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"Is there anything else you would like me to know?": Applying a trauma-informed approach to the administration of the Adverse Childhood Experiences (ACE) questionnaire

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Abstract

Nearly ubiquitous agreement exists regarding the potentially negative impact of adverse childhood experiences (ACE) on health and well-being across the lifespan. This has propelled a movement across the nation for consistent screening of ACEs. Despite agreement regarding the consequences of ACEs, little research related specifically to the administration of the ACE questionnaire exists. Using data from a mixed-methods study of first-time mothers as means of illustration, this paper examines shortcomings of the ACE questionnaire. Participant responses revealed ambiguity with item structure, limited breadth of included events, and failure to capture the gravity of the experience. These shortcomings underscore inadequacies of the measure in accurately understanding individuals' lived experiences and call for the application of trauma-informed values, both in its content and administration. We apply the main tenets of a trauma-informed framework to the ACE questionnaire and make recommendations for its administration, translating theoretical underpinnings of a trauma-informed approach into action.

Keywords

Trauma-informed care; Adverse Childhood Experiences (ACE); Screening; Trauma; Mental health; Adversity; Retraumatization

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There is abundant empirical support for the negative impact of adverse childhood experiences (ACEs) on health and well-being across the lifespan. ACEs have been found to consequence physical and mental health, with increased rates of mental health disorders such as anxiety, depression, and post-traumatic stress disorder among young adults (Lee et al., 2020) and increased risk for a host of illnesses including lung disease (Cunningham et al., 2014) and obesity (Palmisano et al., 2019). A meta-analysis by Hughes and colleagues (2017) confirmed these broad effects and evidenced increased risk for problematic drug and alcohol abuse, sexual risk taking, and interpersonal and self-directed violence. Such empirical evidence has propelled a trauma-informed movement across the nation, underscoring the high prevalence of trauma, its impact on development, the importance of avoiding retraumatization, the value of the person in all aspects of care, and awareness and support of individuals' resilience (Fallot & Harris, 2008; Harris & Fallot, 2001; Jennings, 2004). The trauma-informed movement has also been influential in the call for consistent screening of ACEs in healthcare settings. For example, California will now reimburse Medicaid providers for ACEs screening among adults and children (Underwood, 2020). While there is increased understanding of the ramifications of ACEs across the life course and a call for universal screening as part of a trauma-informed movement, there has been little discussion or guidance around *how* these screenings should occur. The purpose of this paper is to articulate examples of how a trauma-informed approach may be applied to the process of screening for ACEs. Utilizing data from a larger study, The First Time Mother study (Mendel, 2015), this conceptual paper employs directed content analysis of qualitative responses to the ACE questionnaire in an effort to illustrate shortcomings of the measure (Felitti et al., 1998) and to understand the lived experiences of participants. The findings from this directed content analysis, as well as the methods implemented throughout the First Time Mother study, highlight potential trauma-informed adaptations to the administration of the ACE questionnaire in an effort to enliven the values of a trauma-informed approach in the screening process.

Background

Adverse Childhood Experiences (ACEs) Questionnaire

Originally designed as a retrospective assessment of childhood adversity for an epidemiological investigation examining childhood factors that contribute to adult physical and psychological health outcomes (Felitti et al., 1998), the ACE questionnaire has been empirically validated across a variety of samples (e.g., Fredland et al., 2018; Hughes et al., 2017; Mersky et al., 2013; Wade et al., 2016). Extensive research has confirmed a dose-response association between ACE scores and an array of health problems across the lifespan (e.g., Anda et al., 2006; Dong et al., 2003). Recent investigations of the ACE questionnaire have provided empirical support for expanding the content, including additional adverse events such as unsafe neighborhoods and perceived discrimination (Cronholm et al., 2015), peer victimization (Finkelhor et al., 2015; Pournaghash et al., 2019), and maltreatment by school authorities (Pournaghash et al., 2019). In addition, global organizations, such as the World Health Organization (WHO), are working through validation trials on a revised version of the ACE International Questionnaire (ACE-IQ; WHO, 2018). The revised version of the ACE-IQ encompasses a broader spectrum of

adverse experiences responsive to global experiences, such as community and war violence (WHO, 2018).

This line of research highlights a shortcoming of the ACE questionnaire: the original list of 10 ACEs is not a comprehensive representation of individuals' lived experiences. As a checklist, the ACE questionnaire limits what an individual can report (e.g., only the adverse experiences included in the checklist), fails to account for duration and/or severity of a person's adverse childhood experiences, and does not elicit the subjective nature of a person's ACEs or the context in which they occur. Indeed, researchers highlight that in order to best understand the influence of childhood adversity on growth and development, the type, chronicity, severity, and patterns of adverse events is necessary (English et al., 2015). The ACE questionnaire arguably only captures type, however minimally. Furthermore, a person's identity and social context may influence the nature of the ACEs they experience and their perception of those experiences. For example, endorsement of ACEs by LGBTQ+ people might reflect contextual factors such as identity issues, public homophobia, or conversion therapy (which is still a problem worldwide). Additionally, someone who identifies as LGBTQ+ may perceive an experience of peer victimization to be caused by homophobia, where someone who identifies as heterosexual might attribute a similar experience of peer victimization to their socioeconomic class. There is likely great variability in contextual factors just as there is great diversity between communities and the people within them. Therefore, any singled-out endorsement of an ACE item may be as diverse as the person who endorsed the adverse experience. The checklist format of the ACE questionnaire also fails to evoke protective factors or resilience of the individual or "benevolent childhood experiences" (e.g., Crandall et al., 2019, 2020; Narayan et al, 2018) and "positive childhood experiences" (PCEs; Bethell et al., 2019). Another shortcoming of the ACE questionnaire lies in the typical administration procedures (e.g., self-administration, checklist) and lack of empirical guidance related to the administration of the ACE questionnaire.

