1
10 Did a household moreher on to reinon?	
10. Did a household member go to prison? Yes No	Maria const. I
TES PAI	If yes enter I

Your participation is voluntary. Your responses are confidential and will not be shared with other participants. We will acknowledge your participation by name or anonymously in the publication for this study.

In order to participate, you will be required to sign a confidentiality agreement via DocuSign **before** the start of the study.

If you are interested in participating please respond to this email by [7 to 10 days from now] and we will send you a link to the confidentiality agreement.

This study has been approved by the Institutional Research Board (protocol # <u>21-0040</u>). If you have any questions or concerns, please contact Ms. Lisa Maria Krinner (<u>lkrinner@uncc.edu</u>) or Dr. Jan Warren-Findlow (<u>jwarren1@uncc.edu</u>) from the Department of Public Health Sciences at UNC Charlotte.

SUBJECT LINE: Reminder - Invitation to Participate as a Subject Matter Expert on Adverse Childhood Experiences

Dear [name],

A few days ago, you received an email to participate in a Delphi study in the field of Adverse Childhood Experiences. I would like to invite you to participate in our study as a subject matter expert.

Participation involves the completion of 2-3 rounds of short online surveys. Each survey will be administered on the platform Qualtrics. There will be approximately 3 weeks between surveys. The surveys will require about 15-20 minutes to complete via computer, tablet, or smartphone. You will have the opportunity to provide comments and suggestions regarding each item in the survey.

Please find attached for your reference the 10-item ACE-Study questionnaire.

Adverse Childhood Experience (A Finding your ACE Score		naire
Vhile you were growing up, during your first 18 years of life:		
. Did a parent or other adult in the household often Swear at you, insult you, put you down, or humiliate you?		
or	272	
Act in a way that made you afraid that you might be physical		
Yes No	If yes enter 1	_
Did a parent or other adult in the household often Push, grab, slap, or throw something at you?		
ar		
Ever hit you so hard that you had marks or were injured?	1227.000.000	
Yes No	If yes enter I	
Did an adult or person at least 5 years older than you ever  Touch or fondle you or have you touch their body in a sexua or	d way?	
Try to or actually have oral, anal, or vaginal sex with you?		
Yes No	If yes enter 1	_
P. C		
. Did you often feel that		
No one in your family loved you or thought you were impor-	tant or special?	
Vous family dish't look out for each other fact store to each	other or money	reheard.
Your family didn't look out for each other, feel close to each Yes. No		
To No	If yes enter I	
Did you often feel that		
You didn't have enough to eat, had to wear dirty clothes, and	I had no one to prote	ect you?
or	The second second	2.000
Your parents were too drunk or high to take care of you or to	ike you to the doctor	r if you nee
Yes No	If yes enter I	
	No. of the last of	
Were your parents ever separated or divorced?		
Yes No	If yes enter 1	_
. Was your mother or stepmother:	5-7	
Often pushed, grabbed, slapped, or had something thrown at	BEXT	
OF	something by the	
Sometimes or often kicked, bitten, hit with a fist, or hit with	something hard?	
Gr  Ever repeatedly hit over at least a few minutes or threatened	with a non-or-Y-16.	
Yes No		4
Tes No	If yes enter I	_
Did you live with anyone who was a problem drinker or alcoholic	or who used street o	drugs?
Yes No	If yes enter 1	
. 100	ar year commit t	
Was a household member depressed or mentally ill or did a house	hold member attenu	pt suicide?
Yes No	If yes enter I	
1. 0. VII. (1. VIII.)	and Marie Street, or	
0. Did a household member go to prison?		
	If yes enter I	
Yes No	II yes emer i	
Yes No Now add up your "Yes" answers: This is	11 M 1011111111111111111111111111111111	

Your participation is voluntary. Your responses are confidential and will not be shared with other participants. We will acknowledge your participation by name or anonymously in the publication for this study.

In order to participate, you will be required to sign a confidentiality agreement via DocuSign **before** the start of the study.

If you are interested in participating please respond to this email by [7 to 10 days from now] and we will send you a link to the confidentiality agreement.

This study has been approved by the Institutional Research Board (protocol # <u>21-0040</u>). If you have any questions or concerns, please contact Ms. Lisa Maria Krinner (<u>lkrinner@uncc.edu</u>) or Dr. Jan Warren-Findlow (<u>jwarren1@uncc.edu</u>) from the Department of Public Health Sciences at UNC Charlotte.

# Appendix 3-E. Non-disclosure Agreement for Delphi Subject Matter Experts

# **Non-Disclosure Agreement**

This non-disclosure agreement has been created this 15 <sup>th</sup> day of January, 2021, by the principal
investigator Ms. Lisa Maria Krinner (lkrinner@uncc.edu), a doctoral candidate in the
Department of Public Health Sciences at the University of North Carolina at Charlotte, in
relation to the study titled "Delphi Study on Adverse Childhood Experiences Dimensions." This
study has been approved by the University of North Carolina at Charlotte Institutional Review
Board (protocol # 21-0040).
This non disclosure agreement has the nurnose to protect the intellectual property of Ms

study has been approved by the University of No	orth Carolina at Charlotte Institutional I	Review
Board (protocol # 21-0040).		
This non-disclosure agreement has the purpose t	o protect the intellectual property of M	s.
Krinner.		
By signing this non-disclosure agreement, I	(	),
located in agree to:		
(1) keep all communication related to this str	udy confidential;	
(2) not share the study methodology or resul	ts of this study with third parties withou	ut Ms.
Krinner's consent, and;		
(3) not use any information gained through t	his study for future research without M	[s.
Krinner's consent.		
Date:	Signature:	

Date.	Signature.

Appendix 3-F. Delphi Study on Adverse Childhood Experiences Dimensions Round 1

The University of North Carolina at Charlotte

Department of Public Health Sciences

9201 University City Boulevard, Charlotte, NC 28223

## Consent to be Part of a Research Study

Title of the Project: The Conceptual Refinement of the Phenomenon of Adverse Childhood Experiences Principal Investigator: Lisa Maria Krinner, Doctoral Candidate, Department of Public Health Sciences, University of North Carolina at Charlotte Faculty Advisor: Dr. Jan Warren-Findlow, Interim Department Chair, Department of Public Health Sciences, University of North Carolina at Charlotte Co-investigators: Dr. Michele Issel, Research Professor, Academy for Population Health Innovation, University of North Carolina at Charlotte Dr. Jessamyn Bowling, Assistant Professor, Department of Public Health Sciences, University of North Carolina at Charlotte Dr. Charlie Reeve, Professor, Department of Psychological Science, University of North Carolina at Charlotte

## Dear Participant,

Thank you for considering participating in this research study. This Delphi study is part of a doctoral dissertation with the goal to conceptually refine the phenomenon of Adverse Childhood Experiences (ACEs). ACEs and their effect on later-life outcomes have gained considerable attention in the past 20 years; nevertheless, the research on ACEs lacks a clear conceptual structure. The objective of this Delphi study is to develop survey items related to five dimensions that are most commonly associated with an adverse event. You will be asked to complete 2-3 rounds of short online surveys on the platform Qualtrics. There will be approximately 3 weeks between surveys. The surveys will require about 15-20 minutes to complete via computer, tablet, or smartphone. You will have the opportunity to provide comments and suggestions regarding each item in the survey. Findings will be used to help refine the concept of adverse childhood experiences and to improve screening practices for childhood events. There will be no direct harms or benefits for you. We will acknowledge your participation by name or anonymously in the publication for this study. After the study is complete, study data may be shared with other researchers for use in other studies or as may be needed as part of publishing our results. The data we share will not include information that could identify you. Your participation is voluntary. Your responses are confidential and will not be shared with other participants. You can withdraw from the study at any time or refuse to answer particular questions. Please keep all communication related to this study confidential. This study has been approved by the UNC Charlotte IRB (uncc-irb@uncc.edu; protocol #21-0040). If you have any questions or concerns, please contact Lisa Maria Krinner (lkrinner@uncc.edu) or Dr. Jan Warren-Findlow (jwarren1@uncc.edu). If you have further questions or concerns about your rights as a participant in this study, contact the Office of Research Protection and Integrity at (704) 687-1871 or uncc-irb@uncc.edu. You may print this screen for your personal records.

If you have read and understand the information provided and freely consent to participate in the study, you may proceed to the survey. [Click Next if you agree]

Q2.1 The first block of questions relates to the dimension Frequency.

The first part of this question relates to the relevance of frequency for each ACE domain with regards to the impact on the individual's later-life outcomes.

Please indicate for which domains you consider frequency to be relevant in the table below.

	Very irrelevant	Irrelevant	Neither relevant nor irrelevant	Relevant	Very Relevant
1. Emotional Abuse	0	0	0	0	0
2. Physical Abuse	0	0	0	0	0
3. Sexual Abuse	0	0	0	0	0
4. Emotional Neglect	0	0	0	0	0
5. Physical Neglect	0	0	0	0	0
6. Parental Separation/Divorce	0	0	0	0	0
7. Household Violence	0	0	0	0	0
8. Household Substance Use	0	0	0	0	0
9. Household Mental Illness	0	0	0	0	0
10. Household Member Incarceration	0	0	0	0	0

Q2.2 Please leave your comments here (optional):

Q2.3 The second part of this question relates to the  $\underline{\text{wording of the questions}}$  for each ACE dimension and their response options.

Please indicate to which degree you agree or disagree with the way the questions are worded. If

you have suggestions for changes, please indicate these in the comment box below the question. Do you agree with the way this question is worded: "*How often did the event occur?*"

- Strongly Agree
- o Agree
- Neither Agree not Disagree
- o Disagree
- Strongly Disagree

Q2.4 Pleas	e leave your	r comments	here (o	ptional)	:

\_\_\_\_

Q2.5 In our literature review, we identified two common sets of response options for the **frequency** of an adverse event.

Please indicate which of the two options you think is the superior one, or provide an alternative assessment approach.

- o Never, Once, More Than Once, Frequently, Almost all the time
- o this never happened, this happened 1 time, this happened more than once, this happened more than 10 times, this happened more than 20 times
- o If neither of the two, please indicate an alternative assessment approach:

,\_\_\_\_\_

Q2.6 Please leave your comments below (optional):

\_\_\_\_\_

Q3.1 The next block of questions relates to the dimension Timing.

The first part of this question relates to the relevance of timing for each ACE domain with regards to the impact on the individual's later-life outcomes.

Please indicate for which domains you consider timing to be relevant in the table below.

	Very irrelevant	Irrelevant	Neither relevant nor irrelevant	Relevant	Very Relevant
1. Emotional Abuse	0	0	0	0	0
2. Physical Abuse	0	0	0	0	0
3. Sexual Abuse	0	0	0	0	0
4. Emotional Neglect	0	0	0	0	0
5. Physical Neglect	0	0	0	0	0
6. Parental Separation/Divorce	0	0	0	0	0
7. Household Violence	0	0	0	0	0
8. Household Substance Use	0	0	0	0	0
9. Household Mental Illness	0	0	0	0	0
10. Household Member Incarceration	0	0	0	0	O

## Q3.2 Please leave your comments below (optional):

Q3.3 The second part of this question relates to the <u>wording of the questions</u> for each ACE dimension and their response options.

Please indicate to which degree you agree or disagree with the way the questions are worded. If you have suggestions for changes, please indicate these in the comment box below the question.

Do you agree with the way this question is worded: "When did the event occur?"

- Strongly Agree
- o Agree
- o Neither Agree not Disagree
- o Disagree
- o Strongly Disagree

Q3.4 Please	indicate 1	how you	ı would	rewrite	the c	question:
-------------	------------	---------	---------	---------	-------	-----------

Q3.5 In our literature review, we found two approaches for the response options related to the **timing** of adverse events: participants were either asked to indicate (1) their age at the time of the event or (2) the age category the event occurred in.

Please indicate which of the two options you think is the superior, or if neither of the two, please provide an alternative assessment approach.

- o Indicate age in years
- o Indicate age category: 0-2yrs, 3-5yrs, 6-9yrs, 10-13yrs, 14-17yrs
- Other (please specify):

# Q3.6 Please leave your comments below (optional):

\_\_\_\_\_

Q4.1 The next block of questions relates to the dimension Perception.

The first part of this question relates to the <u>relevance</u> of **perception** for each ACE domain with regards to the impact on the individual's later-life outcomes.

Please indicate for which domains you consider perception to be relevant in the table below.

	Very Irrelevant	Irrelevant	Neither Relevant nor Irrelevant	Relevant	Very Relevant
1. Emotional Abuse	0	0	0	0	0
2. Physical Abuse	0	0	0	0	0
3. Sexual Abuse	0	0	0	0	0
4. Emotional Neglect	0	0	0	0	0
5. Physical Neglect	0	0	0	0	0
6. Parental Separation/Divorce	0	0	0	0	0
7. Household Violence	0	0	0	0	0
8. Household Substance Use	0	0	0	0	0
9. Household Mental Illness	0	0	0	0	0
10. Household Member Incarceration	0	0	0	0	0

Q4.2 Please leave	your comments	below	(optional)	):
-------------------	---------------	-------	------------	----

Q4.3 The second part of this question relates to the <u>wording of the questions</u> for each ACE dimension and their response options.

Please indicate to which degree you agree or disagree with the way the questions are worded. If you have suggestions for changes, please indicate these in the comment box below the question.

Do you agree with the way this question is worded: "How would you rate the perceived stressfulness/impact of the event?"

- o Strongly Agree
- o Agree
- Neither Agree not Disagree
- o Disagree
- Strongly Disagree

# Q4.4 Please leave your comments below (optional):

\_\_\_\_\_

Q4.5 In our literature review, we found different approaches for the response options related to the **perception** of adverse events. The assessment approach below was used most frequently.

"Not at all traumatic, a little traumatic, somewhat traumatic, traumatic, very traumatic, extremely traumatic"

Please indicate to which degree you agree or disagree with the way the response options are worded, or provide an alternative assessment approach below.

- o Strongly Agree
- o Agree
- Neither Agree not Disagree
- o Disagree
- Strongly Disagree

Q4.6 Please leave your comments below (optional):

Q5.1 The next block of questions relates to the dimension Perpetrator.

The first part of this question relates to the <u>relevance</u> of the **perpetrator** for each ACE domain with regards to the impact on the individual's later-life outcomes.

Please indicate for which domains you consider the perpetrator to be relevant in the table below.

	Very irrelevant	Irrelevant	Neither relevant nor irrelevant	Relevant	Very Relevant
1. Emotional Abuse	0	0	0	0	0
2. Physical Abuse	0	0	0	0	0
3. Sexual Abuse	0	0	0	0	0
4. Emotional Neglect	0	0	0	0	0
5. Physical Neglect	0	0	0	0	0
6. Parental Separation/Divorce	0	0	0	0	0
7. Household Violence	0	0	0	0	0
8. Household Substance Use	0	0	0	0	0
9. Household Mental Illness	0	0	0	0	0
10. Household Member Incarceration	0	0	0	0	O

# Q5.2 Please leave your comments below (optional):

Q5.3 The second part of this question relates to the <u>wording of the questions</u> for each ACE dimension and their response options.

Please indicate to which degree you agree or disagree with the way the questions are worded. If you have suggestions for changes, please indicate these in the comment box below the question.

Do you agree with the way this question is worded: "Who was the perpetrator?"

- Strongly Agree
- o Agree
- o Neither Agree not Disagree
- o Disagree
- o Strongly Disagree

Q5.4 Please indicate how you would rewrite the question:
----------------------------------------------------------

Q5.5 In our literature review, we found two approaches for response options related to the perpetrator of adverse events.

Please indicate which of the two options you think is the superior, or if neither of the two, please provide an alternative assessment approach.

- o Mother/Stepmother, Father/Stepfather, Other
- o Mother/Stepmother, Father/Stepfather, Other Family Member, an Aquaintance (babysitter, teacher, friend etc.), a Stranger
- Other (please specify): \_\_\_\_\_

Q5.6 Please leave your comments below
---------------------------------------

Q6.1 This last block of dimension questions relates to the dimension **Severity** (**author-rated**). Results from our literature review indicate, that secondary and domain-specific dimensions are used to determine the nuanced severity of ACEs. For example, authors assessed if penetration happened related to sexual abuse, or if medical attention was sought out after physical abuse. Please indicate in the table below for which domains you consider the dimension of **author-rated** severity to be relevant with regards to the impact on the individual's later-life outcomes.

	Very irrelevant	Irrelevant	Neither relevant nor irrelevant	Relevant	Very Relevant
1. Emotional Abuse	0	0	0	0	0
2. Physical Abuse	0	0	0	0	0
3. Sexual Abuse	0	0	0	0	0
4. Emotional Neglect	0	0	0	0	0
5. Physical Neglect	0	0	0	0	0
6. Parental Separation/Divorce	0	0	0	0	0
7. Household Violence	0	0	0	0	0
8. Household Substance Use	0	0	0	0	0
9. Household Mental Illness	0	0	0	0	0
10. Household Member Incarceration	O	0	0	0	O

# Q6.2 Please leave your comments below (optional):

Q6.3 The second part of this question relates to the <u>wording of the questions</u> for each ACE dimension and their response options.

Please indicate to which degree you agree or disagree with the way the questions are worded. If you have suggestions for changes, please indicate these in the comment box below the question.

