

THE ETHICAL ARGUMENT FOR IMPELEMENTING SCREENING FOR
ADVERSE CHILDHOOD EXPERIENCES
IN THE CARE OF ADULT PATIENTS

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ABSTRACT

Childhood trauma greatly impacts the lives of patients and their future health outcomes. Since the discovery of the utility of the Adverse Childhood Experiences (ACEs) screening tool in the 1990s, many providers have attempted to screen and intervene on these past experiences of trauma with mixed results. ACEs have an outsized impact on adult health. There is considerable literature documenting the changing state of screening for ACEs in adult populations, and the compelling rationales for doing so. There are also a number of interventions available currently, but providers face challenges to use them. Ethical considerations and issues with the current state of screening for ACEs exist, due to some of these challenges and differential availability of interventions between populations. Here, I use the principles of urban bioethics to explain the ethical obligation of screening for ACEs despite these challenges and to dispute previous discussions on this topic. This article will show that there are general strategies that providers can take to implement ACEs screening in an ethical manner and specifically talk about trauma-informed care's utility to help achieve these strategies. Through this discussion, I hope to encourage providers to reconsider ACEs screening and give them strategies to do so.

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CHAPTER 1: INTRODUCTION

I am standing in the corner of a crowded hospital room. An attending accompanied by a team of residents quickly lists off discharge instructions to a patient whose COPD exacerbation has finally started to subside. A resident chimes in, scolding the patient that she could have avoided this had she used her BiPAP machine more consistently. He continues that the patient will have to start taking ownership of her healthcare if she doesn't want to end up in the hospital every week. As a medical student, I frequently experienced interactions somewhere along this spectrum of providers blaming a patient's health problems on their actions. This approach often ignores the larger context of a patient. In fact, if the patient in question has experienced trauma, actions like these are counterproductive, often yielding an opposite result from what providers hoped. Instead of encouraging the patient to change their actions, they can further traumatize a patient. The concept of Adverse Childhood Experiences (ACEs) helps explain many of the issues seen in interactions like these such as continuing the cycle of trauma within the healthcare system.

In this paper, I will (1) describe the current research available regarding ACEs and their effect on the health of adults. I will then (2) discuss arguments for screening for ACEs in adult populations and explain the current state of this screening. Then I will (3) detail the current interventions available to mediate the impact of ACEs on the health of adults who have experienced them and explore some challenges of implementing these interventions. I will then (4) show how the current state of knowledge about ACEs, availability of interventions, and minimal implementation of both screening and interventions creates ethical concerns. In this section I will provide an argument for the

ethical obligation of screening for ACEs. To conclude, I will (5) explore strategies available to help providers implement ACEs screening in a manner that allows them to fulfill their ethical obligations to patients more effectively they currently do.

CHAPTER 2

ACES: DISCOVERY AND CURRENT UNDERSTANDING

The field of investigation into ACEs began with the work of Vincent Felitti in the Kaiser Permanent Health system in California in the 1990s. Felitti first started to investigate this topic upon discovering an unexpected, statistically-significant difference between obese patients enrolled in a weight loss program and controls who had always been thin: the two groups had different incidence of sexual abuse, non-sexual abuse, and other markers of childhood dysfunction such as loss of a parent at an early age or the presence of an alcoholic parent. Felitti postulated that this correlation indicated that experiences in childhood left lasting effects on individuals and prompted them to adopt behaviors to overcome the mental anguish of these negative childhood events.¹

In 1998, within the context of the large, managed-healthcare environment of Kaiser Permanente, Felitti et al. collected a broad set of patient demographic data to investigate if adverse childhood experiences effected other health outcomes in addition to obesity. They called this study the Adverse Childhood Experiences (ACE) trial. This data allowed them to determine the incidence of ACEs and correlate them with adult health outcomes. In this study, they collected information on adverse experiences such as sexual and physical abuse and exposure to dysfunction, incarceration of a parent, and neglect. They found that adults who had experienced such trauma in childhood did indeed have worse outcomes than their peers, even when controlling for other risk factors. To summarize, the study found a “strong graded relationship between breadth of exposure to abuse or household dysfunction during childhood and multiple risk factors for several of the leading causes of death in adults.” They also postulated factors that modulated an

individual's health outcomes outside of risk factors such as "attitudes and behaviors toward healthcare, sensitivity to internal sensations, or physiologic functioning in brain centers and neurotransmitter systems."²

After the findings of this study, this team developed a screening tool called the ACE score that allowed providers to quickly ask patients about their childhood and use that data to anticipate future health outcomes. As this field of study has evolved, many other investigators have designed further studies of ACEs and similar concepts for their impact on adult health. These new studies have helped to confirm Felitti et al.'s original theories and further expand them.