To screen for trauma without acknowledgement of the potential emotional labor requisite of the inquiry, a clear purpose for asking such questions, and/or adequate resources in place to respond to individual needs is troublesome and potentially dangerous (Underwood, 2020). To solicit information about a person's trauma history without thoughtful and intentional methods and practices has the potential to be retraumatizing. Accordingly, Kelly-Irving and Delpierre (2019) argue that while the ACE construct is useful for describing population-level health inequalities, it was not designed to diagnose, and falls short in regards to identifying individual-level vulnerabilities, and carries the potential for stigmatizing children and families if used incorrectly. Ultimately, these limitations circumscribe the utility of the ACE questionnaire as it is commonly implemented. However, trauma-informed values provide a road map to improve upon the original 10-item ACE questionnaire and mitigate the aforementioned shortcomings.

A Trauma-Informed (TI) Approach

Trauma is defined as "an event or series of events or circumstances that is experienced by an individual or group as physically or emotionally harmful or life threatening" (Substance Use

and Mental Health Services Administration; SAMHSA, 2019). This definition highlights both the ubiquitous and subjective nature of trauma; requiring our measurement of trauma to be equally open-ended. With the growing awareness of the prevalence and potential consequences of trauma across the lifespan, the broad application of a trauma-informed (TI) approach is gaining international steam across diverse sectors (e.g., schools, hospitals, service organizations, cities; Champine et al., 2019).

Born out of the recognition of the potential impact of trauma across the life course, the inklings of a TI approach emerged in response to the needs of Vietnam veterans and the growing awareness of the challenges faced by survivors of interpersonal trauma in the 1970s (Wilson et al., 2013). In 1994, SAMHSA hosted a conference to explore the prevalence and impact of trauma, highlighting the voices of survivors who told stories of re-victimization in care (Wilson et al., 2013). Following this conference, SAMHSA initiated the "*Women, Co-Occurring Disorders and Violence Study,*" which focused on creating integrated service system strategies for women with both mental health and substance use disorders (McHugo et al., 2005). This study defined a framework of principles to apply to policies and practices related to services for women in recognition of their past or current experiences of trauma and adversity. This framework became the bedrock of trauma-informed care as conceptualized today (Wilson et al., 2013).

Some consider a TI approach to be akin to a universal precaution (Racine et al., 2019), much like putting on gloves before assisting someone who is injured. We do not stop to ask an individual who is bleeding if they live with a blood borne illness, we simply take necessary precautions based on the assumption that everyone we come in contact with is living with a blood borne illness. A trauma-informed approach serves as metaphorical gloves, allowing you to take necessary precaution based on the assumption that each individual with whom we come into contact with may have a trauma history. In general, a TI approach is rooted in the acknowledgment of the widespread nature of trauma and four overarching tenets (i.e., the 4 R's): realization of the symptoms of trauma, recognition of the widespread nature of trauma; response on a systematic level to such recognition; and prevention of re-traumatization (SAMHSA, 2014). More specifically, a trauma-informed approach has been further operationalized to be comprised of 10 key principles or values: safety, trustworthiness, choice, collaboration, empowerment (Fallot & Harris, 2008), peer support, resilience, inclusiveness, cultural, historical, and gender issues, and change process/ responsiveness (SAMHSA, 2014; Table 1). These values guide policies, procedures, and practice at various levels of organizations (i.e., structure, culture, and service provision).

Applying values of a trauma-informed approach to the administration of the ACE questionnaire may help to overcome the noted shortcomings and, more importantly, may help to prevent further silencing or retraumatizing of individuals who have experienced trauma in their childhood through a more collaborative process.

Methods

Enlisting procedures and data from the First Time Mother study (Mendel, 2015), a larger study with first time mothers, the following provides concrete illustrations of how a trauma-

informed (TI) approach can be applied to the administration of the original 10-item ACE questionnaire. Specifically, we articulate the application of a TI approach to the design of the study, and in particular, the use of the ACE questionnaire. Next, we present a directed content analysis of qualitative data from the First Time Mother study that illustrates the shortcomings of the ACE questionnaire in obtaining an understanding of the lived experiences of participants, and provide examples of trauma-informed adaptations made to the administration and configuration of the ACE questionnaire to mitigate such shortcomings.

The First Time Mother Study

The study, conducted in 2014–2015, examined the pathways between maternal childhood health and well-being and pregnancy-related stress among first time mothers. Using a mixed-methods design, first time mothers were interviewed face-to-face regarding their health, well-being, and circumstances during their childhood, adulthood, and pregnancy, as well as their experiences during the perinatal period (i.e., pregnancy, labor, delivery, and postpartum). The interview schedule contained validated quantitative measures, such as the Parental Bonding Index (Parker et al., 1979), the Pregnancy Distress Questionnaire (Yali & Lobel, 1999; Alderdice & Lynn, 2011), the MacArthur Subjective Social Status Ladder (Adler & Stewart, 2007), and the original 10-item ACE questionnaire (Felitti et al., 1998). In addition, open-ended questioning was employed in an effort to better understand the lived experiences of the participants.

English speaking, first time mothers between the ages of 18–35, who had experienced a singleton pregnancy, were not currently pregnant, and whose infant was under the age of two were included in this study. Recruitment for this study was conducted through solicitation for participants at community health clinics, pediatric practices, neonatal intensive care units (NICU), and maternal and child health organizations in a Western New York area. Additional recruitment occurred over Facebook via snowball sampling techniques. Administration of the ACE questionnaire occurred in the context of a face-to-face interview in the location of the mother's choosing. On average, interviews lasted 45 minutes (range 34 minutes to three hours). Interviews were digitally recorded with the permission of the participant and later transcribed verbatim. Transcripts from the interviews were used as the main source of data for this paper. This study was approved by a university Institutional Review Board and all participants provided written informed consent.