Do you agree with the way this question is worded: "How would you rate the severity of the adverse event?"

- o Strongly Agree
- o Agree
- o Neither Agree not Disagree
- o Disagree
- o Strongly Disagree

#### Q6.4 Please leave your comments below (optional):

\_\_\_\_\_

Q6.5 In our review of the literature, we identified several response option approaches for **severity** (author-rated) that differed for most of the 10 conventional ACE domains. Based on our literature review and a review of other ACE literature, we created response options for each of the 10 conventional ACE domains for the dimension **severity** (author-rated). The layout of the response options varies based on the literature.

Please indicate below if you think these response options are <u>relevant</u> for the 10 domains. If you have suggestions for changes or additions, please indicate these in the comment box below the question.

#### Q6.6 1. Emotional Abuse

Please indicate below if you think these response options are relevant for the domain emotional abuse.

When you were growing up, somebody:

	Yes	No
Swore at you	0	0
Insulted you, called you things like "ugly," "lazy," or "stupid"	0	0
Put you down/humiliated you	0	0
Said they hated you	0	0
Said they wish you had never been born	0	0
Threatened to physically hurt you	0	0
Other (please specify):	0	0

#### Q6.7 Please leave your comments below (optional):

#### Q6.8 2. Physical Abuse

Please indicate below if you think these response options are relevant for the domain physical abuse.

When you were growing up, somebody:

	Yes	No
Grabbed, shook, slapped, pinched, spanked on bottom with/without object - no injury	0	0
Grabbed, shook, slapped, pinched, spanked on bottom with/without object - minor injury, left me with bruises or marks	0	0
Punched, kicked, knocked down, hard object thrown - minor injury, left me with bruises or marks	0	0
Punched, kicked, knocked down, hard object thrown - major injury, had to see a doctor or go to the hospital	0	0
Hit with hard object, choked, beaten, burned, threatened with weapon - major injury, had to see a doctor or go to the hospital	0	0
Other (please specify):	0	0

(	)6.9	Please	leave	vour	comments	below	(ontional	)

# Q6.10 3. Sexual Abuse

Please indicate below if you think these response options are relevant for the domain sexual abuse.

When you were growing up, somebody:

	Yes	No
Exposed their private parts to you or your private parts against your will	0	0
Fondled or touched private parts of your body or make you touch theirs against your wishes or when you were asleep	0	0
Threatened to hurt you or tell lies about you unless you did something sexual with them	0	0
Forced anal or vaginal penetration on you with objects	0	0
Forced oral, anal or vaginal penetration on you with their fingers or genitals	0	0
Other (please specify):	0	0

# Q6.11 Please leave your comments below (optional):

Q6.12 4. Emotional Neglect

Please indicate below if you think these response options are relevant for the domain emotional neglect.

When you were growing up:

	Yes	No
You did not feel loved	0	0
You did not feel close to your family members	0	0
People in your family did not look out for each other	0	0
Your parents/guardians did not know what you were doing with your free time when you were not at school or work	0	0
Your parents/guardians did not understand your problems and worries	0	0
Your family did not serve as a source of strength and support	0	0
Other (please specify):	0	0

# Q6.13 Please leave your comments below (optional):

\_\_\_\_\_

# Q6.14 5. Physical Neglect

Please indicate below if you think these response options are relevant for the domain physical neglect.

When you were growing up:

	Yes	No
You had nobody to take care of you and protect you	0	0
You had to wear dirty or unfitting clothes	0	0
Your parents/guardians intentionally did not give you enough food even when they could easily have done so	0	0
Your parents/guardians were too drunk or intoxicated by drugs to take care of you	0	0
There was nobody to take you to the doctor if you needed it	0	0
Other (please specify):	0	0

# Q6.15 Please leave your comments below (optional):

# Q6.16 6. Parental Separation/Divorce

Please indicate below if you think these response options are relevant for the domain parental separation/divorce.

	Yes	No
Your parents separated peacefully and harmoniously	0	0
Your standard of living decreased significantly after the separation/divorce of your parents	0	0
Your parents used lawyers and/or went to court to separate/get divorced	0	0
You had to testify in court/take sides during your parents' separation/divorce	0	0
Other (please specify):	0	0

# Q6.17 Please leave your comments below (optional):

# Q6.18 7. Household Violence

Please indicate below if you think these response options are relevant for the domain household violence.

When you were growing up, you saw a family member:

	Yes	No
Having something thrown at - no injury	0	0
Being grabbed, pushed, shook, pulled - no injury	0	0
Being grabbed, pushed, shook, pulled - minor injury	0	0
Being slapped, bit, hit with minor object, threw something, punched, kicked with injury	0	0
Being choked, hit with major object, burned, threatened with weapon, used weapon, sexual assault - major injury	0	0
Other (please specify):	0	0

# Q6.19 Please leave your comments below (optional):

\_\_\_\_\_

#### Q6.20 8. Household Substance Use

Please indicate below if you think these response options are relevant for the domain household substance use.

When you were growing up:

	Yes	No
A household member was hospitalized because of substance use	0	0
The substance use of a household member negatively influenced your education	0	0
The substance use of a household member interfered with your daily schedule	0	0
Other (please specify):	0	0

# Q6.21 Please leave your comments below (optional):

# Q6.22 9. Household Mental Illness

Please indicate below if you think these response options are relevant for the domain household mental illness.

When you were growing up, a household member:

	Yes	No
Took medication for mental illness	0	0
Attempted suicide	0	0
Was institutionalized because of mental illness	0	0
Blamed you for their mental illness	0	0
Had a mental illness that interfered with your daily schedule	0	0
Had a mental illness that negatively influenced your education	0	0
Other (please specify):	0	0

# Q6.23 Please leave your comments below (optional):

#### Q6.24 10. Household Member Incarceration

Please indicate below if you think these response options are relevant for the domain household member incarceration.

When you were growing up:

	Yes	No
You were not able to visit your family member in prison	0	0
You had to move or live with somebody else because a household member was incarcerated	0	0
Your standard of living decreased significantly because a household member was incarcerated	0	0
You experienced any additional adversity you have not experienced before the incarceration of a household member	0	0
Your education was impacted because a household member was incarcerated	0	0
Other (please specify):	0	0

Q6.25 Please leave your comments below (optional):

\_\_\_\_

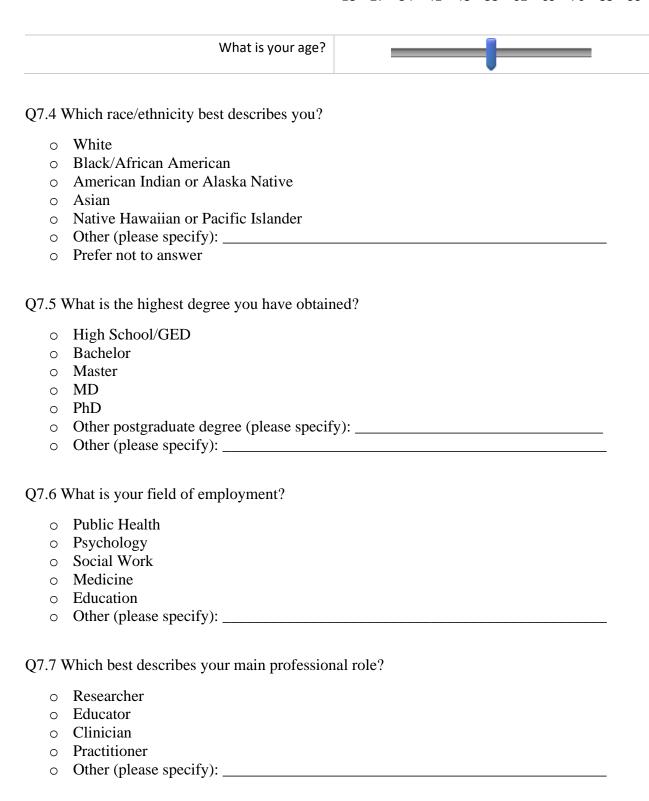
Q7.1 To complete this survey, please provide some basic demographic and professional information about you.

This will only take a few more minutes.

# Q7.2 Which best describes your gender?

- o Male
- o Female
- o Trans femme/woman
- o Trans masculine/man
- o Genderqueer (gender non-binary, gender fluid, agender)
- Other (Please specify):
- o Prefer not to answer

#### 18 27 34 41 48 55 62 69 76 83 99



Q7.8 In a few words, please describe your professional experience in the field of Adverse Childhood Experiences.

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Q7.9 How many years of experience do you have in the field of Adverse Childhood Experiences?

- o Less than 1 year
- o 1-3 years
- o 4-5 years
- o 6-10 years
- o more than 10 years

# Q7.10 Thank you for taking part in our survey!

We will synthesize responses and send out a summary to all participants once we have received all responses.

You will have the opportunity to provide feedback on our summary.

After we have processed your feedback, you will receive a invitation for the next survey round. The second survey round will contain questions mainly related to the scoring of dimensions.

**Appendix 3-G.** Delphi Study on Adverse Childhood Experiences Dimensions Round 2

Dear Subject Matter Expert,

Thank you for participating in Round 2 of our Delphi survey on Adverse Childhood Experiences Dimensions.

In this round, we will ask you how we should proceed if a participant would select more than one response for a given dimension, and about the relative impact of the different dimension response options for each of 10 conventional ACE domains.

The surveys will require about 30 minutes to complete via computer, tablet, or smartphone. You will have the opportunity to provide comments and suggestions regarding each item in the survey. Findings will be used to help refine the concept of adverse childhood experiences and to improve screening practices for childhood events. There will be no direct harms or benefits for you. We will acknowledge your participation by name or anonymously in the publication for this study. After the study is complete, study data may be shared with other researchers for use in other studies or as may be needed as part of publishing our results. The data we share will not include information that could identify you. Your participation is voluntary. Your responses are confidential and will not be shared with other participants. You can withdraw from the study at any time or refuse to answer particular questions.

#### Please keep all communication related to this study confidential.

This study has been approved by the UNC Charlotte IRB (uncc-irb@uncc.edu; protocol #21-0040). If you have any questions or concerns, please contact Lisa Maria Krinner (lkrinner@uncc.edu) or Dr. Jan Warren-Findlow (jwarren1@uncc.edu). If you have further questions or concerns about your rights as a participant in this study, contact the Office of Research Protection and Integrity at (704) 687-1871 or uncc-irb@uncc.edu. You may print this screen for your personal records.

Please note that you have to option to use the back button at any time during the survey if you would like to reread a previous question or change your answer.

# Q2.1 This first block of questions relates to the way we will word an item when **the participant** may have experienced multiple occurrences of a single ACE.

Some dimensions could possibly have more than one response option, such as timing or relationship to the perpetrator. For example, a participant could have experienced physical abuse at multiple ages or had suffered physical abuse at the hands of multiple perpetrators. We need to focus the participant's thinking on a **specific occurrence** of the event when they respond. For the dimensions **timing**, **perception**, **perpetrator**, and **intensity**, which event do we want the participants to think about across the dimensions, if they have experienced an event related to more than one response option? (*Your answer will determine how the questions will ultimately be worded*.)

Should we ask participants to think about:

- the FIRST occurrence of the event
- the most SEVERE occurrence of the event
- the most RELEVANT occurrence of the event to them
- the most FREQUENT occurrence of the event or
- ALL occurrences of the event
- I'm not sure
- Other (please specify):
  \_\_\_\_\_\_\_

Q2.2 Please leave your comments her
-------------------------------------

\_\_\_\_\_

Q3.1 The remaining questions in this survey are about how you would **rank the response options** relative to one another based on how severe you think they are.

For example, we will ask you to tell us if parental separation/divorce experienced in the age group 10-13 years has *more* or *less* impact on later-life health consequences than parental separation/divorce experienced in the age group 3-5 years.

The dimensions **frequency** and **perception** are consistent across the 10 conventional ACE domains. The ranking of the response options for these two dimensions does not differ across domains.

Q3.2 This question relates to the dimension of **frequency** and its response options. The item would be phrased: "*How often did this happen to you?*"

Please rank the intensity of frequency response options on a scale from 1 (has the least impact or later-life health consequences) to 5 (has the highest impact on later-life health consequences).		
Never Once		
More than once/Sometimes		
Frequently Almost all the time		
Q3.3 Please leave your comments here (optional):		
Q3.4 This question relates to the dimension of <b>perception</b> and its response options. The item will be phrased: "Looking back at the event now, what impact did this event have on you?"		
Please rank the intensity of perception response options on a scale from 1 (has the least impact on later-life health consequences) to 6 (has the highest impact on later-life health consequences).		
Very positive		
Positive Neither positive nor negative		
Both negative and positive		
Negative		
Very negative		
Q3.5 Please leave your comments here (optional):		
Q4.1 In the next section, we will ask you to think about the remaining dimensions (timing, perpetrator and intensity) within the context of a specific domain. You will <b>rank the response options</b> for each dimension relative to one another based on how severe you think they are.		
Q4.2 The first block of questions relates to the domain of <i>Emotional Abuse</i> . The stem question in the ACE-Study Questionnaire is:		
Did a parent or other adult in the household <b>often</b> Swear at you, insult you, put you down, or humiliate you? <b>or</b>		
Act in a way that made you afraid that you might be physically hurt?		

For the dimension **timing**, please indicate, which intensity score you would assign to which age group on a scale from  $I=lowest\ impact$  to  $5=highest\ impact$ . The item would be phrased: "How old were you when this happened to you?"

Note that "1" does not mean "not traumatic", it merely means less traumatic than higher intensity items!
0-2yrs3-5yrs (Preschool)6-9yrs (Elementary School)10-13yrs (Middle School)14-17yrs (High School)
Q4.3 Please leave your comments here (optional):
Q4.4 Again, thinking about <i>Emotional Abuse</i> , for the dimension <b>perpetrator</b> , please indicate, which intensity score you would assign to which perpetrator on a scale from $l=lowest\ impact$ to $5=highest\ impact$ . The item will be phrased: "Who did this to you?"
Note that "1" does not mean "not traumatic", it merely means less traumatic than higher intensity items!
Mother/StepmotherFather/StepfatherOther Family MemberOther Adult you knew (babysitter, teacher, family friend etc.)A Stranger
Q4.5 Please leave your comments here (optional):
Q4.6 Again, thinking about <i>Emotional Abuse</i> , for the dimension <b>intensity</b> , please indicate, which intensity score you would assign to which response option on a scale from $I=lowest$ impact to $5=highest$ impact. The item will be phrased: "How intense was this event?"
Note that "1" does not mean "not traumatic", it merely means less traumatic than higher intensity items!
Insulted you, called you things like "ugly," "lazy," or "stupid"  Put you down/humiliated you  Said they hated you or they wish you had never been born  Threatened to leave you  Threatened to physically hurt you

Q4.7 Please leave your comments here (optional):
Q5.1 The next block of questions relates to the domain of <i>Physical Abuse</i> . The stem question in the ACE-Study Questionnaire is:
Did a parent or other adult in the household <b>often</b> Push, grab, slap, or throw something at you? <b>or</b>
Ever hit you so hard that you had marks or were injured? Within the context of <i>Physical Abuse</i> , for the dimension <b>timing</b> , please indicate, which intensity score you would assign to which age group on a scale from <i>1</i> = <i>lowest impact</i> to <i>5</i> = <i>highest impact</i> . The item would be phrased: " <i>How old were you when this happened to you</i> ?"
Note that "1" does not mean "not traumatic", it merely means less traumatic than higher intensity items!
0-2yrs3-5yrs (Preschool)6-9yrs (Elementary School)10-13yrs (Middle School)14-17yrs (High School)
Q5.2 Please leave your comments here (optional):
Q5.3 Again, thinking about <i>Physical Abuse</i> , for the dimension <i>perpetrator</i> , please indicate, which intensity score you would assign to which perpetrator on a scale from $l=lowest\ impact$ to $5=highest\ impact$ . The item will be phrased: "Who did this to you?"
Note that "1" does not mean "not traumatic", it merely means less traumatic than higher intensity items!
Mother/Stepmother Father/Stepfather Other Family Member
Other Adult you knew (babysitter, teacher, family friend etc.)  A Stranger
Q5.4 Please leave your comments here (optional):

Q5.5 Again, thinking about *Physical Abuse*, for the dimension **intensity**, please indicate, which intensity score you would assign to which response option on a scale from l=lowest

<i>impact</i> to 5=highest impact. The item will be phrased: "How intense was this event?"
Note that "1" does not mean "not traumatic", it merely means less traumatic than higher intensity
items!
Grabbed, shook, slapped, pinched, spanked you on bottom with/without object - no
injury
Grabbed, shook, slapped, pinched, spanked you on bottom with/without object - minor
injury, left me with bruises or marks
Punched, kicked, knocked you down, threw a hard object at you - minor injury, left me
with bruises or marks
Punched, kicked, knocked you down, threw a hard object at you - major injury, had to
see a doctor or go to the hospital
Hit you with a hard object, choked, beat, burned you, or threatened you with a weapon -
major injury, had to see a doctor or go to the hospital
Q5.6 Please leave your comments here (optional):
Q6.1 The next block of questions relates to the domain of <i>Sexual Abuse</i> . The stem question in
the ACE-Study Questionnaire is:
Did on a late on many of last 5 areas although a resonance
Did an adult or person at least 5 years older than you <b>ever</b>
Touch or fondle you or have you touch their body in a sexual way?
or
Try to or actually have oral, anal, or vaginal sex with you?
Wishing the context of Course I Alexan for the dimension timing allows indicate
Within the context of <i>Sexual Abuse</i> , for the dimension <i>timing</i> , please indicate,
which intensity score you would assign to which age group on a scale from <i>1=lowest impact</i> to
5=highest impact. The item would be phrased: "How old were you when this happened to you?"
Note that "1" does not mean "not traumatic", it merely means less traumatic than higher intensity
items!
0-2yrs
3-5yrs (Preschool)
6-9yrs (Elementary School)
10-13yrs (Middle School)
14-17yrs (High School)
O6.2 Places lacva your comments hare (ontional):
Q6.2 Please leave your comments here (optional):
O6.3 Again, thinking about <i>Sexual Abuse</i> , for the dimension <i>nernetrator</i> , please indicate.