Participant Characteristics

Participants included 99 first-time mothers who were, on average, 29 years old (SD = 4.29) at the time of the interview and approximately 28 years old (SD = 4.46) when they delivered their first child. All participants received prenatal care, and more than half of the sample (55.6%) had an annual household income over $50,000 USD. Of the sample, 83% identified as White, 5% identified as Black, 4% identified as Bi-racial, and 7% identified as African or Asian. The majority were married (66.7%), and had received either their Bachelor's (27.3%) or graduate degree (33.3%). The administration of the ACE questionnaire revealed that over a third (35.4%) of the participants had experienced four or more ACEs, placing such

individuals in a high-risk category for adverse health and behavioral health outcomes (Felitti et al., 1998; see Table 2).

Design: Applying Trauma-Informed Values to the Administration of the ACE

Trauma-informed (TI) values served as an organizing framework for the administration of the ACE questionnaire in face-to-face interviews with first time mothers. While acknowledgement, validation of experiences, and thoughtful language are important avenues of engaging TI values, intentionality in the design of the research interview protocol is equally important. Such intentionality, including clear intentions as to the purpose of inquiring about adverse childhood experiences, careful consideration of timing of the trauma measurement in the overall battery of measures, clear and transparent expectations and protocol, and embedded emotional safety check-ins throughout the research process, transmits acknowledgement of the prevalence of trauma and the effort to prevent retraumatization. Working to co-create a sense of emotional safety with an individual before asking them to disclose their experiences of trauma can be beneficial for the rapport between researcher and participant.

Purpose—A key question when considering screening for ACEs is why? Why do we as the assessor/researcher need to know such information, and what will be done with the information? For the First Time Mother study, the ACE questionnaire, among other rather intimate measures, was used to achieve the overall purpose of the study: to increase understanding of the etiology of pregnancy related stress by operationalizing largely conceptual understandings of social determinants of health and cumulative disadvantage in an effort to translate theory into tangibles, illuminating points of clinical and policy intervention and prevention. Although a requirement of institutional review boards, clearly stating the purpose of why we are asking such questions of a participant and what the intention is regarding use of such information in a way that is easily understood by the participant is in itself trauma-informed. Such a practice of articulating purpose and intent not only allows the individual to make an informed decision whether or not to participate but also enlivens the trauma-informed tenets of trustworthiness through transparency and choice.

Timing of the ACE—The ACE questionnaire was embedded in the larger interview schedule of the First Time Mother Study. After each participant was screened for eligibility and provided initial consent to participate, the interview commenced with relatively innocuous questions about current age, age at pregnancy, utilization of prenatal care, and a checklist of childhood health concerns that the participant may have experienced. The intention of commencing the interview with a largely mundane line of questioning is to attempt to create an emotionally safe environment and to create an opportunity to build rapport before embarking on a more invasive line of questioning.

The next portion of the interview following the opening series of questions was a measure of stability in the home during the first 18 years of the participant's life. Adapting the MacArthur Scale of Subjective Social Status (Adler & Stewart, 2007), the primary researcher invited each participant to detail the circumstances in the home at birth, such as who was living in the home at the time, what their caregivers did for work, and who was

caring for them most often in their infancy. Used much like a life history calendar (Caspi et al., 1996), participants then detailed any changes they recalled over the course of their first 18 years in their family's circumstance, noting with each change where they felt their family ranked regarding social status in comparison to their immediate community at the time and within the United States, more broadly. This measure was intentionally used as a pre-cursor to the ACE questionnaire, as it allowed women to dialogue about their childhood, build rapport with the interviewer, and maintain control over how they told their story.

Forewarnings—Individuals who have experienced trauma have survived unexpected, non-consensual situations of personal threat and harm. Providing a road map of what an individual might expect while engaging with you can promote a sense of safety and the opportunity for them to assert their power in deciding what, if anything, they want to share. Within the First Time Mother Study, forewarnings included providing a general overview of the interview schedule, reminders about what would be covered in future sections of the interview, as well as frequent reminders regarding the voluntary nature of their participation —in the overall study and in their completion of the ACE questionnaire. Specifically for the ACE questionnaire, participants were provided with options as to how they could complete the questionnaire, either by endorsing individual ACEs or simply providing a score at the end of the measure. Additionally, individuals were reminded that they could determine whether the questionnaire was completed with the interviewer or on their own in a private setting. In short, the individual chose if, how, when, and where they answered each question or reported their ACE score.

Introductions for the overall interview as a whole and specifically for the ACE questionnaire emphasized these trauma-informed values via reminders of informed consent, the voluntary nature of their participation, and an outline of the interview schedule components. Providing details of what is to come for an individual and acknowledging (repeatedly) the power an individual has in the process can help to build a sense of emotional safety and trustworthiness through transparency, voice and choice. Below is an example of the introduction to the interview used in the First Time Mother study:

> We start off super easy and gentle, and even though we are in your own space, I'll still give you a heads up when we are going to transition into something a bit more personal so that you are not emotionally blindsided by the switch in topics. Again, any answer you don't feel comfortable with, just let me know and we will skip right over it.

Similarly, the researcher also provided forewarnings to each participant when transitioning to interview questions that may have been triggering for some participants. For example, when moving from the measure of stability in the home to the ACE questionnaire, the researcher stated the following:

> This is where it gets far more personal, it may not pertain to you at all, would you rather I hand it to you or are you comfortable with me reading them out loud?… This is literally a checklist of adverse childhood experiences…Yes or no are perfectly good answers for me, or skip if you'd rather not answer or just grab it from me and you can fill it out.

Employing these “heads-up” moments was also an intentional act to remind the participant that she was in control over how she chose to respond or not respond to any questions asked of her.

Check-ins/Short Debriefings—Check-ins and short debriefings occurred at the end of more invasive lines of questioning given the potential for questions to be triggering for some participants, as well as at the end of interview. Throughout the interview, particularly after the ACE measure, the researcher would check-in with the participant if she had disclosed significant experiences or if she was emotional following a particular line of questioning. The brief check-ins were intended to provide an opportunity for the participant to decide how they wanted to proceed. For example, if a participant was tearful following the ACE questionnaire or appeared unsettled or agitated, the researcher would ask if she felt comfortable continuing the interview, if she was in need of a break, or if she felt that she wanted to process how she was feeling for a moment.

At the close of the interview, the researcher asked each participant to rate the degree to which she felt overwhelmed by the material or information shared on a scale of 0–10. If she indicated a score above four, the researcher offered to facilitate a short grounding exercise, providing three different options. Only four participants reported a score of four or above, and only two of these individuals chose to participate in a brief grounding exercise (breathing exercise). All participants were provided with the number to the local emergency/crises hotline as a measure of working to ensure emotional safety following the interview.

Similar to the forewarnings discussed above, employing check-ins/short debriefings was intended to promote a continually emotionally safe environment and to serve as a reminder that the choice and power to participate is in the hands of each individual participant at all times. Carefully considering the timing of the administration of the ACE measure in a battery of forms or interview questions, offering transparency and forewarnings as to what a participant can expect and when the material is shifting to something potentially triggering, and building in regular check-in points following potentially triggering questions, are just a few of the ways in which a trauma-informed approach can be operationalized in the design and implementation of a study.

Directed Content Analysis

In addition to articulating the TI approach to the research design of the study, a directed content analysis was applied to participant transcripts. More specifically, we used this analytic approach to examine participant responses to the ACE questionnaire portion of the First Time Mothers study interviews. Directed content analysis is useful as a strategy for coding qualitative data in situations where qualitative codes are determined a priori by the researchers (Hsieh & Shannon, 2005). In this study, directed initial content coding was used to identify instances of shortcomings of the ACE Questionnaire. Two researchers separately read each interview and coded passages of the interviews that broadly identified shortcomings of the ACE questionnaire. Following initial content coding, the researchers reached consensus on four separate themes arising from the data, including a) severity and duration of the participants’ adverse experiences, b) influence of the double- and triple-

barreled nature of the ACE questions, c) limited breadth of included items, and d) use of presumptive language.

Findings

Shortcomings of the ACE Questionnaire

Severity and Duration—In the First Time Mother study, several shortcomings of the original 10-item ACE questionnaire were laid bare. One in particular is the failure of the ACE questionnaire to ascertain the severity and/or duration of an individual's lived experience. An example of this shortcoming was brought to light in the disclosure of a participant. Despite an ACE score of 1, this participant detailed extensive abuse over a span of 12 years of her childhood that resulted in 7 miscarriages (Participant 051, ACE score = 1). The severity and duration of this individual's lived experience was not represented in her ACE score and, if not provided the opportunity to expound upon her endorsement on the checklist, would not be have been known to the interviewer. This shortcoming of the ACE questionnaire to fully elicit the interviewee's lived experience creates a dynamic that may stifle (retraumatize) the individual and may leave a researcher without a clear indication of the severity of adversity the individual has survived or the degree of risk she may carry, which may compromise care.

Double- and Triple-barreled Items—The double and triple-barreled items raised questions among the participants, often creating confusion. For example, in response to ACE question 1 (Did a parent or other adult in the household often or very 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), a participant asked, *"*Umm, do I answer to the first question or the second question?" (Participant 069, ACE = 5). In response to ACE question 5 (Did you often or very 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?) a participant responded, "Yes, it's one or the other, it doesn't have to be both? (Participant 084, ACE = 5). Another offered this in response to ACE question 5, "Not to everything except for a few times when my dad was watching me he would take too much prescription medicine or have alcohol…neglectful" (Participant 074, ACE = 5). Participant responses revealed this underlying ambiguity with item structure (e.g., double-barreled items) and therefore potential lack of clarity or accuracy in response.

Limited Breadth of Included Experiences—Through the First Time Mother study, it was also revealed that the ACE questionnaire exhibited a limited breadth of included events, thereby potentially retraumatizing survivors through inadvertent silencing. As will be discussed in greater detail below, the addition of an open-ended question was added to the 10-item ACE measure that revealed a number of additional adverse experiences, such as, deaths of family members important to the individual, abandonment, sibling abuse, childhood illnesses, bullying, and racial discrimination (see Table 3).

Presumptive Language—The ACE questionnaire is also presumptuous at times, asking in question number 6 if an individual's "parents were ever separated or divorced." This

question implies that individuals experienced a two-parent household at some point in their childhood and that their parents were legally married. For several (n=5) in this study, the question did not reflect their lived experience, with some indicating that they did not know one of the biological parents and/or that their parents were never married.

Mitigating ACE Shortcomings through the Application of TI Values

Using many of the values of the trauma-informed approach detailed in Table 1, below are explications of how TI values were employed to mitigate the known shortcomings that were highlighted in the administration of the ACE in the First Time Mother study.

Severity and Duration: Limited Breadth of Included Experiences—In this study, an open-ended question was added to the end of the ACE questionnaire that read: “Is there anything else that you would like to share with me about your experiences of difficult or trying times in your childhood?” Adding this question to an otherwise closed-ended measure embodies the trauma-informed values of voice and choice in that it allows for the interviewee to articulate what experiences they perceive as traumatic, and provides a chance for them to be heard, and for their feelings and experiences to be witnessed. It also embodies the TI values of collaboration and mutuality, and empowerment. By providing an opportunity for the individual to elaborate on an indicated ACE or to share additional experiences that are not solicited by the questionnaire, the completion of the questionnaire becomes a collaborative effort with the power left in the hands of the individual to tell their story, if they so choose.