Q6.3 Again, thinking about *Sexual Abuse*, for the dimension *perpetrator*, please indicate, which intensity score you would assign to which perpetrator on a scale from l=lowest impact to 5=highest impact. The item will be phrased: "Who did this to you?"

Note that "1" does not mean "not traumatic", it merely means less traumatic than higher intensity items!
Mother/Stepmother Father/Stepfather Other Family Member Other Adult you knew (babysitter, teacher, family friend etc.) A Stranger
Q6.4 Please leave your comments here (optional):
Q6.5 Again, thinking about <i>Sexual Abuse</i> , for the dimension <i>intensity</i> , please indicate, which intensity score you would assign to which response option on a scale from $l=lowest$ impact to $6=highest$ impact. The item will be phrased: "How intense was this event?"
Note that "1" does not mean "not traumatic", it merely means less traumatic than higher intensity items!
Exposed your private parts or their private parts to you against your will Forced you to watch others engaged in sexual acts Fondled or touched private parts of your body or made you touch theirs against your
wishes Threatened to hurt you or tell lies about you unless you did something sexual with them Forced anal or vaginal penetration on you with objects Forced oral, anal, or vaginal penetration on you with their fingers or genitals
Q6.6 Please leave your comments here (optional):
Q7.1 The next block of questions relates to the domain of <i>Emotional Neglect</i> . The stem question in the ACE-Study Questionnaire is:  Did you <b>often</b> feel that
No one in your family loved you or thought you were important or special? <b>or</b>
Your family didn't look out for each other, feel close to each other, or support each other?
Within the context of <i>Emotional Neglect</i> , for the dimension <b>timing</b> , please indicate,

which intensity score you would assign to which age group on a scale from l=lowest impact to

=*highest impact*.

Note that "1" does not mean "not traumatic", it merely means less traumatic than higher intensity items!	
0-2yrs3-5yrs (Preschool)6-9yrs (Elementary School)10-13yrs (Middle School)14-17yrs (High School)	
Q7.2 Please leave your comments here (optional):	
Q7.3 Again, thinking about <i>Emotional Neglect</i> , for the dimension <i>perpetrator</i> please indicate, which intensity score you would assign to which perpetrator on a scale from 1=lowest impact to 5=highest impact. The item will be phrased: "Who did this to you?"	
Note that "1" does not mean "not traumatic", it merely means less traumatic than higher intensity items!	
Mother/StepmotherFather/StepfatherOther Family MemberOther Adult you knew (babysitter, teacher, family friend etc.)A Stranger	
Q7.4 Please leave your comments here (optional):	
Q7.5 Again, thinking about <i>Emotional Neglect</i> , for the dimension <b>intensity</b> , please indicate, which intensity score you would assign to which response option on a scale from <i>I=lowest impact</i> to <i>5=highest impact</i> . The item will be phrased: " <i>How intense was this event?</i> "  Note that "1" does not mean "not traumatic", it merely means less traumatic than higher intensity items!	
You did not feel loved by your family members	
People in your family did not care about your emotional needs	
People in your family did not look out for each other Your parents/guardians did not know what you were doing with your free time when you	
were not at school or work	
Your parents/guardians did not understand your problems and worries	

Q7.6 Please leave your comments here (optional):
Q8.1 The next block of questions relates to the domain of <i>Physical Neglect</i> . The stem question in the ACE-Study Questionnaire is: Did you <b>often</b> feel that You didn't have enough to eat, had to wear dirty clothes, and had no one to protect you? <b>or</b> Your parents were too drunk or high to take care of you or take you to the doctor if you needed
it?
Thinking about <i>Physical Neglect</i> , for the dimension <b>timing</b> , please indicate, which intensity score you would assign to which age group on a scale from <i>1=lowest impact</i> to <i>5=highest impact</i> .  The item would be phrased: "How old were you when this happened to you?"
Note that "1" does not mean "not traumatic", it merely means less traumatic than higher intensity items!
0-2yrs3-5yrs (Preschool)6-9yrs (Elementary School)10-13yrs (Middle School)14-17yrs (High School)
Q8.2 Please leave your comments here (optional):
Q8.3 Again, thinking about <i>Physical Neglect</i> , for the dimension <b>perpetrator</b> , please indicate, which intensity score you would assign to which perpetrator on a scale from $I=lowest\ impact$ to $5=highest\ impact$ . The item will be phrased: "Who did this to you?"
Note that "1" does not mean "not traumatic", it merely means less traumatic than higher intensity items!
Mother/Stepmother Father/Stepfather Other Family Member Other Adult you knew (babysitter, teacher, family friend etc.) A Stranger

Q8.4 Please leave your comments here (optional):
Q8.5 Again, thinking about <i>Physical Neglect</i> , for the dimension <b>intensity</b> , please indicate, which intensity score you would assign to which response option on a scale from $I=lowest$ impact to $5=highest$ impact. The item will be phrased: "How intense was this event?"
Note that "1" does not mean "not traumatic", it merely means less traumatic than higher intensity items!
You had nobody to take care of you and protect you You did not have enough clothes to wear to keep you warm or protected from the weather
Your parents/guardians did not give you enough food even when they could easily have done so
Your parents/guardians were too drunk or intoxicated by drugs to take care of you There was nobody to take you to the doctor if you needed it
Q8.6 Please leave your comments here (optional):
Q9.1 The next block of questions relates to the domain of <i>Parental Separation/Divorce</i> . The stem question in the ACE-Study Questionnaire is:  Were your parents <b>ever</b> separated or divorced?
Thinking about <i>Parental Separation/Divorce</i> , for the dimension <b>timing</b> , please indicate, which intensity score you would assign to which age group on a scale from $l=lowest\ impact$ to $5=highest\ impact$ . The item would be phrased: "How old were you when this happened to you?"
Note that "1" does not mean "not traumatic", it merely means less traumatic than higher intensity items!
0-2yrs 3-5yrs (Preschool)
6-9yrs (Elementary School)
10-13yrs (Middle School) 14-17yrs (High School)
Q9.2 Please leave your comments here (optional):

Q9.3 Thinking about *Parental Separation/Divorce*, for the dimension **intensity**, please indicate, which intensity score you would assign to which response option on a scale from I=lowest impact to 5=highest impact. The item will be phrased: "How intense was this event?"

Note that "1" does not mean "not traumatic", it merely means less traumatic than higher intensity items!
Your parents/guardians separated peacefully and harmoniously Your standard of living decreased significantly after the separation/divorce of your parents/guardians Your parents/guardians said bad things about each other and tried to get you on their side You lost contact with one parent/guardian after the separation/divorce You had to talk to a lawyer or judge during your parents'/guardians' separation/divorce
Q9.4 Please leave your comments here (optional):
Q10.1 The next block of questions relates to the domain of <i>Household Violence</i> . The stem question in the ACE-Study Questionnaire is:  Was a parent or other adult in the household  Often pushed, grabbed, slapped, or had something thrown at her?
or Sometimes or often kicked, bitten, hit with a fist, or hit with something hard? or Ever repeatedly hit over at least a few minutes or threatened with a gun or knife?
Within the context of <i>Household Violence</i> , for the dimension <b>timing</b> , please indicate, which intensity score you would assign to which age group on a scale from $l=lowest\ impact$ to $5=highest\ impact$ . The item would be phrased: "How old were you when this happened to you?"
Note that "1" does not mean "not traumatic", it merely means less traumatic than higher intensity items!
0-2yrs3-5yrs (Preschool)6-9yrs (Elementary School)10-13yrs (Middle School)14-17yrs (High School)
Q10.2 Please leave your comments here (optional):
Q10.2 Please leave your comments here (optional):  O10.3 Again, thinking about Household Violence, for the dimension perpetrator, please

Q10.3 Again, thinking about *Household Violence*, for the dimension **perpetrator**, please indicate, which intensity score you would assign to which perpetrator on a scale from l=lowest impact to 4=highest impact. The item will be phrased: "Which household member was this?"

Note that "1" does not mean "not traumatic", it merely means less traumatic than higher intensit items!
Mother/Stepmother Father/Stepfather Other Family Member Other Adult living in your household (e.g., mother's boyfriend, a family friend etc.)
Q10.4 Please leave your comments here (optional):
Q10.5 Again, thinking about <i>Household Violence</i> , for the dimension <b>intensity</b> , please indicate, which intensity score you would assign to which response option on a scale from $1=lowest$ impact to $5=highest$ impact. The item will be phrased: "How intense was this event?"
Note that "1" does not mean "not traumatic", it merely means less traumatic than higher intensit items!
You saw a household member:
Being called names or having something thrown at - no injury Being grabbed, pushed, shook, pulled - minor injury Being slapped, bit, hit with a minor object, threw something, punched, kicked with injury Being choked, hit with a major object, burned, threatened with a weapon, or misused - major injury Being killed by another family member
Q10.6 Please leave your comments here (optional):

Q11.1 The next block of questions relates to the domain of *Household Substance Use*. The stem question in the ACE-Study Questionnaire is:

Did you live with anyone who was a problem drinker or alcoholic or who used street drugs? Thinking about *Household Substance Use*, for the dimension **timing**, please indicate, which intensity score you would assign to which age group on a scale from l=lowest impact to 5=highest impact. The item would be phrased: "*How old were you when this happened to you?*"

Note that "1" does not mean "not traumatic", it merely means less traumatic than higher intensity items!
0-2yrs
3-5yrs (Preschool)
6-9yrs (Elementary School)
10-13yrs (Middle School)
14-17yrs (High School)
Q11.2 Please leave your comments here (optional):
Q11.3 Again, thinking about <i>Household Substance Use</i> , for the dimension <b>perpetrator</b> , please indicate, which intensity score you would assign to which perpetrator on a scale from $I=lowest$ impact to $4=highest$ impact. The item will be phrased: "Which household member was this?"
Note that "1" does not mean "not traumatic", it merely means less traumatic than higher intensity items!
Mother/Stepmother
Father/Stepfather
Other Family Member
Other Adult living in your household (e.g., mother's boyfriend, a family friend etc.)
Q11.4 Please leave your comments here (optional):
Q11.5 Again, thinking about <i>Household Substance Use</i> , for the dimension <b>intensity</b> , please indicate, which intensity score you would assign to which response option on a scale from $l$ =lowest impact to $5$ =highest impact. The item will be phrased: "How intense was this event?"
Note that "1" does not mean "not traumatic", it merely means less traumatic than higher intensity items!
A household member was hospitalized/institutionalized because of substance use
You did not have your daily needs fulfilled because of a household member's substance
use (e.g., you did not have enough food)
You had to take on additional responsibilities because of a family member's substance
use (e.g., you had to take care of your siblings)
The substance use of a household member negatively influenced your education
A household member died because of substance use

Q11.6 Please leave your comments here (optional):
Q12.1 The next block of questions relates to the domain of <i>Household Mental Illness</i> . The stem question in the ACE-Study Questionnaire is:  Was a household member depressed or mentally ill or did a household member attempt suicide?
In the context of <i>Household Mental Illness</i> , for the dimension <b>timing</b> , please indicate, which intensity score you would assign to which age group on a scale from $l=lowest\ impact$ to $5=highest\ impact$ . The item would be phrased: "How old were you when this happened to you?"
Note that "1" does not mean "not traumatic", it merely means less traumatic than higher intensity items.
0-2yrs3-5yrs (Preschool)6-9yrs (Elementary School)10-13yrs (Middle School)14-17yrs (High School)  Q12.2 Please leave your comments here (optional):
Q12.3 Again, thinking about <i>Household Mental Illness</i> , for the dimension <b>perpetrator</b> , please indicate, which intensity score you would assign to which perpetrator on a scale from $I=lowest$ impact to $4=highest$ impact. The item will be phrased: "Which household member was this?"
Note that "1" does not mean "not traumatic", it merely means less traumatic than higher intensity items!
Mother/Stepmother Father/Stepfather Other Family Member Other Adult living in your household (e.g., mother's boyfriend, a family friend etc.)
Q12.4 Please leave your comments here (optional):
Q12.5 Again, thinking about <i>Household Mental Illness</i> , for the dimension <b>intensity</b> , please indicate, which intensity score you would assign to which response option on a scale from <i>1=lowest impact</i> to 6=highest impact. The item will be phrased: "How intense was this event?"

Note that "1" does not mean "not traumatic", it merely means less traumatic than higher intensity

items! When you were growing up, a household member:
Took medication and/or received treatment for mental illness Attempted suicide Was institutionalized because of mental illness Blamed you for their mental illness Had a mental illness that negatively influenced your education and daily needs Had a mental illness and did not receive treatment for it
Q12.6 Please leave your comments here (optional):
Q13.1 The next block of questions relates to the domain of <i>Household Member Incarceration</i> . The stem question in the ACE-Study Questionnaire is: Did a household member go to prison?
Within the context of <i>Household Member Incarceration</i> , for the dimension <b>timing</b> , please indicate, which intensity score you would assign to which age group on a scale from $l=lowest$ impact to $5=highest$ impact. The item would be phrased: "How old were you when this happened to you?"
Note that "1" does not mean "not traumatic", it merely means less traumatic than higher intensity items!
0-2yrs3-5yrs (Preschool)6-9yrs (Elementary School)10-13yrs (Middle School)14-17yrs (High School)
Q13.2 Again, thinking about <i>Household Member Incarceration</i> , for the dimension <b>perpetrator</b> , please indicate, which intensity score you would assign to which perpetrator on a scale from $I=lowest\ impact$ to $4=highest\ impact$ . The item will be phrased: "Which household member was this?"
Note that "1" does not mean "not traumatic", it merely means less traumatic than higher intensity items!
Mother/Stepmother Father/Stepfather Other Family Member Other Adult living in your household (e.g., mother's boyfriend, a family friend etc.)

Q13.3 Please leave your comments here (optional):
Q13.4
Again, thinking about <i>Household Member Incarceration</i> , for the dimension <b>intensity</b> , please indicate, which intensity score you would assign to which response option on a scale from $l$ =lowest impact to $6$ =highest impact. The item will be phrased: "How intense was this event?"
Note that "1" does not mean "not traumatic", it merely means less traumatic than higher intensity items!
When you were growing up:
You were not able to stay in contact with a household member after they were incarcerated
You witnessed a household member's arrest You had to move or live with somebody else because a household member was
incarcerated  Your standard of living decreased significantly because a household member was incarcerated
You experienced any additional adversity you have not experienced before the incarceration of a household member
Your education was impacted because a household member was incarcerated
Q13.5 Please leave your comments here (optional):
Q14.1 Thank you for taking part in our survey!

We will synthesize responses and send out a summary to all participants once we have received all responses. You will have the opportunity to provide feedback on our summary.

If you want to be acknowledged by name in our publication for this study, please follow the link below to a *separate textbox* to enter your full name, title, and email address.

We will not be able to tie your name to your responses to the Round 2 survey.

# Chapter 4: A Pilot Study of the Adverse Childhood Experiences – Dimensions Questionnaire (ACE-DQ): Associations with Depression

**Background**. Recent research on ACEs proposed a set of standardized items to assess ACE dimensions, such as the frequency or timing of adverse events, that can be added to the original ACE-Study Questionnaire. The goal of the present study was to test the refined ACE-Dimensions Questionnaire (ACE-DQ) to determine its predictive validity and compare scoring approaches.

**Methods**. We conducted a cross-sectional online survey to collect data on the ACE-Study Questionnaire and the newly developed ACE dimension items, mental health outcomes, and demographics. We compared ACE exposure as assessed with the ACE index and the ACE-DQ, and their associations with depression outcomes. We used logistic regression to compare the predictive validity of different ACE scoring approaches for depression outcomes.

Results. Participants (n=450) were on average 36 years old, half were female, and the majority were White. Almost half reported depressive symptoms and approximately two-thirds had experienced at least one ACE. Participants reporting depression had significantly higher ACE scores for the ACE index and the ACE-DQ. All ACE-DQ scoring approaches were consistent with ACE index results and in the expected direction. Only between one- and two-thirds of participants perceived the impact of the ACEs they experienced as negative. Correlations between ACEs and depression symptoms were largest for the ACE index and smallest for perception weighted ACE-DQ scores. Using the ACE index, participants with ACEs were 45% more likely to report depression symptoms than participants without ACEs (OR 1.45, 95%CI 1.33-1.58). When using perception weighted ACE-DQ scores, participants had smaller, yet significant odds of reporting depression outcomes.