The addition of an open-ended question also creates an opportunity for participants to describe additional adverse experiences beyond the scope of the original ACE 10 items (e.g., peer to peer victimization, lack of inclusion, systemic racism), or provide more context around their endorsement of ACE items. It also creates an opportunity for individuals to share which experiences, if any, felt hardest to bear. As articulated by one participant with an ACE score of 10, not only did she live through prolonged traumatic experience related to lack of inclusion and systemic racism that was not included in the original 10-item questionnaire, she also described this as the most difficult of all the childhood traumas she experienced:

> …the most difficult thing that won’t be illustrated or talked about umm, is that me and my brother are mixed so we were the only kids on our whole block, in our whole neighborhood, in our whole school that were mixed… I feel like (this) impacted me more than all of those other traumas… and I think that otherness led into isolation, led into being targeted for bullying… (Participant 095, ACE = 10)

Double- and Triple-barreled Items & Presumptive Language—Offering an option to read the questionnaire out loud created an opportunity for women to clarify the meaning of the question, as well as to respond in a way that more accurately reflected their lived experience. This was illustrated in a participant’s response to ACE question #5 (Did you often or very 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?): “No, just the protect thing but I always had clothes” (Participant 65, ACE = 6).

The opportunity to clarify often then lead to a sharing of more specific details that may not have been disclosed if the individual were completing the questionnaire on her own. For example, in response to ACE question 3 (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 attempt or actually have oral, anal, or vaginal intercourse with you?), one woman stated: “Yes- when I was 15, I was gang raped - I don’t remember, I was drunk but I know, I was told” (Participant 054, ACE = 6).

Although not identified as a shortcoming of the ACE items themselves, the utilization of the ACE questionnaire as a self-report checklist curtails opportunity of the researcher to validate the feelings and experiences of the participant. While providing the option to complete the ACE as a self-report checklist might feel more comfortable to some participants, offering to complete the ACE questionnaire with an individual carries the possibility to enliven the TI values of voice, choice, and empowerment, and creates multiple opportunities for validation of their feelings and experiences, as well as opportunities to acknowledge the individual’s strengths.

Co-creating safe spaces through collaboration, working to minimize the power differential, and honoring voice and choice may promote individuals feeling comfortable to ask questions, clarify their answers, and choose to share more details of their lived experiences. This allows for the potential for more open communication and deeper understanding.

Discussion

As trauma is a wholly subjective experience; fostering opportunities for individuals to express *what* they carry with them from their childhood may create opportunities to understand *how* they carry such experiences into their adulthood, allowing for responsive care. The application of trauma-informed tenets such as safety, collaboration, voice and choice, empowerment, resilience, and strength to our assessment practices can create such opportunities; acknowledging the prevalence of trauma and the capacity of individuals to heal.

A trauma-informed approach, although originally designed to guide organizational cultural change (Fallot & Harris, 2009), offers utility to practices and procedures of measurement and assessment through its guiding values. As awareness of the potential lifelong consequences of childhood trauma expands (e.g., Champine, et al., 2019) and the utilization of the ACE questionnaire gains popularity as a standard screening tool (Underwood, 2020), it is imperative that we are thoughtful and deliberate in the ways in which we engage with individuals around their traumatic experiences. In accordance with the 4 R’s of a TI approach (SAMHSA, 2014), responding on a systematic level to our understanding of the prevalence and symptoms of trauma requires an integration of such understanding into policies and procedures. Thoughtful and deliberate assessment is indicative of a “Response” to our growing understanding of trauma and its potential deleterious effects. The experiences

of participants in the First Time Mothers Study using the ACE questionnaire highlight shortcomings of the widely used measure and support a call for the application of trauma-informed values, both in its content and administration.

Although originally designed to be used as an assessment tool in an epidemiological study (Felitti et al., 1998), the ACE questionnaire continues to grow in popularity as a measure of trauma exposure across a host of settings (Watson, 2019). Despite its widespread use, the shortcomings of the ACE questionnaire, as illustrated herein and by others (Finkelhor, 2018; Lacey & Minnis, 2020), underscore inadequacies of the measure in accurately understanding individuals' lived experiences. More specifically, the original 10-item ACE questionnaire fails to ascertain the severity and/or duration of adverse experiences. This was made particularly clear by the participant who had an ACE score of 1 and yet suffered over a decade of abuse that resulted in numerous miscarriages. Similarly, as noted by a host of others (Finkelhor, 2018; Racine, et al., 2019), the original ACE questionnaire is limited in the breadth of experiences. In the First Time Mother study, multiple participants indicated significant adverse events not included in the ACE questionnaire, such as death of a loved one, prolonged illness of a parent, or peer victimization. This shortcoming was illuminated through the story of one self-identified bi-racial participant who had an ACE score of 10 and disclosed that the most challenging thing she experienced as a child was being "othered" for not being white enough or black enough to belong.

Additionally, the construction of the items of the ACE questionnaire is problematic. Researchers have questioned the validity of the items and rigorous psychometric evaluations have not been conducted (Finkelhor, 2018). Indeed, the double- and, at times, quadruple-barreled questions were found to be confusing for participants in the First Time Mother Study. Participants indicated that they had experienced a portion of an item and, at times, would express concern over agreeing to the entirety of the item, as it did not represent their lived experience. The language of a number of the items is also problematic, in that some of the wording is presumptive. For instance, asking if the individual's parents were ever separated or divorced implies that both parents were present to some degree in the individual's life and the individual's parents were married at some point.

Although the ACE questionnaire and related research has been found to be tremendously useful with regard to broadly estimating adversity and has been instrumental in raising awareness of the ubiquitous nature of adversity and the consequences to public health (Felitti et al.1998), implications of noted shortcomings as they relate to the quality and accuracy of information garnered from the questionnaire are numerous. In simply tabulating an ACE score, we potentially underestimate, or worse yet, dismiss the lived experiences of the individual. Therefore, applying a trauma-informed approach to its administration is arguably imperative. Quantifying years of abuse and loss as "1" adverse childhood experience may be harmful to the individual, as it is potentially retraumatizing and dehumanizing to the individual. Similarly, the limited breadth of included experiences may also be received as silencing, diminishing the weight of lived experiences not included on the ACE questionnaire. Confusing, multi-faceted items detailing forms of adversity and the use of presumptive language may further negate the realities of an individual's lived experiences of trauma and adversity. Ultimately, failing to understand a person's true lived

experience of adversity may result in a failure to understand the risk and resilience of that individual, and may jeopardize any subsequent analyses or supports offered.