**Discussion**. Our results suggest that the ACE index may overestimate the impact of ACEs and the effects of ACEs on depression outcomes. Adding the comprehensive set of conceptual dimensions to more fully weight participants' experience of adverse events can increase the accuracy of ACE measurement but will also increase participant burden considerably. We recommend including items to assess a person's perception of each adverse event for improved screening efforts and for research focused on cumulative adversity.

#### Introduction

Adverse childhood experiences (ACEs) are increasingly recognized as a major contributor to mental illness (Anda et al., 2007) and many researchers recommend routine screening for ACEs in certain populations or environments, such as college students (Karatekin, 2018), or pediatric health care settings (Barnes et al., 2020). Despite the recognized association with laterlife health consequences, the assessment of ACEs has not generally been incorporated as a standard procedure in clinical or educational settings (Rariden, SmithBattle, Yoo, Cibulka, & Loman, 2021). In cases in which ACEs are assessed, simplistic screening tools such as the 10item ACE-Study Questionnaire (Felitti et al., 1998) are used. These equally weighted binary measures do not reflect the magnitude of potential consequences of ACEs (Anda, Porter, & Brown, 2020). Even within the same ACE score, individual experiences can vary widely from one person to another (Anda et al., 2020). For example, a person with an ACE score of 1 could have experienced the divorce of their parents, or could have experienced frequent sexual abuse over years by multiple perpetrators. In addition, while a person might have experienced a certain ACE, they might not consider the effect as negative. An example would be the incarceration of a violent or abusive household member, which would remove a negative influence from a child's life.

Most research is still focused mainly on the cumulative effect of different types of ACEs, also called ACE domains, without distinguishing between the different types or other aspects of the stressors (e.g. Hughes et al., 2017). The ACE index has been widely applied in state-wide screening programs (Anda et al., 2020). However, the effects different domains can elicit in a person may depend on a variety of other specific factors, also called dimensions, including the frequency and timing of events, or a person's perception of the event. Different theories underlie

the idea of conceptual dimensions described in relation to ACEs. These are for example the Theory of Stress and Coping (Folkman & Lazarus, 1984), which relates to the perception of events, and Betrayal Trauma (Freyd, 2008), and Attachment Theory (Kwako, Noll, Putnam, & Trickett, 2010), which relate to the role of the perpetrator. While the ACE-Study Questionnaire is a quick and easy tool to assess the overall prevalence of ACEs, it does not measure these additional factors (Zarse et al., 2019).

#### **ACEs and Mental Health Disorders**

Childhood is an incubation period for many disorders that affect the health of the whole population (Forrest & Riley, 2004). Most childhood abuse-related psychopathology sets on between the ages of 18 and 35 (Lupien, McEwen, Gunnar, & Heim, 2009), and can lead to the development of maladaptive behaviors that can influence health throughout the lifespan (Cukor & McGinn, 2006). Previous research has demonstrated a graded dose-response relationship between childhood trauma and mental health issues in later life (Anda et al., 2007; Kalmakis & Chandler, 2015; Zarse et al., 2019). For example, persons with four or more ACEs have increased risks for depression (Odds ratio (OR) 4.4, 95% Confidence Interval (CI) 3.5-5.5) and anxiety (OR 3.7, 95% CI 2.6-5.2) with  $\geq$ 4 ACEs (Hughes et al., 2017). The use of antidepressant medication significantly increases with increased ACE exposure; persons with 5 or more ACEs are 3 times as likely to take antidepressants compared to persons with no ACEs (Risk ratio (RR)) 2.9, 95% CI 2.4-3.6; Anda et al., 2007). Persons with ACEs are more likely to have negative affect, have higher rates of personality disorders, and higher rates of substance use disorders (Herzog & Schmahl, 2018; Merrick et al., 2017; Neumann, 2017; Raglan, Schmidt, & Schulkin, 2017).

However, not all research has found a significant relationship between ACEs and mental health outcomes (Zarse et al., 2019), and some researchers even found an inverse relationship between ACEs and depression symptoms (Warne et al., 2017). Research suggests that there is a linear relationship between the intensity of child abuse and the degree of depression (Cukor & McGinn, 2006), which might explain different outcomes for studies using an unweighted ACE index.

# **Significance and Hypotheses**

For adults at risk of having adverse outcomes because of ACEs, it is crucial to further assess such details about their experiences and the way in which they affect their life so we can allocate resources in a meaningful way. Researchers call for the development and use of more advanced ACE measurement tools to be able to distinguish between the effects of different ACEs (Anda et al., 2020; Zarse et al., 2019). Including the exposure dimensions of ACEs will be helpful in increasing the accuracy of ACE assessment tools to inform decision-making about public health resource allocation, and to increase the understanding of the downstream effects of experiencing childhood adversity.

This study will fill a gap in the literature by examining the value of assessing different conceptual dimensions in the measurement of adverse childhood experiences and their relationship with later-life outcomes, specifically with different depression outcomes. We are particularly looking at the role of a person's perception of an adverse event for its effect on depression symptoms in later life. We hypothesize that the (1) ACE index is an overestimation of the impact of ACEs, and it inflates the relationship between ACEs and depression outcomes, and that (2) effect sizes will be more refined and precise when conceptual dimensions are taken into

consideration. Overall, results from this study will contribute to the usefulness of conceptual dimensions of ACEs for research and practice, and will lay the basis for further research targeted to conceptual refinement.

#### **Research Questions**

- 1. What are the characteristics of the ACE Dimensions Questionnaire (ACE-DQ) using various scoring options as compared to the ACE-Study Questionnaire?
- 2. How does the addition of dimensions to ACE domains change the relationship between ACEs and depression outcomes?
- 3. How do predictions of depression outcomes differ for the ACE index and different ACE-DQ scoring approaches?

#### **Methods**

#### **Sampling Plan**

We used a convenience sample of online survey respondents who are registered with Amazon's Mechanical Turk (MTurk; <a href="https://www.mturk.com/">https://www.mturk.com/</a>). Amazon's MTurk provides access to a national sample of U.S. adults, that is likely younger and more educated than the general U.S. population (Walters, Christakis, & Wright, 2018). To be eligible for this study, participants had to be based in the U.S., be at least 18 years of age, have reading literacy in English, and are registered as an MTurk Worker. A description of the survey and study objectives accompanied by a link to the anonymous online survey built in Qualtrics (<a href="www.Qualtrics.com">www.Qualtrics.com</a>) was shared with participants via the MTurk. Participants were reimbursed \$0.50 for the completion of the survey. The study was available for completion on desktop, tablet, and smartphone and was open for 2 weeks.

#### **Sample Size Calculation**

We used the sample size estimation formula for cross-sectional studies by Aday and Cornelius (2006) for our sample size calculation:  $n = \frac{z_{1-\alpha/2}^{*} * P(1-P)}{d^2}$ , where P=estimated proportion, and d=desired precision. We estimate that half of our study population have experienced ACEs and set  $\alpha$ =0.05. Based on these criteria, our sample size estimation for the present study is  $n = \frac{1.96^2*(0.5)(0.5)}{0.05^2} = 384$  participants.

#### **Human Subjects Protocols**

Ethical approval for this study was obtained from the university's Institutional Review Board. At the beginning of the Qualtrics survey, participants were informed about the study purpose, the estimated time for completion, and any potential harms to them. By clicking the "next" button on the first survey page, participants submitted their online consent. We provided links to mental health resources in the form of websites and hotlines for participants who may have become disturbed responding to survey questions on the last page of the survey, as well as after the ACE and mental health sections. Contact information to the research team was provided in case participants wanted to reach out with questions or concerns about the study.

#### Instrumentation

The online survey in Qualtrics contained a minimum of 55 and a maximum of 113 items, depending on the number of ACE domains a participant has experienced.

Exposure. The main exposure was a history of childhood adversity, as assessed by the 10-item ACE-Study Questionnaire (Felitti et al., 1998) as well as the ACE dimensions items developed in Krinner Dissertation Paper 2. If an ACE domain stem question was answered with

"no," the questionnaire skipped to the next ACE domain stem question without listing the ACE dimensions items. For example, if participants answer "no" to the Household Mental Illness stem question "Was a household member depressed or mentally ill or did a household member attempt suicide?" they were not asked the dimension questions for this domain and moved to the next domain item. Therefore, the ACE section of the survey had a minimum of 10 and a maximum of 48 items.

Outcome. To screen for depression symptoms, we used the Patient Health Questionnaire-2(PHQ-2; Kroenke, Spitzer, & Williams, 2003b). Questions assess how often a participant has been bothered by certain problems over the last 2 weeks on a 4-point scale from 0=not at all to 3=nearly every day. The PHQ-2 has shown good psychometric properties and is a valid measure for depression screening (Kroenke, Spitzer, & Williams, 2003a). PHQ-2 scores range from 0-6. A score of 3 represents a cutpoint for possible major depressive disorder (Kroenke et al., 2003a). We created a binary variable for logistic regression for depression symptoms based on this cutpoint. Additionally, participants were asked if they have ever been diagnosed with depression, and if they have ever taken or been prescribed antidepressant medication.

Confounding Variables. We assessed demographic variables including age, gender, and race/ethnicity, and education level because of their social and biological relevance. To screen for anxiety, we used the General Anxiety Disorder-2 (GAD-2; Kroenke, Spitzer, Williams, Monahan, & Löwe, 2007). The GAD-2 showed reasonable sensitivity and specificity in different populations and is a valid tool to assess 4 different anxiety disorders (Kroenke et al., 2007). GAD-2 scores range from 0-6. A score of 3 or more indicates a possible clinically significant anxiety disorder (Kroenke et al., 2007). We created a binary variable for anxiety disorders based

on this cutpoint. Additionally, participants were asked if they have ever been diagnosed with an anxiety disorder, and if they have ever taken or been prescribed anxiolytic medication.

We assessed self-rated emotional health (SREH) using a single-item measure on 5-point Likert-scales from 1=poor to 5=excellent, as self-rated health has been connected to ACEs (Krinner, Warren-Findlow, & Bowling, 2020), depression and anxiety (Ambresin, Chondros, Dowrick, Herrman, & Gunn, 2014; Vogel & Barry, 2019). We created a dichotomous variable for poor or fair SREH.

## **Data Analysis**

All analyses were conducted in SPSS version 27 (IBM Corp., 2021). After downloading the data from the Qualtrics server, we cleaned the data and excluded responses of participants who have not completed the survey, completed the survey in an unreasonably short or long amount of time, or who had missing data in the main variables.

## **Scoring**

The ACE-Study Questionnaire was scored according to Felitti et al. (1998): affirmative responses to the domain stem questions were counted as "1" and added up to create an index of all ACEs (range 0-10). We used the continuous version of the index for analyses. We compared the properties of the ACE index scoring to four different ACE-DQ scoring approaches: (1) the sum of all dimension values within a domain; (2) a mean dimension value for each domain; (3) a domain-specific, perception weighted mean of the dimension values for frequency, timing, perpetrator, and intensity or (4) perception weighted ACE index domains.

For scoring, response options for the dimensions of frequency, timing, perpetrator, and intensity had a possible impact value between 1 and 5. For example, values for the dimension of

timing within the domain of Physical Neglect had the values 1 (14-17yrs (High School)), 2 (10-13yrs (Middle School)), 3 (6-9yrs (Elementary School)), 4 (0-2yrs), and 5 (3-5yrs (Preschool)).

For the scoring approach (2) and (3), in which all dimensions are added up, the dimension of perception had the values 2 (*very negative*), 1 (*negative*), 0 (*neither positive nor negative OR both positive and negative*), -1 (*positive*), and -2 (*very positive*). For the scoring approaches (1) and (4) the values for frequency, timing, perpetrator, and intensity are multiplied i.e., weighted by the participant's perception of the event. Higher domain scores represent a larger negative impact on later-life outcomes, lower domain scores represent a smaller negative impact. For these scoring approaches, the dimension of perception had the values 3 (*very negative*), 2 (*negative*), 1 (*neither positive nor negative OR both positive and negative*), 1/2 (*positive*), and 1/3 (*very positive*).

# Statistical Analyses

We used descriptive statistics to calculate participant demographic and health information. Chi<sup>2</sup>-analyses were used to compare demographic and health information for participants with and without depression. We present the proportion of participants who report that they have experienced a certain ACE domain, and how they rated the impact of the experience.

For research question 1, we present descriptive information on the different ACE operationalization approaches; we compared score ranges based on the ACE index and the four ACE dimension scoring approaches. We compared ACE prevalence between the ACE index and ACE-DQ prevalence based on those ACE domains which were perceived as *negative* or *very negative*.

For research question 2, we correlated continuous ACE exposure for all operationalization approaches with the continuous PHQ-2 score to investigate the discriminant validity of adding

dimensions to the measurement of ACEs (Rönkkö & Cho, 2020). To determine outcome distribution, we compared average ACE exposure for participants with versus without depression outcomes (PHQ-2≥3, ever been diagnosed, take or have been prescribed medication) based on all operationalization approaches. T-tests were used to assess if ACE scores differed significantly between the outcome groups.

To answer research question 3, we used unadjusted and adjusted logistic regressions to examine the relationship between ACEs in all operationalization approaches and depression outcomes. In the final models, we adjusted for demographic characteristics.

### Results

We completed data collection within 4 days. Of 1,035 total responses, 226 were incomplete. We excluded a further 359 responses due to missing or invalid data for the main variables, leaving an analytic sample of 450 participants.

# **Demographic and Health Characteristics**

Table 1 shows participants' demographic and health information for the entire sample, and for participants with and without depression symptoms. Participants (n=450) were between 18-and 79-years old (Mean (SD) = 36.1 (11.8)); half were female. The majority of the sample was White and had completed a 4-year college education. Almost half of the participants had an indication for an anxiety disorder (GAD-2≥3). One-fifth of participants reported poor or fair SREH. Almost half of the participants had a PHQ-2 score ≥3; approximately one-third reported a previous depression diagnosis (36%) and that they were taking or have been prescribed antidepression medication (31%).

We present descriptive data for participants with and without depression based on the PHQ-2 cutpoint of 3. Participants with depression symptoms were significantly younger and more likely to be male. Participants with depression symptoms had significantly higher rates of anxiety and poor or fair SREH. Participants with depression symptoms were more educated, more likely to have a previous depression diagnosis, and more likely to use or have been prescribed antidepression medication.

	Total	Depression Symptoms (PHQ-2≥3) <sup>‡</sup>		
Characteristics	% (n) n=450	yes n=213	no n=304	
Age – mean (SD)	36.1 (11.8)	34.6 (10.2)	37.2 (12.7)**	
Gender – male	50.0 (225)	59.1 (110)	43.6 (115)**	
Race				
White	75.1 (338)	79.0 (147)	72.3 (191)	
Black	13.3 (60)	15.1 (28)	12.1 (32)	
Other non-White	11.6 (52)	5.9 (11)	15.5 (41)*	
Completed a 4-year College Education	66.4 (299)	71.0 (132)	63.3 (167)	
Depression Diagnosis	36.4 (164)	46.5 (99)	21.4 (65)**	
Use of Anti-depression Medication	31.1 (140)	36.2 (77)	20.7 (63)**	
Anxiety (GAD-2≥3) ‡	41.3 (186)	80.6 (150)	13.6 (36)**	
Poor/fair Self-rated Emotional Health	18.9 (85)	31.2 (58)	10.2 (27)**	

<sup>\*</sup>p\le .05; \*\*p\le .01

Table 4.1. *Participant Demographic and Health Characteristics* (*n*=450)

Table 2 shows the prevalence of participants who have indicated that they have experienced an ACE domain and how they rated the impact of the ACE domain on their life. Emotional Abuse had the highest prevalence (41%, n=186) and Household Member Incarceration was experienced the least (11%, n=49). Approximately one-third of the participants reported that they have experienced Physical Abuse, Emotional Neglect, or Parental Separation/Divorce; approximately one-fourth reported Household Violence, Household Substance Use, and Household Mental Illness.

For most domains, between half and two-thirds of the participants who reported that they have experienced a specific ACE domain perceived the impact of the event as *negative* or *very negative* (49% for Physical Neglect to 66% for Household Mental Illness). Only one third perceived the impact of Household Member Incarceration as *negative* or *very negative*. For all domains, between 16 and 39% (Household Mental Illness and Household Violence, respectively) of those who reported experiencing a specific ACE domain perceived the impact of the experience as *both negative and positive* or *neither negative nor positive*. Twenty-nine percent of the participants who had experienced Household Member Incarceration perceived the experience as *positive* or *very positive*. For all other domains, between 11 and 22% (Parental Separation/Divorce and Physical Neglect, respectively) perceived the impact of their experience as *positive* or *very positive*.

ACE Domains	Participants Who Reported That They Have Experienced an ACE Domain	Negative or Very Negative	Both Negative and Positive Or Neither Negative Nor Positive	Positive or Very Positive		
	% (n)	%				
<b>Emotional Abuse</b>	41 (186)	63.4	22.6	14.0		
Physical Abuse	35 (156)	58.4	26.3	15.4		
Sexual Abuse	17 (76)	54.0	27.6	18.4		
<b>Emotional Neglect</b>	32 (141)	62.4	23.4	14.1		
Physical Neglect	20 (88)	48.9	29.5	21.6		
Parental Separation/	32 (142)	58.5	30.3	11.3		
Divorce						
Household Violence	21 (93)	61.3	38.7	11.9		
Household Substance	25 (113)	60.2	25.7	14.2		
Use						
<b>Household Mental</b>	24 (107)	66.4	15.9	17.7		
Illness						
Household Member	11 (49)	34.7	36.7	28.6		
Incarceration						

Table 4.2. Proportion of Participants Who Reported that they Have Experienced and ACE Domain and Rating of the Impact of ACE Domains (n=450)

# **Research Question 1**

We examined 4 different scoring approaches for the ACE-DQ. Characteristics for all ACE scoring approaches are presented in Table 3. Possible domain scores and overall ACE scores vary between the different scoring approaches with the smallest range for the ACE index and the largest range for the sum of all dimension responses for each domain (Table 3, Scoring Approach 1). In the present study, participants did not reach the full scoring range for the scoring approaches (1), (2), and (3). The ACE index mean and scoring approach (1) mean in the present study fall into the second-lowest quintile of the respective possible score range. Scoring approach (2), (3), and (4) means fall into the lowest quintile. Scoring approaches range in complexity with the easiest scoring procedure for the ACE index and the most complex scoring procedure for the perception weighted ACE dimensions mean (Table 3, Scoring Approach 3).

Characteristics	ACE Index	(1) Sum of Dimension Responses for each ACE Domain	(2) Mean of Dimension Responses for each ACE Domain	(3) Dimension Mean Weighted by Domain Perception	(4) ACE Domains Weighted by Perception Response
Range per Domain	0-1	0-22 (PSD: 0-	0-4.4 (PSD:0-4)	0-15	0-3
		12)			
Possible Total Range	0-10	0-210	0-43.6	0-150	0-30
<b>Total Range Present</b>	1-10	0-169	0-34.75	0-115.6	0-30
Study					
Present Study Mean	2.8 (2.9)	34.2 (37.7)	7.2 (7.8)	16.1 (20.7)	4.6 (5.9)
(SD)					
Complexity of	Easy	Relatively easy	Somewhat	Complex	Relatively Easy
Scoring Approach			complex		

<sup>\*</sup>PSD=Parental Separation/Divorce

Table 4.3. Scoring Aspects of the ACE Index and Different ACE Dimension Scoring Approaches (n=450)

Figure 1 shows the ACE prevalence for the ACE index and the ACE-DQ. Based on the ACE index, approximately one-third of the participants reported no ACEs, one-third 1-3 ACEs, and one-third 4-10 ACEs. When the perceived impact of the experience is factored in, using the

ACE-DQ, over half had no ACE or no negative impact from ACEs, 29% had 1-3 negative ACEs, and only 18% had 4-10 negative ACEs.

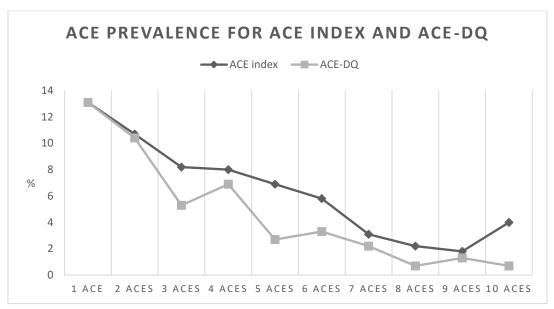


Figure 4.1. ACE Prevalence for the ACE index and the ACE-DQ

## **Research Question 2**

Table 4 shows correlations of ACE scores with the continuous PHQ-2. The continuous ACE index had a significant, very large positive correlation with the continuous PHQ-2 (r=.49, p=.00). All ACE-DQ scoring approaches had a significant large positive correlation with the continuous PHQ-2 (r=.31-.45, p=.00). All correlations were in the expected direction. The sum of dimension responses (scoring approach (1)) and the mean of dimensions responses (scoring approach (2)) had lower correlations with the continuous PHQ-2, but within 10% of the ACE index correlation. Funder and Ozer (2019) and Brydges (2019) describe how effect sizes/correlations above r=.40 in psychological and gerontological research appear to be gross overestimations. The perception weighted scores (scoring approaches (3) and (4)) were more than 30% lower, but were still highly correlated with the PHQ-2, as compared to the ACE index.

All ACE-DQ scoring approaches were highly correlated with the ACE index (r=.78-.98, p=.01; not shown in the table).

ACE Operationalization Approach Outcome	ACE Index	(1) Sum of Dimension Responses for each ACE Domain	(2) Mean of Dimension Responses for each ACE Domain	(3) Dimension Mean Weighted by Domain Perception	(4) ACE Domains Weighted by Perception Response
Depression Symptoms (PHQ- 2) r (sig).	.487**	.450**	.450**	.308**	.325**

<sup>\*\*</sup>p=.00

Table 4.4. Correlations Between Continuous ACE index, ACE-DQ using Different Scoring Approaches and Continuous Depression Scores (n=450)

We used t-tests to compare average ACE exposure for participants with and without depression using 3 different outcome measures (PHQ-2, ever been diagnosed, take or have been prescribed medication) for the ACE index and the four ACE dimension scoring approaches (Table 5). Consistently, participants with depression had significantly higher ACE scores compared to participants without depression regardless of the ACE measure or the depression outcome. All ACE-DQ scoring approaches were consistent with ACE index results and in the expected direction. For all depression outcomes, perception weighted ACE-DQ scores detected the smallest mean difference in depression outcomes between participants with and without ACEs.

		(1) Sum of	(2) Mean of	(3) Dimension	(4) ACE
ACE		Dimension	Dimension	Mean	Domains
Operationalization	ACE Index	Responses for	Responses for	Weighted by	Weighted by
Approach		each ACE	each ACE	Domain	Perception
		Domain	Domain	Perception	Response
Outcome			Mean (SD)		
<b>Depression Symptoms</b>					
(PHQ-2≥3)					
Yes	4.1 (3.1)	5.7 (40.3)	10.6 (8.3)	21.0 (21.4)	6.5 (6.1)
No	1.5 (2.1)	19.4 (30.4)	4.1 (6.3)	10.6 (18.6)	3.2 (5.3)
t-test (sig.)	-10.7**	-9.4**	-9.4**	-5.5**	-6.1*
<b>Depression Diagnosis</b>					
Yes	4.1 (3.2)	53.5 (43.4)	11.1 (9.0)	24.7 (24.8)	7.5 (7.0)
No	1.7 (2.2)	20.2 (28.6)	4.3 (5.9)	9.4 (15.0)	2.9 (4.5)
t-test (sig.)	-9.5**	-9.7**	-9.6**	-8.1**	-8.3**
Use of Anti-					
depression Medication					
Yes	4.2 (3.4)	55.1 (44.5)	11.4 (9.2)	25.3 (24.8)	7.6 (7.1)
No	1.8 (2.2)	22.2 (29.7)	4.7 (6.1)	10.3 (16.2)	3.2 (4.7)
t-test (sig.)	-8.8**	-9.2**	-9.1 **	-7.6**	-7.8**

<sup>\*</sup>p\le .01, \*\*p\le .01

Table 4.5. Comparison of Participants' Average ACE Exposure in form of the ACE index and Different ACE Dimension Scoring Approaches with Depression Outcomes (n=450)

# **Research Question 3**

The above analyses suggest that scoring approaches (1) and (2) might be overestimations of the impact of ACEs and of the effects of ACEs on depression outcomes. Because of the apparent relevance of a person's perception, we focused on the perception-weighted dimension scoring approaches for further analyses. Table 6 presents unadjusted and adjusted logistic regressions to examine the relationship between ACEs and depression outcomes.

In the unadjusted model using the ACE index (Model 1), persons with ACEs were 45% more likely to report depression symptoms based on the PHQ-2 (OR 1.45, 95% CI 1.33-1.58). When we adjusted the ACE index for demographics (Model 2), the association between ACEs and depression symptoms increased slightly and remained significant.

In models 3 and 4 we conducted similar models for each ACE-DQ scoring approach to examine how weighting by perception affects the associations with depression symptoms. Associations between the sum of the perception weighted ACE dimensions mean (Model 3) and depression symptoms were negligible, yet significant and in the expected direction (OR 1.03, 95%CI 1.02-1.04). When using the sum of the perception weighted ACE domains (Model 4), participants with ACE had 11% higher odds of reporting depression symptoms compared to participants without ACEs (OR 1.11, 95%CI 1.07-1.15). Associations increased slightly and remained significant in the adjusted model.

Associations between the ACE index and the ACE-DQ and other depression outcomes were comparable and showed the same patterns in all models.

	ACE	Index	ACE-DQ Perception Weighted Scoring Approaches				
Depression Outcomes	Unadjusted Individual Domain Models (Model 1)	Adjusted Complete Domains Model (Model 2)*	(3) Unadjusted Perception Weighted ACE Dimensions Mean Models (Model 3)	Adjusted Perception Weighted ACE Dimensions Mean Models (Model 3a)*	(4) Unadjusted Perception Weighted Domains Models (Model 4)	Adjusted Perception Weighted Domains Model (Model 4a)*	
	OR (95% CI)						
Depression Symptoms (PHQ-2 ≥3)	1.45 (1.33-1.58)	1.48 (1.35-1.62)	1.03 (1.02-1.04)	1.03 (1.02-1.04)	1.11 (1.07-1.15)	1.12 (1.08-1.16)	
Depression Diagnosis	1.38 (1.27-1.49)	1.39 (1.28-1.51)	1.04 (1.03-1.05)	1.04 (1.03-1.06)	1.15 (1.11-1.20)	1.16 (1.11-1.21)	
Use of Anti- depression Medication	1.34 (1.24-1.45)	1.34 (1.24-1.45)	1.04 (1.03-1.05)	1.04 (1.03-1.05)	1.14 (1.09-1.18)	1.13 (1.09-1.18)	

<sup>\*</sup>models adjusted for age, gender, and race/ethnicity

Table 4.6. Unadjusted and Adjusted Logistic Regression Models for ACE Domains with and without Perception Weighted Dimensions and their Association with Depression Outcomes (n=450)

# **Discussion**

In this study, we compared the conventional ACE index to a new measure (ACE-DQ) that incorporated dimensions previously found to be relevant to ACE domains. Four different

ACE-DQ scoring approaches were examined. We hypothesized that (1) the ACE index is overestimating the impact and effects of ACEs on depression outcomes and that (2) associations for the relationship between ACEs and depression outcomes would be more refined and precise when conceptual dimensions are taken into consideration.

In our sample, ACE index prevalence was comparable to previous research (Cronholm et al., 2015; Merrick, Ford, & Ports, 2019). Rates of depression symptoms (PHQ-2) were distinctly higher in our sample compared to previous research (Ottenhoff et al., 2019; Schilling et al., 2016), which might be related to the global pandemic COVID-19. Only between one- and two-thirds of participants perceived the ACEs they reported as *negative* or *very negative*. These proportions highlight the importance of including the assessment of perception in the measurement of ACEs. Including ACE dimensions in general can increase the accuracy and the content and construct validity of ACE assessment (Morgado, Meireles, Neves, Amaral, & Ferreira, 2017).

For research question 1, we examined the characteristics of the different ACE-DQ scoring approaches in comparison to the ACE index. Only counting childhood experiences which have been perceived as *negative* or *very negative*, ACE prevalence was lower for the ACE-DQ compared to the ACE index. If a person reports that a certain childhood experience had a *positive* or *very positive* impact on them, the experience should not be classified as adverse. The ACE index cannot detect these nuances. This partially supports our hypothesis that the ACE index potentially overestimates the impact of ACEs. However, adding all the conceptual dimensions will increase the complexity of the scoring approach needed. This could decrease the scale's usefulness as a measurement tool in the field.

For research question 2, we examined the relationship between ACEs in different scoring approaches to the continuous PHQ-2 score. All ACE-DQ scoring approaches had significant large correlations with the PHQ-2. As expected, most ACE-DQ scoring approaches had smaller correlations with PHQ-2 scores compared to the ACE index. Unweighted ACE-DQ scores (scoring approaches (1) and (2)) had similarly large correlations with the PHQ-2, which suggest an overestimation (Brydges, 2019; Funder & Ozer, 2019). The unweighted scoring approaches mimic issues with the ACE index by creating an average of the effects of all assessed dimensions.

Perception-weighted scores had distinctly lower, yet still substantial correlations with PHQ-2 scores. These lower effect sizes point to the importance of using a weighted dimensions approach to obtain a more accurate estimation of the effects of ACE on depression outcomes. This again partially supports our hypothesis that the ACE index is an overestimation of the relationship between ACEs and depression symptoms, and points to the importance of including weighted ACE dimensions.

Finally, to answer research question 3, we conducted logistic regression models to examine the effects of ACEs on depression outcomes. Overall, associations were largest for the ACE index and smallest for the sum of perception weighted ACE dimensions mean scoring approach (Scoring Approach (3)). When different ACE dimensions were taken into consideration, the magnitude of effects ACEs on depression symptoms decreased considerably. These results were expected, as smaller predictor ranges (ACE index) can more easily detect differences between predictor intervals than larger ranges (Cleophas & Zwinderman, 2012). Predictor ranges of the perception weighted ACE score are small enough to detect effect sizes even in smaller populations and appear to be more accurate than the ACE index. Relative to their

effect size, perception-weighted ACE scores had more narrow confidence intervals compared to the ACE index. These results partly support our hypothesis that the inclusion of conceptual ACE dimensions can increase the accuracy of ACE measurement.

# **Implications**

Based on the results of this study, we make two sets of recommendations for the inclusion of conceptual dimensions in the assessment of ACEs:

# (1) ACE screening for practice:

We propose adding the assessment of a person's perception to each of the 10 ACE items in clinical and practice settings with response options very negative, negative, neither negative nor positive OR both positive and negative, positive, and very positive. By assessing a person's perception of ACEs, practitioners can immediately see which adverse experiences to focus their intervention and prevention efforts on based on if the person perceived an experience as positive, neutral, or negative. No further scoring of response options is needed. This information can be used to tailor treatment for the negatively perceived individual ACE domains as opposed to applying generalized treatment for adversity. Applying targeted treatment has the potential to distinctly improve outcomes of ACE intervention and prevention efforts. Challenging Anda et al.'s (2020) critique of the ACE score, Lewicki and Rosenfeld (2021) point to the usability and ease of application of the ACE index as a justification for its widespread use. By adding only one item for each ACE stem question answered with "yes", the participant burden increases minimally. Additionally, clinicians and practitioners need not calculate an overall score, but can recommend interventions directly targeted to the experiences that the individual perceives as being traumatic (i.e., negative).

## (2) ACE measurement for research and theoretical work:

Taken from the results of our logistic regressions on different ACE scoring approaches, we recommend the use of a perception-weighted ACE domains overall score for research purposes (scoring Approach (4)). This would only require the inclusion of the perception dimension items and not the full range of dimension items; a minimal increase in participant burden. This scoring approach is relatively simple and more accurately includes the participant's assessment of the experience into an overall ACE score.

Because of its complexity and relatively large range, the perception weighted ACE dimensions mean (scoring approach (3)) is less likely to detect associations between ACEs and health outcomes. Therefore, using the perception weighted ACE dimensions mean (scoring approach (3)) as an overall score would require large sample sizes to obtain meaningful results (Uttley, 2019). Additionally, participant burden and analysis effort increase considerably with the inclusion of all dimension items for all 10 ACE domains. We suggest using the perception weighted dimensions mean only for research focused on individual ACE domains. By using standardized assessment of ACE dimensions for individual domains, researchers can distinguish better between the impacts of each type of ACE.

### **Future Directions**

This study focused on the 10 original ACE domains. Future research should include a more comprehensive list of ACE domains and their dimensions. Additionally, more research needs to be directed towards the lesser researched individual ACE domains. The usability of a pen-and-paper survey might be decreased by adding conceptual dimensions; however, future research could explore the use of a mobile application to quickly assess ACEs e.g., in primary

care patients. We used a summed ACE domains score for our analyses. Prior research indicates how the effects of ACEs can vary from one ACE domain to another (Ajnakina et al., 2018; Zarse et al., 2019). To be able to more accurately evaluate the perceived impact of adverse experiences, future studies should examine the effects of *individual* ACE domains, while controlling for the effects of other ACEs and their dimensions on later-life health outcomes. In this study, we did not take into account potential intermediate factors between adversity and depression outcomes, such as resilience or post-traumatic growth. Future research should evaluate the potentially mediating and moderating effects of different concepts.

## **Limitations and Strengths**

We note a few limitations of this study. All data collected are cross-sectional; we cannot make definitive statements about causal relationships beyond the temporal sequence of the main variables. This study only includes the 10 conventional ACE domains (Felitti et al., 1998) and a limited number of mental health outcomes. Since only MTurk workers were able to participate and participants self-selected into the study, there is a potential non-response and self-selection bias, and the final sample might not represent the general population.

This study has a number of strengths. Using platforms such as Amazon's MTurk for recruitment is very easy, time-efficient, and inexpensive. The MTurk is a reliable source to obtain geographically diverse samples. Our sample size exceeded the sample size estimation. We used validated measurement tools to assess our main variables. Three different measures were used to capture depression outcomes; our results were consistent across all three depression outcomes. Lastly, we used a variety of analytic approaches to test our hypotheses.