Given the growing and widespread use of the ACE questionnaire as a measure of adversity (often labeled as trauma) it is imperative that both its content and administration be considered in light of trauma-informed values – intentionally working to create environments and interactions that promote emotional safety, trustworthiness, collaboration, choice, and empowerment. As illustrated in the First Time Mother Study, thoughtful consideration regarding the use of the questionnaire and the timing of the questionnaire is indicative of a trauma-informed approach. Providing clear information regarding the reasoning for asking about adverse childhood experiences, the intended use of the information gathered, and regular reminders of the voluntary nature of participation embodies the TI values of trustworthiness, collaboration, and choice. Timing, with respect to when the ACE questionnaire is administered within the overall protocol of assessments, is also an important consideration. While leading with the ACE questionnaire could be triggering or retraumatizing, contributing to an environment that may be perceived as unpredictable, unsafe, and untrustworthy, beginning with more innocuous questions can help create an emotionally safe environment. This type of structure to a clinical interview is in accordance with trauma-informed values. In a similar vein, setting clear expectations and operating from a place of transparency throughout an interview can be helpful, especially for those who have experienced trauma. Unfortunately, often those who have experienced trauma have been acted upon without warning or consent. Regularly stating what the individual can expect to happen next helps to promote safety and trustworthiness and reinforces the individual's choice in participating—all of which are core trauma-informed values (SAMHSA, 2014).

Clarity and transparency with regard to the purpose, timing, and expectations in utilizing the ACE questionnaire embody TI values and yet do not address the shortcomings of the measure itself highlighted by the First Time Mother study and other research efforts (Finkelhor, 2018; Racine et al., 2019). Therefore, to mitigate the shortcomings of the ACE questionnaire in both its content and administration, the following TI strategies were applied. The addition of an open-ended question, to an otherwise closed measure, embodies the trauma-informed values of collaboration and empowerment. By creating an opportunity for the individual to elaborate on an indicated ACE or to share additional experiences that are not solicited by the questionnaire, the completion of the questionnaire becomes a collaborative effort with the power left in the hands of the individual to tell their story. The inclusion of an open-ended question like the one used in the First Time Mothers study at the end of the questionnaire also helps to ensure that the individual's experiences are accurately represented and understood; effectively validating their experiences. Additionally, going beyond self-report and engaging collaboratively with participants in the First Time Mothers Study to complete the ACE questionnaire helped address issues of accuracy of information gathered, particularly with regard to the problematic item construction (double-, triple-, quadruple- barrel questions). This collaborative approach also helped generate opportunities for the interviewer to offer support and acknowledge participants' strength in overcoming adversity throughout the process while simultaneously gaining a better understanding of what an individual endured, and how they perceived their own experiences.

Research Implications

The ACE questionnaire was originally designed to be a tool within a large epidemiological study (Felitti et al., 1998), but it has become commonplace in research since. Researchers across disciplines have worked to improve the ACE questionnaire, adding items (Cronholm et al., 2015; Finkelhor et al., 2015) and specificity regarding the target population, such as the ACE-Q for children and youth (Bucci et al., 2015; Harris & Renschler, 2015) and the international ACE-IQ put forth by the World Health Organization (WHO, 2018). Some shortcomings of the original ACE questionnaire identified herein have been addressed through these subsequent iterations (see Table 4 for a comparison). Accordingly, some of these newer ACE measures have added response items that assess frequency of the endorsed ACE items (although not severity or duration), and some have endeavored to separate the double- and triple-barreled items found in the original ACE questionnaire. Most new iterations have added new questions, including items that assess peer victimization and community violence. The question regarding separation or divorce has been retained in most iterations, adapted in one of the measures to eliminate the presumption of marriage, and eliminated altogether in another. In two of the updated measures the language has been updated to refer to parents broadly when asking about domestic violence rather than solely referring to the mother figure.

These efforts, while laudable, have largely focused on the content of the questionnaire rather than its administration. Applying TI values to both the content and the administration, as articulated in this paper, may help to prevent retraumatization, promote safe, trustworthy, and collaborative engagement with research participants, and provide direct benefits for research participants (Hutchinson et al., 1994). A trauma-informed approach also honors the opportunity for individuals with trauma histories to participate in meaningful research and share their stories, (Bay-Cheng, 2009; Griffin et al., 2003). In addition, trauma-informed approaches (as proposed herein) redress the tendency to silence victims by excluding them from research, which is a form of stigmatization (Bay-Cheng, 2009). Promoting such qualities within a research setting ties to the fundamental principles of sound and ethical research, abiding by the core tenet of beneficence (United States National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979) and goes beyond the “trickle-down” theory of research benefits (Bay-Cheng, 2009). These trauma-informed and participant-centered approaches are particularly useful when working with marginalized populations. Further research is needed to explore the efficacy of the application of TI values to the administration and content of the ACE questionnaire from the perspective of participants.

Measurement Implications

The proposed changes to the administration and content of the ACE questionnaire warrant consideration of the potential consequences such changes may have to the psychometric properties of the questionnaire as an assessment tool. For example, it is possible that the proposed changes could compromise the reliability and validity of the questionnaire; however, tools like the Evaluating Measures of Patient-Reported Outcomes (EMPRO; Valderas et al., 2008) may be helpful to examine the impact of our suggested changes. The EMPRO is designed to assess the reliability, validity, and responsiveness of measures of

patient-reported outcomes in a standardized fashion. In addition, the EMPRO evaluates the burden of a measure on the individual, considering the time and capacity required, literacy level, acceptableness of design of the measure, as well as the potential emotional toll on the individual. The EMPRO also considers the potential burden on the individual administering the measure in terms of time, resources, training, and skills.