## **Conclusion**

With this pilot study, we examined the value of adding conceptual dimensions to the assessment of adverse childhood experiences. Our results suggest that the ACE index may be an overestimation of the impact of ACEs and their effects on depression outcomes. Adding conceptual dimensions to more fully weight participants' experience of adverse events can increase the accuracy of ACE measurement, but can also increase participant burden considerably. Our results point to the importance of a person's perception of the impact of adversity on their life. We suggest including the assessment of a person's perception of adverse events for screening efforts and for research focused on cumulative adversity.

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# Appendix 4-A. IRB Approval Letter



To: Lisa Krinner Graduate School

From: Office of Research Protections and Integrity

Date: 4/21/2021

RE: Notice of Approval of Exemption with No End Date Exemption Category: 2. Survey, interview, public observation

Study #: 21-0012

Study Title: Adverse Childhood Experiences Dimensions and Health

This submission has been reviewed by the Office of Research Protections and Integrity (ORPI) and was determined to meet the Exempt category cited above under 45 CFR 46.104(d). This determination has no expiration or end date and is not subject to an annual continuing review. However, you are required to obtain IRB approval for all changes to any aspect of this study before they can be implemented.

# <u> Important Information :</u>

- Human Subjects Research (HSR) activities that can be conducted virtually/remotely should be conducted virtually/remotely. Protocol Modifications are required to adjust data collection procedures to remote data collection (e.g., phone, online or virtual).
- The operational status of the research/study location where HSR activities will occur will guide whether the activities should occur.
- Off-campus HSR activities may occur if the organization, institution, agency, business, etc. is operational and is willing to support the researcher to conduct the research.
  - Researchers will be representing the University and therefore, regardless of the organization's standards, researchers must adhere to University, local, and state requirements regarding the use of face coverings, physical distancing standards, group size limitations, etc.
- Conducting HSR activities on-campus (Main campus, Center City campus, and other locations that may be extensions of the University) is subject to the operational status of the University.
  - Researchers must adhere to all University, local, and state public health and safety requirements including wearing face coverings whenever indoors and maintaining physical distancing.
  - Researchers must adhere to the Niner Nation Cares requirements including the 6 Ws (Wash, Wear, Wait, Wipe, Watch, and Wave) and limitations on the size of gatherings.
- 5. Should the operational status of off-campus study locations change, the University's operational status change, Mecklenburg County and/or the state of North Carolina impose higher restrictions (stay-at-home orders), researchers must comply with these requirements and therefore HSR activities, regardless of whether the activities are off-campus or on-campus may need to halt.

#### Study Description:

Adverse Childhood Experiences (ACEs) have been subject to extensive research over the past 30 years. Yet, conceptualization discrepancies persist. The purpose of this dissertation is to develop a refined measure of ACEs including concept dimensions, such as the frequency or timing of adverse events.

We will collect primary data via the Amazon MTurk using the 10-item ACE Study questionnaire and the respective ACE dimensions developed earlier in the project. We will examine, how ACE prevalence differs and how the effect of ACEs on certain health outcomes differ between the two operationalization approaches.

Your approved consent forms (if applicable) and other documents are available online at http://uncc.myresearchonline.org/irb/index.cfm?event=home.dashboard.irbStudyManagement&irb\_id=21-0012.

The Investigator Responsibilities listed below apply to this study. Carefully review the Investigator

### Responsibilities.

#### Investigator's Responsibilities:

The above-cited determination has no expiration or end date and is not subject to annual continuing review.

However, the Principal Investigator needs to comply with the following responsibilities:

- Modifications must be submitted for review and approval before implementing the modification. This includes changes to study procedures, study materials, personnel, etc.
- Data security procedures must follow procedures as approved in the protocol and in accordance with ITS Guidelines for Data Handling.
- Promptly notify the IRB (<u>uncc-irb@uncc.edu</u>) of any adverse events or unanticipated risks to participants or others.
- Complete the Closure eform via IRBIS once the study is complete.
- Be aware that this study is now included in the Office of Research Protections and Integrity (ORPI) Post-Approval Monitoring program and may be selected for post-review monitoring at some point in the future
- Reply to ORPI post-review monitoring and administrative check-ins that will be conducted periodically to update ORPI as to the status of the study.
- Three years (3) following this Exemption determination, ORPI will request a study status update (active/not active).

Please be aware that approval may still be required from other relevant authorities or "gatekeepers" (e.g., school principals, facility directors, custodians of records).

## **Appendix 4-B.** Amazon MTurk Recruitment Message

Dear Participant,

Researchers in the Department of Public Health Sciences at the University of North Carolina at Charlotte are conducting a study on experiences with childhood events, current health behaviors (such as physical activity or diet), and health status (such as high blood pressure or diabetes). The survey requires approximately 15-20 minutes to complete via computer, tablet, or smartphone.

You will receive \$0.50 for completing the survey.

There are no direct benefits to you for taking the survey. Some questions may ask about sensitive topics such as alcohol use, childhood adversity or abuse, or experiences with mental health concerns. You have the option to select the "prefer not to answer" choice for any question and you can choose to exit the survey at any time. Findings will be used to help refine the concept of adverse childhood experiences and to improve screening practices for childhood events.

After the study is complete, study data may be shared with other researchers for use in other studies or as may be needed as part of publishing our results. The data we share will not include information that could identify you.

You will need to complete the survey in ONE session.

Your participation is voluntary. Your responses are confidential. We will not collect any identifying information, including your MTurk ID. You can withdraw from the study at any time or refuse to answer particular questions. This study has been approved by the UNC Charlotte IRB (uncc-irb@uncc.edu; protocol #21-0012).

If you have any questions or concerns, please contact Lisa Maria Krinner (lkrinner@uncc.edu) or Dr. Jan Warren-Findlow (jwarren1@uncc.edu). If you have further questions or concerns about your rights as a participant in this study, contact the Office of Research Protections and Integrity at (704) 687-1871 or uncc-irb@uncc.edu. You may print this screen for your personal records.

If you are 18 years of age or older, have read and understand the information provided and freely consent to participate in the study, you may proceed to the survey by clicking the link below.

## **Appendix 4-C.** Amazon MTurk Online Survey

### **Childhood Experiences and Health**

The University of North Carolina at Charlotte Department of Public Health Sciences 9201 University City Boulevard, Charlotte, NC 28223

## Consent to be Part of a Research Study

Title of the Project: Adverse Childhood Experiences and Health

Principal Investigator: Lisa Maria Krinner, Doctoral Candidate, Department of Public Health Sciences, University of North Carolina at Charlotte

Faculty Advisor: Dr. Jan Warren-Findlow, Interim Department Chair and Professor, Department of Public Health Sciences, University of North Carolina at Charlotte

Co-investigators:

Dr. Michele Issel, Research Professor, Academy for Population Health Innovation, University of North Carolina at Charlotte

Dr. Jessamyn Bowling, Assistant Professor, Department of Public Health Sciences, University of North Carolina at Charlotte

Dr. Charlie Reeve, Professor, Department of Psychological Science, University of North Carolina at Charlotte

### Dear Participant,

Researchers in the Department of Public Health Sciences at the University of North Carolina at Charlotte are conducting a study on **experiences with childhood events, current health behaviors** (such as physical activity or diet), **and health status** (such as high blood pressure or diabetes). The survey requires approximately 15-20 minutes to complete via computer, tablet, or smartphone. You will need to complete the survey in ONE session. You will receive \$0.50 for completing the survey.

There are no direct benefits to you for taking the survey. Some questions may ask about sensitive topics such as alcohol use, childhood adversity or abuse, or experiences with mental health concerns. You have the option to select the "prefer not to answer" choice for any question and you can choose to exit the survey at any time. Findings will be used to help refine the concept of adverse childhood experiences and to improve screening practices for childhood events.

After the study is complete, study data may be shared with other researchers for use in other studies or as may be needed as part of publishing our results. The data we share will not include information that could identify you. Your participation is voluntary. Your responses are confidential. We will not collect any identifying information, including your MTurk ID. You can withdraw from the study at any time or refuse to answer particular questions. This study has been approved by the UNC Charlotte IRB (uncc-irb@uncc.edu; protocol #21-0012). If you have any questions or concerns, please contact Lisa Maria Krinner (lkrinner@uncc.edu) or Dr. Jan Warren-Findlow (jwarren1@uncc.edu). If you have further questions or concerns about your rights as a participant in this study, contact the Office of Research Protections and Integrity at (704) 687-1871 or uncc-irb@uncc.edu. You may print this screen for your personal records. If you are 18 years of age or older, have read and understand the information provided and freely consent to participate in the study, you may proceed to the survey.

[Click Next if you agree]

Q2.1 The first few questions are about your overall health. In general, would you say your **PHYSICAL HEALTH** is

- Poor
- Fair
- Good
- Very good
- Excellent
- Prefer not to answer

Q2.2 In general, would you say your EMOTIONAL HEALTH is

- Poor
- Fair
- Good
- Very good
- Excellent
- Prefer not to answer

Q2.3 In general, would you say your **DIET QUALITY** is

- Poor
- Fair
- Good
- Very good
- Excellent
- Prefer not to answer

Q3.1 The next set of questions specifically ask about your experiences during your <u>CHILDHOOD</u> (before you were 18 years old).

Some of these questions may be sensitive.

Your answers are confidential.

If you are feeling upset, disturbed, or if taking part in this survey has brought up uncomfortable feelings, please contact your local psychological support service.

National Child Abuse Hotline: **800-422-4453** National Sexual Assault Hotline: **800-656-4673** 

SAMHSA's Substance Abuse and Mental Health National Helpline: 800-662-4357

You can find more information about emergency psychological services on https://www.mentalhealth.gov/get-help/immediate-help.

If you have thoughts about ending your life, please contact the National Suicide Prevention Lifeline available 24 hours a day in English and Spanish at **800-273-8255**.

If immediate assistance is needed, especially if the situation is potentially life-threatening, please call 911.

Q3.2 When you were growing up, did a parent or other adult in the household **often** ... Swear at you, insult you, put you down, or humiliate you? **or** Act in a way that made you afraid that you might be physically hurt?

- Yes
- No
- Prefer not to answer

Skip To: Q3.9 If When you were growing up, did a parent or other adult in the household often ... Swear at you, insu...! = Yes

Q3.3 How often did this happen to you?

- Once
- More than once
- Frequently
- Almost all the time
- Prefer not to answer

Q3.4 Thinking about your most meaningful experience of this, how old were you when this happened to you?

- 0-2yrs
- 3-5yrs (Preschool)
- 6-9yrs (Elementary School)
- 10-13yrs (Middle School)
- 14-17yrs (High School)
- Prefer not to answer

Q3.5 Thinking about your **most meaningful experience** of this, who did this to you?

- Mother/Stepmother
- Father/Stepfather
- Other Family Member
- Other Adult you knew (babysitter, teacher, family friend etc.)
- A Stranger
- Prefer not to answer

Q3.6 Which of these answers best reflects your **most meaningful experience** of this?

When you were growing up, somebody:

- Insulted you, called you things like "ugly," "lazy," or "stupid"
- Put you down/humiliated you
- Said they hated you or they wish you had never been born
- Threatened to leave you
- Threatened to physically hurt you
- None of the above
- Prefer not to answer

Skip To: Q3.8 If Which of these answers best reflects your most meaningful experience of this? When you were growi... != None of the above

Q3.7 If none of the above, please describe briefly what you are thinking about.

Q3.8 Looking back at your most meaningful experience of this, what impact did this event have on you?

- Very negative
- Negative
- Neither positive nor negative
- Both negative and positive
- Positive
- Very positive
- Prefer not to answer

Q3.9 When you were growing up, did a parent or other adult in the household **often** ... Push, grab, slap, or throw something at you? **or Ever** hit you so hard that you had marks or were injured?

- Yes
- No
- Prefer not to answer

Skip To: Q3.16 If When you were growing up, did a parent or other adult in the household often ... Push, grab, slap....!= Yes

- Q3.10 How often did this happen to you?
  - Once
  - More than once
  - Frequently
  - Almost all the time
  - Prefer not to answer
- Q3.11 Thinking about your **most meaningful experience** of this, how old were you when this happened to you?
  - 0-2yrs
  - 3-5yrs (Preschool)
  - 6-9yrs (Elementary School)
  - 10-13yrs (Middle School)
  - 14-17yrs (High School)
  - Prefer not to answer
- Q3.12 Thinking about your **most meaningful experience** of this, who did this to you?
  - Mother/Stepmother
  - Father/Stepfather
  - Other Family Member
  - Other Adult you knew (babysitter, teacher, family friend etc.)
  - A Stranger
  - · Prefer not to answer
- Q3.13 Which of these answers best reflects your **most meaningful experience** of this?

When you were growing up, somebody:

- Grabbed, shook, slapped, pinched, spanked you on bottom with/without object no injury
- Grabbed, shook, slapped, pinched, spanked you on bottom with/without object minor injury, left me with bruises or marks
- Punched, kicked, knocked you down, threw a hard object at you minor injury, left me with bruises or marks
- Punched, kicked, knocked you down, threw a hard object at you major injury, had to see a doctor or go to the hospital
- Hit you with a hard object, choked, beat, burned you, or threatened you with a weapon major injury, had to see a doctor or go to the hospital
- None of the above
- Prefer not to answer

Skip To: Q3.15 If Which of these answers best reflects your most meaningful experience of this? When you were growi... != None of the above

Q3.14 If none of the above, please describe briefly what you are thinking about.

\_\_\_\_\_

- Q3.15 Looking back at your most meaningful experience of this, what impact did this event have on you?
  - Very negative
  - Negative
  - Neither positive nor negative
  - Both negative and positive
  - Positive
  - Very positive
  - Prefer not to answer
- Q3.16 When you were growing up, did an adult or person at least 5 years older than you **ever**... Touch or fondle you or have you touch their body in a sexual way? **or** Try to or actually have oral, anal, or vaginal sex with you?
  - Yes
  - No
  - Prefer not to answer

Skip To: Q3.23 If When you were growing up, did an adult or person at least 5 years older than you ever... Touch or f...! = Yes

- Q3.17 How often did this happen to you?
  - Once
  - More than once
  - Frequently
  - Almost all the time
  - Prefer not to answer
- Q3.18 Thinking about your most meaningful experience of this, how old were you when this happened to you?
  - 0-2yrs
  - 3-5yrs (Preschool)
  - 6-9yrs (Elementary School)
  - 10-13yrs (Middle School)
  - 14-17yrs (High School)
  - Prefer not to answer
- Q3.19 Thinking about your most meaningful experience of this, who did this to you?
  - Mother/Stepmother
  - Father/Stepfather
  - Other Family Member
  - Other Adult you knew (babysitter, teacher, family friend etc.)
  - A Stranger
  - Prefer not to answer

Q3.20 Which of these answers best reflects your <u>most meaningful experience</u> of this? When you were growing up, somebody:

- Exposed your private parts or their private parts to you against your will
- Forced you to watch others engaged in sexual acts
- Fondled or touched private parts of your body or made you touch theirs against your wishes
- Threatened to hurt you or tell lies about you unless you did something sexual with them
- Forced anal or vaginal penetration on you with objects
- Forced oral, anal or vaginal penetration on you with their fingers or genitals
- None of the above
- Prefer not to answer

Skip To: Q3.22 If Which of these answers best reflects your most meaningful experience of this? When you were grow...! = None of the above

Q3.21 If none of the above, please describe briefly what you are thinking about.

Q3.22 Looking back at your most meaningful experience of this, what impact did this event have on you?

- Very negative
- Negative
- Neither positive nor negative
- Both negative and positive
- Positive
- Very positive
- Prefer not to answer

Q3.23 When you were growing up, did you often feel that ...

No one in your family loved you or thought you were important or special? or

Your family didn't look out for each other, feel close to each other, or support each other?

- Yes
- No
- Prefer not to answer

Skip To: Q3.30 If When you were growing up, did you often feel that ... No one in your family loved you or thought yo...! = Yes

Q3.24 How often did this happen to you?

- Once
- · More than once
- Frequently
- Almost all the time
- Prefer not to answer

Q3.25 Thinking about your <u>most meaningful experience</u> of this, how old were you when this happened to you?

- 0-2yrs
- 3-5yrs (Preschool)
- 6-9yrs (Elementary School)
- 10-13yrs (Middle School)
- 14-17yrs (High School)
- Prefer not to answer

### Q3.26 Thinking about your most meaningful experience of this, who did this to you?

- Mother/Stepmother
- Father/Stepfather
- Other Family Member
- Other Adult you knew (babysitter, teacher, family friend etc.)
- A Stranger
- Prefer not to answer

### Q3.27 Which of these answers best reflects your most meaningful experience of this?

- You did not feel loved by your family members
- People in your family did not care about your emotional needs
- · People in your family did not look out for each other
- Your parents/guardians did not know what you were doing with your free time
- when you were not at school or work
- Your parents/guardians did not understand your problems and worries
- None of the above
- Prefer not to answer

Skip To: Q3.29 If Which of these answers best reflects your most meaningful experience of this? != None of the above

Q3.28 If none of the above, please describe briefly what you are thinking about.

Q3.29 Looking back at your most meaningful experience of this, what impact did this event have on you?

- Very negative
- Negative
- Neither positive nor negative
- Both negative and positive
- Positive
- Very positive
- Prefer not to answer

#### Q3.30 When you were growing up, did you **often** feel that ...

You didn't have enough to eat, had to wear dirty clothes, and had no one to protect you? or

Your parents were too drunk or high to take care of you or take you to the doctor if you needed it?

- Yes
- No
- Prefer not to answer

Skip To: Q3.37 If When you were growing up, did you often feel that ... You didn't have enough to eat, had to wear di...! = Yes

## Q3.31 How often did this happen to you?

- Once
- More than once
- Frequently
- Almost all the time
- · Prefer not to answer

Q3.32 Thinking about your most meaningful experience of this, how old were you when this happened to you?

- 0-2yrs
- 3-5yrs (Preschool)
- 6-9yrs (Elementary School)
- 10-13yrs (Middle School)
- 14-17yrs (High School)
- Prefer not to answer

### Q3.33 Thinking about your most meaningful experience of this, who did this to you?

- Mother/Stepmother
- Father/Stepfather
- Other Family Member
- Other Adult you knew (babysitter, teacher, family friend etc.)
- A Stranger
- Prefer not to answer

## Q3.34 Which of these answers best reflects your **most meaningful experience** of this?

When you were growing up:

- You had nobody to take care of you and protect you
- You did not have enough clothes to wear to keep you warm or protected from the weather
- Your parents/guardians did not give you enough food even when they could easily have done so
- Your parents/guardians were too drunk or intoxicated by drugs to take care of you
- There was nobody to take you to the doctor if you needed it
- None of the above
- Prefer not to answer

Skip To: Q3.36 If Which of these answers best reflects your most meaningful experience of this? When you were growin...! = None of the above

Q3.35 If none of the above, please describe briefly what you are thinking about.

Q3.36 Looking back at your most meaningful experience of this, what impact did this event have on you?

- Very negative
- Negative
- Neither positive nor negative
- Both negative and positive
- Positive
- Very positive
- Prefer not to answer

Q3.37 When you were growing up, were your parents ever separated or divorced?

- Yes
- No
- Prefer not to answer

Q3.38 Thinking about your most meaningful experience of this, how old were you when this happened to you?

- 0-2yrs
- 3-5yrs (Preschool)
- 6-9yrs (Elementary School)
- 10-13yrs (Middle School)
- 14-17yrs (High School)
- Prefer not to answer

Q3.39 Which of these answers best reflects your **most meaningful experience** of this?

When you were growing up:

- Your parents/guardians separated peacefully and harmoniously
- Your standard of living decreased significantly after the separation/divorce of your parents/guardians
- Your parents/guardians said bad things about each other and tried to get you on their side
- You lost contact with one parent/guardian after the separation/divorce
- You had to talk to a lawyer or judge during your parents'/guardians' separation/divorce
- None of the above
- Prefer not to answer

Skip To: Q3.41 If Which of these answers best reflects your most meaningful experience of this? When you were growi...! = None of the above

Q3.40 If none of the above, please describe briefly what you are thinking about.

Q3.41 Looking back at your most meaningful experience of this, what impact did this event have on you?

- Very negative
- Negative
- Neither positive nor negative
- Both negative and positive
- Positive
- Very positive
- Prefer not to answer

Q3.42 When you were growing up, was a member of your household:

**Often** pushed, grabbed, slapped, or had something thrown at her? **or** 

Sometimes or often kicked, bitten, hit with a fist, or hit with something hard? or

Ever repeatedly hit over at least a few minutes or threatened with a gun or knife?

- Yes
- No
- Prefer not to answer

Skip To: Q3.49 If When you were growing up, was a member of your household: Often pushed, grabbed, slapped, or had s...! = Yes

Q3.43 How often did this happen to you?

- Once
- More than once
- Frequently
- Almost all the time
- Prefer not to answer

Q3.44 Thinking about your **most meaningful experience** of this, how old were you when this happened to you?

- 0-2yrs
- 3-5yrs (Preschool)
- 6-9yrs (Elementary School)
- 10-13yrs (Middle School)
- 14-17yrs (High School)
- Prefer not to answer

Q3.45 Thinking about your most meaningful experience of this, which household member was this?

- Mother/Stepmother
- Father/Stepfather
- Other Family Member
- Other Adult living in your household (e.g., mother's boyfriend, a family friend etc.)
- Prefer not to answer

Q3.46 Which of these answers best reflects your **most meaningful experience** of this?

When you were growing up, you saw a household member:

- Being called names or having something thrown at no injury
- Being grabbed, pushed, shook, pulled minor injury
- Being slapped, bit, hit with minor object, threw something, punched, kicked with injury
- · Being choked, hit with major object, burned, threatened with a weapon, or misused major injury
- Being killed by another family member
- None of the above
- Prefer not to answer

Skip To: Q3.48 If Which of these answers best reflects your most meaningful experience of this? When you were growi...! = None of the above

Q3.47 If none of the above, please describe briefly what you are thinking about.

Q3.48 Looking back at your most meaningful experience of this, what impact did this event have on you?

- Very negative
- Negative
- Neither positive nor negative
- Both negative and positive
- Positive
- Very positive
- Prefer not to answer

Q3.49 When you were growing up, did you live with anyone who was a problem drinker or alcoholic or who used street drugs?

- Yes
- No
- Prefer not to answer

Skip To: Q3.56 If When you were growing up, did you live with anyone who was a problem drinker or alcoholic or who...! = Yes

Q3.50 How often did this happen to you?

- Once
- More than once
- Frequently
- Almost all the time
- · Prefer not to answer

Q3.51 Thinking about your most meaningful experience of this, how old were you when this happened to you?

- 0-2yrs
- 3-5yrs (Preschool)
- 6-9yrs (Elementary School)
- 10-13yrs (Middle School)
- 14-17yrs (High School)
- Prefer not to answer

Q3.52 Thinking about your most meaningful experience of this, which household member was this?

- Mother/Stepmother
- Father/Stepfather
- Other Family Member
- Other Adult living in your household (e.g., mother's boyfriend, a family friend etc.)
- Prefer not to answer

Q3.53 Which of these answers best reflects your **most meaningful experience** of this? When you were growing up:

- A household member was hospitalized/institutionalized because of substance use
- You did not have your daily needs fulfilled because of a household member's substance use (for example: you did not have enough food)
- You had to take on additional responsibilities because of a family member's substance use (for example: you had to take care of your siblings)
- The substance use of a household member negatively influenced your education
- A household member died because of substance use
- None of the above
- Prefer not to answer

Skip To: Q3.55 If Which of these answers best reflects your most meaningful experience of this? When you were growin...! = None of the above

Q3.54 If none of the above, please describe briefly what you are thinking about.

<del>,\_\_\_\_\_</del>\_\_\_

Q3.55 Looking back at your most meaningful experience of this, what impact did this event have on you?

- Very negative
- Negative
- Neither positive nor negative
- Both negative and positive
- Positive
- Very positive
- Prefer not to answer

Q3.56 When you were growing up, was a household member depressed or mentally ill or did a household member attempt suicide?

- Yes
- No
- Prefer not to answer

Skip To: Q3.63 If When you were growing up, was a household member depressed or mentally ill or did a household mem... != Yes

Q3.57 How often did this happen to you?

- Once (1)
- More than once (8)
- Frequently (9)
- Almost all the time
- · Prefer not to answer

Q3.58 Thinking about your most meaningful experience of this, how old were you when this happened to you?

- 0-2yrs
- 3-5yrs (Preschool)
- 6-9yrs (Elementary School)
- 10-13yrs (Middle School)
- 14-17yrs (High School)
- Prefer not to answer

Q3.59 Thinking about your most meaningful experience of this, which household member was this?

- Mother/Stepmother
- Father/Stepfather
- Other Family Member
- Other Adult living in your household (e.g., mother's boyfriend, a family friend etc.)
- Prefer not to answer

Q3.60 Which of these answers best reflects your **most meaningful experience** of this?

When you were growing up, a household member:

- Took medication and/or received treatment for mental illness
- Attempted suicide
- Was institutionalized because of mental illness
- Blamed you for their mental illness
- · Had a mental illness that negatively influenced your education and daily needs
- Had a mental illness and did not receive treatment for it
- None of the above
- Prefer not to answer

Skip To: Q3.62 If Which of these answers best reflects your most meaningful experience of this? When you were growi...! = None of the above

Q3.61 If none of the above, please describe briefly what you are thinking about.

Q3.62 Looking back at your most meaningful experience of this, what impact did this event have on you?

- Very negative
- Negative
- Neither positive nor negative
- Both negative and positive
- Positive
- Very positive
- Prefer not to answer

Q3.63 When you were growing up, did a household member go to prison?

- Yes
- No
- Prefer not to answer

# Skip To: Q3.70 If When you were growing up, did a household member go to prison? != Yes

Q3.64 How often did this happen to you?

- Once
- More than once
- Frequently
- Almost all the time
- Prefer not to answer

Q3.65 Thinking about your **most meaningful experience** of this, how old were you when this happened to you?

- 0-2yrs
- 3-5yrs (Preschool)
- 6-9yrs (Elementary School)
- 10-13yrs (Middle School)
- 14-17yrs (High School)
- Prefer not to answer

Q3.66 Thinking about your most meaningful experience of this, which household member was this?

- Mother/Stepmother
- Father/Stepfather
- Other Family Member
- Other Adult living in your household (e.g., mother's boyfriend, a family friend etc.) (14)
- Prefer not to answer

Q3.67 Which of these answers best reflects your **most meaningful experience** of this? When you were growing up:

- You were not able to stay in contact with a household member after they were incarcerated
- You witnessed a household member's arrest
- You had to move or live with somebody else because a household member was incarcerated
- · Your standard of living decreased significantly because a household member was incarcerated
- You experienced any additional adversity you have not experienced before the incarceration of a household member
- Your education was impacted because a household member was incarcerated
- None of the above
- · Prefer not to answer

Skip To: Q3.69 If Which of these answers best reflects your most meaningful experience of this? When you were growi...! = None of the above

Q3.68 If none of the above, please describe briefly what you are thinking about.

Q3.69 Looking back at your most meaningful experience of this, what impact did this event have on you?

- Very negative
- Negative
- Neither positive nor negative
- Both negative and positive
- Positive
- Very positive
- Prefer not to answer

#### Q3.70

If you are feeling upset, disturbed, or if taking part in this survey has brought up uncomfortable feelings, please contact your local psychological support service.

National Child Abuse Hotline: **800-422-4453** National Sexual Assault Hotline: **800-656-4673** 

SAMHSA's Substance Abuse and Mental Health National Helpline: 800-662-4357

You can find more information about emergency psychological services on <a href="https://www.mentalhealth.gov/get-help/immediate-help">https://www.mentalhealth.gov/get-help/immediate-help</a>. If you have thoughts about ending your life, please contact the National Suicide Prevention Lifeline available 24 hours a day in English and Spanish at **800-273-8255**.

If immediate assistance is needed, especially if the situation is potentially life-threatening, please call 911.

Q4.1 The following set of questions asks about any **CHANGES** that might have occurred in your life **as a result of your childhood experiences**. There are no right or wrong answers.

Please indicate for each of the statements below the degree to which this change occurred in your life as a result of your childhood experiences.

your childhood	I did not experience this change as a result of my crisis.	I experienced this change to a very small degree as a result of my crisis.	I experienced this change to a small degree as a result of my crisis.	I experienced this change to a moderate degree as a result of my crisis.	I experienced this change to a great degree as a result of my crisis.	I experienced this change to a very great degree as a result of my crisis.	Prefer not to answer
I changed my priorities about what is important in life.	0	0	0	0	0	0	0
I have a greater appreciation for the value of my own life.	0	0	0	0	0	0	0
I am able to do better things with my life.	$\bigcirc$	$\circ$	$\circ$	$\circ$	$\circ$	$\bigcirc$	$\circ$
I have a better understanding of spiritual matters.	0	$\circ$	$\circ$	$\circ$	$\circ$	$\circ$	$\circ$
I have a greater sense of closeness with others.	0	$\circ$	$\circ$	$\circ$	$\circ$	$\circ$	$\circ$
I established a new path for my life.	$\bigcirc$	$\circ$	$\circ$	$\circ$	$\circ$	$\circ$	$\circ$
I know better that I can handle difficulties.	$\circ$	$\circ$	$\circ$	$\circ$	$\circ$	$\circ$	$\circ$
I have a stronger religious faith.	$\bigcirc$	$\circ$	$\circ$	$\circ$	$\circ$	$\circ$	$\circ$
I discovered that I'm stronger than I thought I was.	0	$\circ$	$\circ$	$\circ$	$\circ$	$\circ$	$\circ$
I learned a great deal about how wonderful people are.	0	0	0	$\circ$	0	0	0

Q5.1 We just have a few more questions about your current health. The rest of the survey will take **approximately 5 more minutes**.

The following set of questions asks about your <u>HEALTH STATUS</u>. There are no right or wrong answers. Your responses are confidential.

Over the <u>last 2 weeks</u>, how often have you been bothered by the following problems?

	Not at all	Several days	More than half the days	Nearly every day	Prefer not to answer
1.Little interest or pleasure in doing things	0	0	0	0	0
2.Feeling down, depressed, or hopeless.	0	$\circ$	0	0	0

Q5.2 Have you ever been <u>diagnosed</u> with **depression**?

- Yes
- No
- Not sure
- Prefer not to answer

Q5.3 Have you ever taken any <u>drug/medication</u> for **depression** or have you been <u>prescribed</u> any medication for **depression** but do not take it?

- Yes
- No
- Not sure
- Prefer not to answer

Q5.4 Over the **last 2 weeks**, how often have you been bothered by the following problems?

	Not at all	Several days	More than half the days	Nearly every day	Prefer not to answer
1. Feeling nervous, anxious, or on edge	0	0	0	0	0
2. Not being able to stop or control worrying	0	0	0	$\circ$	0

Q5.5 Have you ever been <u>diagnosed</u> with an **anxiety disorder** (Generalized Anxiety Disorder, Panic Disorder, Social Anxiety Disorder, etc.)?

- Yes
- No
- Not sure
- Prefer not to answer

Q5.6 Have you ever taken any <u>drug/medication</u> for **anxiety** or have you been <u>prescribed</u> any medication for **anxiety** but do not take it?

- Yes
- No
- Not sure
- Prefer not to answer

#### Q5.7

If you are feeling upset, disturbed, or if taking part in this survey has brought up uncomfortable feelings, please contact your local psychological support service.

National Child Abuse Hotline: **800-422-4453** National Sexual Assault Hotline: **800-656-4673** 

SAMHSA's Substance Abuse and Mental Health National Helpline: 800-662-4357

You can find more information about emergency psychological services on https://www.mentalhealth.gov/get-help/immediate-help.

If you have thoughts about ending your life, please contact the National Suicide Prevention Lifeline available 24 hours a day in English and Spanish at **800-273-8255**.

If immediate assistance is needed, especially if the situation is potentially life-threatening, please call 911.

Q5.8 Have you ever been diagnosed with hypertension/high blood pressure?

- Yes
- No
- Not sure
- Prefer not to answer

Q5.9 Have you ever taken any drug/medication for hypertension/high blood pressure or have you been prescribed any medication for hypertension/high blood pressure but do not take it?

- Yes
- No
- Not sure
- Prefer not to answer

Q5.10 Have you ever been diagnosed with type 2 diabetes?

- Yes
- No
- Not sure
- Prefer not to answer

Q5.11 Have you ever taken any drug/medication for type 2 diabetes or have you been prescribed any medication for type 2 diabetes but do not take it?

- Yes
- No
- Not sure
- Prefer not to answer

Q6.1 The following set of questions asks about your **HEALTH BEHAVIORS**. There are no right or wrong answers. We are just interested in your current activities.

# Physical Activity

# How many of the past 7 days did you:

now many of the pa	0 days	1 day	2 days	3 days	4 days	5 days	6 days	7 days	Prefer not to answer
Do at least 30 minutes total of physical activity?	0	0	0	0	0	0	0	0	$\circ$
Do a specific exercise activity (such as swimming, walking, or biking) other than what you do around the house or as part of your work?	0	0	0	0	0	0	0	0	0
Engage in weight lifting or strength training (other than what you do around the house or as part of your work)?	0	0	0	0	0	0	0	0	0
Do any repeated heavy lifting or pushing/pulling of heavy items either for your job or around the house or garden?	0	0	0	0	0	0	0	0	0

Oo.2 Smoking	06.2	<b>Smoking</b>
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	How	many	of	the	past	7	days	did	vou
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	0 days	1 day	2 days	3 days	4 days	5 days	6 days	7 days	Prefer not to answer
Use tobacco products (cigarette, e- cigarette, vape, cigar etc.), even just one puff?	0	0	0	0	0	0	0	0	0
Stay in a room or ride in an enclosed vehicle while someone was using tobacco products (cigarette, e- cigarette, vape, cigar etc.)?	0	0	0	0	0	0	0	0	0

#### Q6.3 Alcohol

The next three questions are about alcohol consumption. A drink of alcohol is defined as: One, 12 oz. can or bottle of beer; One, 4 ounce glass of wine; One, 12 oz. can or bottle of wine cooler; One mixed drink or cocktail; Or 1 shot of hard liquor.

	0 days	1 day	2 days	3 days	4 days	5 days	6 days	7 days	Prefer not to answer
On average, how many days per week do you drink alcohol?	0	0	0	0	0	0	0	0	0

Q6.4 On a typical day that you drink alcohol, how many drinks do you have?