When considered under the EMPRO framework, the TI approach and modifications to the original ACE questionnaire suggested herein (i.e., the addition of an open-ended question and the collaborative approach to completing the questionnaire) have the potential to ease the burden on the individual by allowing them to have more control over how and how much of their experiences are shared (voice and choice) in its completion. Similarly, collaboratively completing the measure may help to alleviate confusion and navigate concerns regarding item design (e.g., double/triple barreled self-report questions) and/or literacy issues. While our suggested changes to the mode of administration (i.e., collaborative as opposed to self-report) may minimally increase the burden on the administrator with regard to time and training, these are likely necessary changes. That is, our recommendations may require additional time to complete the assessment and require that professionals obtain additional training related to protocol for responding to those burdened with trauma in need of immediate intervention/support/resources, but these steps are in line with ethical and responsive care for clients/patients/participants. To determine how a TI approach to the administration of the ACE questionnaire may impact the measurement properties of the questionnaire, scores could be compared between the original ACE and a TI administration to the ACE questionnaire in relation to specific outcomes.

Although it is beyond the scope of this manuscript to carry out an EMPRO comparison, it may be proffered that the application of the suggested TI approach to the original ACE questionnaire will yield more accurate, truly reflective data than the typical self-report checklist approach. Through a TI approach, individuals are able to specifically indicate what components of each ACE item applies to them and how.

Clinical Implications

Although we applied TI values to the ACE questionnaire within the context of a mixed-methods research study, such opportunities have potential salience in clinical settings. Engaging TI values in the preparation, administration, and content of the original 10-item ACE questionnaire increases the potentiality of building both trust and rapport between practitioner and client while relinquishing power and control to the client. Creating opportunity for individuals to have their experiences reflected in the questionnaire and validated in a clinical relationship may help to enrich the practitioner’s understanding, and bolster dynamics of collaboration, trustworthiness, and empowerment within the practitioner/client relationship. While practitioners are often confined by time limitations and ever-increasing caseloads, engaging TI values in the administration of the ACE questionnaire is an efficient way to foster a better understanding of the context surrounding the presentation of current symptoms or challenges. Some, including Dr. Nadine Burke-Harris and providers in her pediatric practice, have already adopted a collaborative approach to administering the ACE questionnaire in a clinic setting (Burke-Harris, 2018).

Indeed, debate over universal screening of trauma (Racine et al., 2019; Underwood, 2020) and controversy over a uniform definition, operationalization, and measurement of a TI approach (Champine et al. 2019) persist. With states like California instituting polices of universal screening of trauma using the ACE questionnaire among Medicaid recipients (Underwood, 2020), considerable discussion ensues regarding the safety and efficacy of such screening. Despite good intentions and evidence suggesting the benefits of early detection and intervention regarding health outcomes related to trauma, some argue that universal screening may generate an increase in unnecessary/unwarranted reports to child protection agencies (Underwood, 2020) and retraumatization and stigmatization of those with histories of ACEs (Racine et al., 2019). Additionally, some argue that universal screening of trauma without commensurate wraparound services in place to meet the needs of those screened (Underwood, 2020) or adequate training in trauma-informed care and response for those administering the questionnaire (Racine et al., 2019) may cause more harm than good. While the application of trauma-informed values to the administration of the ACE questionnaire fail to address such concerns, such application provides a tangible, feasible, and realistic way for practitioners/clinicians currently utilizing the questionnaire to do so in a more trauma-informed manner. This is important because administration of the ACE provides many with an opportunity to share their history of adversity in a supportive environment, one that is validating and free of judgment.

Increased screening for trauma undoubtedly exacerbates demand on systems to operate from a trauma-informed approach and offer trauma-informed services. However, a uniform definition of a trauma-informed approach does not exist (Hanson & Lang, 2016), which creates variation in how a trauma-informed approach is brought to life (operationalized), and complicates efforts to measure or evaluate the efficacy of a trauma-informed approach (Becker-Blease, 2017; Champine et al., 2019; Hanson & Lang, 2016). Extant literature often focuses on the efficacy of trauma-informed treatments on the well-being of a trauma survivor, or more recently, is concerned with embracing systems-based approaches to foster trauma-informed awareness (Champine et al. 2019). Screening for trauma is the step between fostering trauma-informed awareness and offering trauma focused intervention, however, is just one interaction within a system of care. As such, considerable systematic change is necessary to provide a continuum of trauma-informed care, from fundamentally reconfiguring culture and practices to embody its values (Racine et al., 2019), to screening practices, to developing, supporting, and sustaining trauma-focused interventions.

Strengths and Limitations

There are a number of strengths and limitations to this research. A strength of this work is that it details concrete strategies for applying TI values to the use, administration, and content of the ACE questionnaire, helping to operationalize what may otherwise be viewed as theoretical constructs. In addition, this work provides illustrations of the shortcomings of the ACE questionnaire rooted in the lived experiences of participants, offering insight into how the use of the ACE questionnaire may be perceived by individuals. Accordingly, this study promotes the application of TI values in future use of the ACE questionnaire. Despite these strengths, this work is simply an illustration rather than an empirical exploration of the application of TI principles to the administration and content of the original 10-item ACE

questionnaire. Research is needed to explore the efficacy of such application. It is also important to consider the sample of the First Time Mother study. The study sample was predominantly white (83%) and well-educated (60% with a college degree), with more than half (55%) reporting an annual income of $50, 000 or more. Although a considerable number of participants reported having experienced ACEs, it is important to acknowledge that such a homogenous sample may represent an underestimation of ACEs in the larger population. It is well documented that Black and Brown communities experience disproportionate rates of adversity in childhood, largely due to social and economic inequities (London et al., 2017; Newcomb et al., 2009). Although beyond this scope of this paper, it is important to note that considerable work is needed both in research and clinical arenas to address the historical and intergenerational trauma embodied by marginalized communities through our approach to assessment.

Conclusions

In light of the growing movement toward consistent screening for ACEs, born out of the substantive literature regarding the negative role of adverse childhood experiences across the lifespan, it is crucial to consider both the utility and the limitations of existing measures. Careful consideration of the content of popular tools (i.e., the original 10-item ACE questionnaire) and the ways in which we engage in assessment is prudent. Utilizing a trauma-informed approach in assessment is one intentional step towards minimizing the hurt already embodied and preventing further retraumatization.

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Table 1

SAMHSA's Trauma-Informed Approach Guiding Principles (2014)

Trauma-Informed Key Principle/ Value	Description of Principle/Value
Safety	Working to ensure physical & emotional safety; the physical setting is safe, and the interpersonal exchanges promote safety
Trustworthiness and Transparency	Maximize trustworthiness through transparency and consistency
Collaboration and Mutuality	Leveling of the power hierarchy; shared decision making
Empowerment	Strengths are recognized and validated; prioritizing skill building
Voice & Choice	Maximizing survivor choice and control. Recognizing the need for unique/individual approach
Peer Support & Mutual Self-Help	Organizational level of support, building trust, promoting safety and empowerment
Resilience & Strengths Based	Belief in the ability of individuals and communities to heal; promote recovery from trauma
Inclusiveness & Shared Purpose	Everyone has a role to play in a trauma-informed approach; not all are trauma therapists but all can help create therapeutic spaces
Cultural, Historical, and Gender Issues	Moving past cultural stereotypes and biases; gender responsive services; acknowledges and addresses historical trauma
Change Process	Intentional, evolving responsiveness to new knowledge and needs

Table 2

Total Number of ACEs Indicated by First Time Mother Study Participants

ACE	Description	n (%)
ACE 1	Swear at you, insult you, put you down, or humiliate you? Or afraid that you might be physically hurt?	29
ACE 2	Push, grab, slap, or throw something at you? Or ever hit you so hard that you had marks or were injured?	24
ACE 3	Person at least 5 years older than you ever… Touch or fondle you or have you touch their body in a sexual way?	26
ACE 4	No one in your family loved you or thought you were important or special? or Your family didn't look out for each other	30
ACE 5	You didn't have enough to eat, had to wear dirty clothes? Or Your parents were too drunk or high to take care of you	12
ACE 6	Parents ever separated or divorced?	33
ACE 7	Mother or stepmother often or very often pushed, grabbed, slapped… kicked, bitten, hit with a fist, or hit with something hard…threatened with gun or knife?	19
ACE 8	Problem drinker or alcoholic, or who used street drugs?	43
ACE 9	Family member depressed or mentally ill, or did a household…attempted suicide	49
ACE 10	Family member in prison	17

Table 3

Categories of Additional Adverse Childhood Events Indicated by Study Participants

Items not included in the ACE	Number of Participants
Death of Family Member (Parent, Sibling, or Grandparent)	10
Significant Breakup	1
Legal Struggle Related to Prosecution of Abuser	1
Abandonment by Parent (physical or emotional)	5
Hypervigilance (ex., Role of protector of siblings/parent from abuse; being on edge in anticipation of father's behavior)	4
Foster or Kinship Care	3
Issue with lineage (Unknown birth father; found out had multiple unknown siblings)	2
Abuse by Sibling	3
Intimate Partner Violence (by peer; rape by peer)	2
Isolation/ "Othered" (felt like didn't belong; left home alone frequently)	4
Miscarriages (related to abuse)	1
Socioeconomic Stress (due to parents' substance use; due to avoidance of child support remit; due to father's job loss; loss of family livelihood)	4
Robbery (home invasion)	1
Childhood Illness (brain tumor; eating disorder & depression)	2
Held Hostage (by boyfriend as teen; padlocked in room by parent)	2
Inconsistency of Parent Involvement	2
Bullying by Peers	2
Family Member Illness (sibling with CP and multiple surgeries; prolonged illness of mother; sibling with significant disability)	3
Parent Jailed (but not imprisoned)	1
Multiple Moves	1
Racial Discrimination	1

Table 4

Mitigating Shortcomings: A Comparison of Modifications Across Selected Iterations of ACE Measures

Shortcoming	ACE questionnaires						
	Original ACE (Felitti et al., 1998)	**Revised ACE (Finkelhor et al. 2015)**	**Center for Youth Wellness ACE-Q (Burke-Harris & Renschler, 2015)**	**BRFSS ACE (Centers for Disease Control & Prevention, 2008)**	**BARC Pediatric ACE (Koita et al., 2018)**	**Philadelphia ACE (Pachter et al., 2017)**	**ACE-IQ (WHO, 2018)**
Severity and duration not assessed	X	X	X	Some questions about frequency	X	Some questions about frequency	Most questions ask about frequency
Inclusion of double-and triple-barreled items	X	X	X	Items are separated	X	Items are separated	Items are separated
Limited breadth of included experiences	X	Added: - Peer victimization - Peer isolation/ rejection - Community violence - Low socioeconomic status	Added: - Foster care - Peer bullying - Death of parent or caregiver - Separated from caregiver due to deportation or immigration - Child had serious illness - Community violence - Discrimination	Eliminated: -Questions regarding neglect (original ACE items 4 and 5)	Added: - Community violence - Discrimination - Housing insecurity - Food insecurity - Separation from caregiver due to foster care/immigration - Parent had physical illness/disability - Death of parent or caregiver	Added: - Community violence - Peer bullying - Presence of supportive adult - Food insecurity - Discrimination - Foster care - Several questions related to illnesses during childhood	Added: - Child marriage - Additional neglect items - Death of parent or caregiver - Peer bullying - Involvement in fights - Community violence - Items related to war/ collective violence
Use of presumptive language	X	X	X	Refers to parents broadly as potential victims of domestic violence rather than mother figure only as potential victim	Presumptive question regarding parental marriage adapted to apply more broadly	Presumptive question regarding parental marriage eliminated Refers to parents broadly as potential victims of domestic violence rather than mother figure only as potential victim	X