- # of drinks \_\_\_\_\_
- Prefer not to answer

Q6.5 What is the largest number of drinks that you've had on any given day within the last month?

- # of drinks
- Prefer not to answer

Q7.1 Tell us a little about yourself - you're almost finished.

WILL Last Last Town CENDED											
Which best describes your <u>GENDER</u> ?  • Male											
• Female											
Trans femme/woman											
Trans masculine/man											
• Genderqueer (gender non-binary, gender fluid, age	nder)										
Other (Please specify):							_				
Prefer not to answer											
Q7.2 Which best describes your <b>SEXUAL IDENTITY</b> ?											
Heterosexual											
<ul> <li>Asexual or demisexual</li> </ul>											
<ul> <li>Bisexual or pansexual</li> </ul>											
• Gay											
• Lesbian											
• Queer											
• Questioning/not sure											
Other (Please specify):											
<ul> <li>Prefer not to answer</li> </ul>											
Q7.3 What is your <b>AGE</b> ?											
27.5 White 15 your <u>1802</u> .	18	26	34	42	50	59	67	75	83	91	99
						_					
Years ()				_				_		!	
						•					
Q7.4 What is your height in <b>INCHES</b> ? (1 foot = 12 inche	s)										
• indicate inches											
<ul> <li>Prefer not to answer</li> </ul>											
Q7.5 What is your weight in <b>POUNDS</b> ? (only enter digits	c e o	157)									
• indicate lbs	, c.g.	137)									
Prefer not to answer					•						
Q7.6 Which <b>RACE</b> best describes you?											
• White											
Black/African American											
<ul> <li>American Indian or Alaska Native</li> </ul>											
<ul><li>Asian</li></ul>											

• Native Hawaiian or Pacific Islander

• Biracial/Multiracial

• Prefer not to answer

#### Q7.7 What is your ETHNICITY?

- Hispanic
- Non-Hispanic
- Prefer not to answer

### Q7.8 What is your current **RELATIONSHIP STATUS**?

- Married
- · Living as a couple
- Divorced or Separated
- Single
- Widowed
- Other (Please specify):\_\_
- Prefer not to answer

### Q7.9 What is the **HIGHEST EDUCATION LEVEL** you completed?

- Less than 8th grade
- I completed 8th grade
- I went to secondary/high school but did not graduate
- I graduated secondary/high school
- I have taken some college courses
- I have a 2-year college degree
- I have a 4-year college degree
- I have a master's degree or law degree
- I have a doctorate or medical degree
- Prefer not to answer

### Q8.1 Thank you for taking part in our survey!

On the next page, you will receive your <u>MTurk Completion Code</u>. Paste the code into the box on MTurk to receive credit for taking our survey.

If you are feeling upset, disturbed, or if taking part in this survey has brought up uncomfortable feelings, please contact your local psychological support service.

National Child Abuse Hotline: **800-422-4453**National Sexual Assault Hotline: **800-656-4673** 

SAMHSA's Substance Abuse and Mental Health National Helpline: 800-662-4357

You can find more information about emergency psychological services on https://www.mentalhealth.gov/get-help/immediate-help.

If you have thoughts about ending your life, please contact the National Suicide Prevention Lifeline available 24 hours a day in English and Spanish at **800-273-8255**.

If immediate assistance is needed, especially if the situation is potentially life-threatening, please call 911.

OCCUPATION OF THE PROPERTY OF

Q8.2 Here is your MTurk Completion Code: \$[e://Field/Random%20ID]

Copy this value to paste into MTurk.

When you have copied your code, please click the next button to submit your survey.

## **Chapter 5: Discussion**

Adverse Childhood Experiences (ACEs) are a major contributor to various later-life consequences (e.g. Kalmakis & Chandler, 2015) including anxiety and depression (Hughes et al., 2017; Kalmakis & Chandler, 2015). Despite an abundance of research on the effects of ACEs on later-life outcomes, the concept is underdeveloped, has a vague foundation in theory, and there is no agreement in how the concept should be defined and hence measured. Most research is still focused mainly on the types of ACEs, without considering other aspects of the adverse experiences. (e.g. Hughes et al., 2017). However, the effects different domains can elicit in a person may depend on a variety of other specific factors, also called dimensions, including the frequency and timing of events, or a person's perception of the event. No comprehensive effort has been made to review and systematically delineate the full range of dimensions within and across established ACE domains. No standardized measurement has been developed to assess a larger number of conceptual ACE dimensions in relation to different ACE domains.

This dissertation project addressed these gaps by reviewing different conceptual dimensions of ACEs, developing standardized measurement for conceptual ACE dimensions for the 10 original ACE domains, and pilot testing the newly developed ACE dimensions items.

### **Review of Findings**

The first study was a scoping literature review, I synthesized the assessment and analysis of conceptual ACE dimensions in empirical ACE literature published after 1998. This study served as a deductive approach to scale development. I found 4 primary dimensions that were used in most ACE domains – frequency, timing, perception, and the role of the perpetrator. Additionally, I found a number of secondary and domain-specific dimensions, which generally seem to relate

to the intensity of traumatic events. There was a lack of detail provided in how dimensions were assessed and used in analyses. Many studies did not provide details on how they operationalized and worded questions on ACE dimensions (e.g., Carlson, McNutt, & Choi, 2003). In studies that include this information, the operationalization of ACE dimensions varied distinctly between articles. Overall, I identified five commonly used ACE dimensions, but these lacked standardized phrasing of items and response options.

Based on the insights gained in Study 1, Study 2 used a Delphi methodology to develop ACE dimensions items that can be added to the 10-item ACE-Study Questionnaire (Dube et al., 2001; Felitti et al., 1998), and establish their content validity. This study served as an inductive approach to scale development. I proposed item and response option wording for 5 ACE dimensions based on the review in Study 1. I asked subject matter experts (SMEs) to (1) evaluate the relevance of ACE dimensions for each of the 10 original ACE domains; (2) provide their opinion on how dimension items and response options should be worded; (3) how dimension items should be anchored; and (4) how dimension response options should be ranked based on their negative impact on later-life health outcomes.

SMEs considered most conceptual dimensions relevant for all 10 original ACE domains. These results support my research objective. SMEs provided feedback on the wording of dimension items, and I revised the items accordingly. For some dimensions, e.g., for the dimension of perpetrator, I created two different item versions for certain domains.

Most SMEs agreed that participants should be asked to focus on the adverse event most meaningful to them. While anchoring can introduce bias in decision-making processes (e.g., Saposnik, Redelmeier, Ruff, & Tobler, 2016), SMEs suggest that asking participants to focus on a specific event will reduce recall bias and ensure consistent answers across dimensions within a

domain. Regarding the development of a scoring approach for the dimension items, SMEs generally agreed on the ranking of response options for the dimensions of frequency, perpetrator, and perception, and for most intensity items. However, there was great variability in the interpretation of the intensity of the negative effects on later-life outcomes of other dimension response options. These results again support my goal to develop targeted scoring for different dimensions within the domains, as opposed to using a uniform scoring approach for dimensions within each domain.

Based on these results, the proposed ACE-Dimensions Questionnaire (ACE-DQ) has a minimum of 10 questions (the 10 original ACE domain items) if each domain stem question is answered with "no." If all original ACE domain stem questions are answered with "yes," the new ACE-DQ has a maximum of 48 items.

The third study in this project pilot tested the newly developed dimension items and provided recommendations for the use of ACE dimension items in research and practice. The goal of this study was to compare scoring approaches for the refined ACE-DQ and determine its predictive validity. I compared ACE exposure as assessed with the ACE index and the ACE-DQ, and their associations with depression outcomes. Based on the ACE index, approximately one-third of the participants reported no ACEs, one-third 1-3 ACEs, and one-third 4-10 ACEs. Only between one- and two-thirds of participants perceived the impact of the ACEs they experienced as negative. When the perceived impact of the experience is factored in, using the ACE-DQ, over half had no ACE or no negative impact from ACEs, 29% had 1-3 negative ACEs, and only 18% had 4-10 negative ACEs. This suggests that the ACE index might be an overestimation of the impact of ACEs.

The ACE index and the equally weighted ACE-DQ scoring approaches (sum of all ACE dimensions and mean of all ACE dimensions) had very large correlations with depression symptoms. Funder and Ozer (2019) and Brydges (2019) describe how effect sizes/correlations above *r*=.40 in psychological and gerontological research appear to be gross overestimations. Perception-weighted dimension scoring approaches (perception-weighted dimensions mean and perception-weighted ACE domains) had lower, but still strong correlations with depression symptoms. Predictions for depression outcomes were larger for the ACE index compared to the perception-weighted ACE-DQ scores.

# **Collective Implications**

The three studies in this dissertation project have distinct implications for research and practice. Study 1 is the first attempt to review a comprehensive list of conceptual dimensions associated with adverse childhood experiences. It is the first study to describe different conceptual ACE dimensions and how they have been used in research to this point. The findings of the first study contribute to an understanding of the dimensionality of ACEs and can support the development of a comprehensive definition of ACEs. Insights gained from this study can be used to better understand different theories underlying the conceptual dimensions of ACEs, such as the Theory of Cumulative Inequality (Ferraro et al., 2009), developmental and life-course frameworks (Ben-Shlomo & Kuh, 2002; P. S. Nurius et al., 2015), or the Theory of Stress and Coping (Folkman & Lazarus, 1984).

The second study has several implications for the measurement of adverse childhood experiences and for theory development. This study was the first attempt to develop standardized items for the assessment of ACE dimensions. When asked for the relevance of ACE dimensions

for the measurement of ACEs, SMEs considered all five included dimensions relevant for nine of the 10 original ACE domains, and three dimensions for the tenth domain. These results indicate that dimensions should be included in the measurement of ACEs. Dimension item and response option wording, and the scoring of the dimensions as determined by the SMEs varied distinctly between domains. This highlights the difference between the dimensions within separate domains and supports my intent to develop a targeted scoring approach for dimensions within different domains. Results from Study 2 can inform the development of a comprehensive definition for ACEs including conceptual dimensions. Moreover, insights gained from this study can lead to the refinement of theories underlying conceptual ACE dimensions.

Study 3 was used to pilot test the ACE-DQ in a geographically diverse population of U.S. adults. I explored the value of adding five conceptual ACE dimensions to the assessment of ACEs. Results from this study have direct implications for the measurement of ACEs in research and practice. Study 3 highlights the importance of a person's perception of the impact of childhood experience. The ACE index does not capture this important information. The inclusion of ACE dimensions can potentially improve the accuracy and predictive validity of an ACE measure. Overall, the results from Study 3 suggest that the ACE index, as well as equally weighted dimension scoring approaches, might be overestimations of the impact of ACEs and of the effects of ACEs on depression outcomes. The effects of ACEs on later-life depression outcomes were distinctly lower when perception was taken into account compared to the ACE index and to unweighted dimension scoring approaches.

Because of its complexity and relatively large range, measurement including all ACE dimensions is less likely to detect associations between ACEs and health outcomes, and would increase participant burden considerably. Therefore, I recommend the use of a perception-

weighted ACE domain overall score for the assessment of cumulative adversity. The inclusion of the perception dimension items as opposed to the full range of dimension items leads only to a minimal increase in participant burden. Including additional ACE dimensions should be limited to research focused on individual ACE domains.

#### **Overall Limitations**

This dissertation project has a few overall caveats that warrant discussion. This entire project focused on the 10 conventional ACE domains. The 10-items of the ACE-Study Questionnaire have not been developed systematically based on theory (McLennan, MacMillan, & Afifi, 2020) and do not represent a comprehensive list of potentially adverse experiences. Other experiences in addition to these 10 domains might be relevant for the prediction of laterlife health outcomes.

Study 1 served as a foundation for the following studies; however, none of the articles in the review assessed the whole ACE set. Articles mainly focused on physical and sexual abuse; some domains were not included in the review altogether. Equally, I was not able to include SMEs with specific knowledge of each of the 10 ACE domains in Study 2. Based on the variance of specialized SME expertise, SMEs were not able to reach a complete consensus related to all research questions. Overall, these factors might mean that this project was not able to establish nuanced factors on lesser-researched ACE domains.

The understanding of ACEs is context and culture-bound. This project focused on reviewing studies from the U.S. and Canada only. Study 3 only included U.S.-based participants registered with Amazon's MTurk. In addition to these factors, the global pandemic COVID-19

might have influenced the participation rate of participants in Study 3 and responses related to depression outcomes, anxiety, and self-rated emotional health.

# **Overall Strengths**

Despite its limitations, this dissertation project makes important contributions to the field and has several strengths. Although the ACE-Study Questionnaire has its shortcomings, it is still the basis for many ACE measurement tools and is widely used in research and practice.

Therefore, this project can help to improve the accuracy of commonly used ACE scales and serves as a basis for future research on the dimensionality of ACEs. This dissertation project included the three steps of scale development: item generation, theoretical analysis, and psychometric analysis (Morgado et al., 2017). The studies include both a deductive and inductive approach to scale development (Morgado et al., 2017). The combination of both approaches is advised when there is ambiguity in the definition or dimensionality of the construct, as is the case for ACEs (Tay & Jebb, 2017). Study 3 used three different measures to capture depression outcomes; results were consistent across all three depression outcomes. Lastly, a variety of analytic approaches was used to test the validity of the newly developed ACE-DQ.

#### **Future Directions**

This dissertation project provides a number of starting points for future research. Study 3 suggests the inclusion of a person's perception of adverse experience into ACE assessment. The most immediate future research should use the perception weighted ACE index to examine the effects of ACEs on a larger number of health outcomes. Additionally, prior research indicates how the effects of ACEs can vary from one ACE domain to another (Ajnakina et al., 2018; Zarse

et al., 2019). To be able to more accurately evaluate the perceived impact of adverse experiences, future studies should examine the effects of *individual* ACE domains and their dimensions on later-life health outcomes.

Other avenues for future research emerged from this dissertation project. As evidence emerges for the relevance of other adverse events in childhood, such as bullying and poverty, more research on the dimensionality of ACEs is needed including their applicability to a more inclusive list of ACE domains to inform theory development and refinement.

Additionally, more research needs to be directed towards the lesser researched individual ACE domains. Researchers might consider using a similar Delphi approach as has been used in Study 2 focused on additional ACE domains to develop a more specific dimension assessment approach.

The results of this project suggest a need to return to the theoretical foundations of ACE dimensions to inform scale development and to conceptually refine ACEs. More research on intensity-related dimensions is needed to inform the development of a comprehensive ACE theory. The usability of a pen-and-paper survey might be decreased by adding conceptual dimensions; however, future research could explore the use of a mobile application to quickly assess ACEs e.g., in primary care patients. In this study, I did not take into account potential intermediate factors between adversity and depression outcomes, such as resilience or post-traumatic growth. Future research should evaluate the potentially mediating and moderating effects of different concepts. Future research should review the dimensionality of ACEs in other cultures or specific populations.

#### **Conclusion**

Adverse childhood experiences are a complex phenomenon. The findings of this dissertation project illustrate the lack of standardization in terminology and measurement of ACE dimensions. This shortcoming points towards a greater need to return to theory for the conceptual refinement of ACEs. The ACE index may be an overestimation of the prevalence of adverse experiences and of the effects of ACE on depression symptoms. This dissertation project endorses the relevance of conceptual dimensions for the assessment of ACEs, especially the assessment of a person's perception of childhood experiences. Adding conceptual dimensions to more fully weight participants' experience of adverse events might increase the accuracy of ACE measurement, but can also increase participant burden considerably. I recommend including the assessment of a person's perception of adverse events for screening efforts and for research focused on cumulative adversity.

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# Appendix. Adverse Childhood Experiences (ACE) Questionnaire

# Adverse Childhood Experience (ACE) Questionnaire Finding your ACE Score ra hbr 10 24 06

While you were growing up, during your first 18 years of life:

Now add up	your "Y	Yes" answers:	This is yo	our ACE Score	
10. Did a household me	ember go Yes N			If yes enter 1	
9. Was a household men	mber der Yes N		ill or did a household	d member attemp If yes enter 1	
8. Did you live with any	yone who		inker or alcoholic or	who used street d If yes enter 1	_
Ever repeatedly	or y hit ove Yes N		utes or threatened wi	th a gun or knife' If yes enter 1	?
Sometimes or		cked, bitten, hit wit	h a fist, or hit with so	mething hard?	
7. Was your mother or of Often pushed,			mething thrown at he	r?	
6. Were your parents ev	er separ Yes N			If yes enter 1	
Your parents w	rere too d		e care of you or take	you to the doctor If yes enter 1	
5. Did you often feel th You didn't have		n to eat, had to wea	r dirty clothes, and ha	ad no one to prote	ect you?
Your family did	dn't look Yes N		feel close to each ot	her, or support ea If yes enter 1	
4. Did you often feel th No one in your		oved you or though	it you were important	or special?	
Try to or actual	lly have o	oral, anal, or vagina lo	al sex with you?	If yes enter 1	
Did an adult or perso     Touch or fondle			you ever ir body in a sexual w	ay?	
Ever hit you so	or hard tha Yes N	at you had marks o	r were injured?	If yes enter 1	
<ol><li>Did a parent or other Push, grab, slap</li></ol>	o, or thro	the household ofte w something at you			
Act in a way th	at made		might be physically	hurt? If yes enter 1	
Did a parent or other     Swear at you, in		the household ofte 1, put you down, or			