ACEs have attracted a great deal of interest in the medical field due to their broad and varied impact on patients' health. Research has shown an impact on mental health, physical health, and an individual's general health status. In terms of mental health, conditions like depression and substance use disorder increase with an increase in ACE score. ACEs also affect multiple systems under the heading of physical health including heart, lung, and bone disease. They also correlate with specific conditions such as fibromyalgia and irritable bowel syndrome. Additionally, patients who have experienced ACEs tend to report poorer rating of their general health and increased disability from physical health issues. Further, those impacted by ACEs tend to experience "multimorbidity" more frequently than those who do not. Unfortunately, this combination of factors means those who have experienced ACEs often suffer a premature death.^{3,4,5,6,7}

In addition to the clear impact of ACEs on individual health, they also have an influence on the larger healthcare system. The combination of these effects on an individual's health means that patients who have experienced ACEs tend to use more,

and higher cost, health services, which in turn has caused the cost of healthcare to rise. ACEs' effect on the physician-patient relationship also impacts the healthcare system. Providers often write off patients as "difficult" or "non-compliant" due to their continued engagement in harmful behavior. Patients notice this differential treatment to the point where patients who have experienced trauma frequently report more negative interactions with providers. This cycle creates a lack of partnership between patients and providers and causes a barrier that serves to worsen outcomes.⁸

Providers themselves can also experience burnout secondary to ACEs. Those who have an antagonistic relationship with their difficult patients can quickly become frustrated working with them. Conversely, those who attempt to work with patients in an empathetic manner can experience vicarious trauma as the patient describes their past experiences with trauma.⁸

While these broad negative impacts on the health of individuals and on the healthcare system prove ACEs' importance on their own, further interest still in ACEs comes from the fact that "many of these conditions begin early in childhood and are reversible or preventable by mitigating risk factors."⁷ In fact, some providers view "many adult diseases ... as development disorders that begin early in life."⁹ In other words, unlike genetic developmental disorders, providers can prevent and reverse the effects of ACEs with appropriate intervention.

Due to these multiple areas of importance of ACEs, many authors have sought to understand them more on a physiological level. Investigators have researched the mechanism by which ACEs impact adult health to further understand ACEs themselves, but also to develop effective interventions against their effects on adult health.

Understanding the mechanisms behind the impact of ACEs allows a more comprehensive understanding of the current modalities of intervention.

There are two important general ways in which ACEs impact adult health. Korotana et al. lay out a model of these two general effects looking specifically at the body's response to stress. They see direct and indirect responses to stress in a patient's life course. The indirect impact manifests as impaired functioning across multiple areas due to chronic stress and adopting coping mechanisms to combat chronic stress, as Felitti et al. found. First, chronic stress leads to impaired "social, cognitive, and emotional functioning" that impede a patient's ability to engaged in their healthcare and live a healthy life. Second, people who have adverse experiences in childhood can experience increased sensations of stress and turn to methods of coping like "drinking, smoking, or having multiple partners" in order to handle this feeling of stress.^{10,11} These coping behaviors expose them to more negative health risk factors than others. These risk factors do not, however, fully explain the effect of childhood trauma on adult health, as Felitti et al postulated. A negative impact of ACES exists independent of other factors including health risk factors and demographic factors like socioeconomic status.¹²

The direct effect of stress helps to explain how patients' actions only play a partial role in their negative health outcomes.⁶ The direct response encompasses all the specific physiological changes in a patient's body caused by chronic stress. As with the health outcomes they influence, the impact of direct stress is seen across multiple organ systems. The physiological changes include dysfunctional neuroendocrine responses to stress in the sympathetic nervous system and abnormal hormone signaling due to changes in the hypothalamic-pituitary-adrenal axis.¹² For example, those with a higher ACE score

have different levels of blood stream cortisol than others. These abnormal levels have systemic effects on health outcomes, leading to increased risk of metabolic dysfunction like diabetes and heart disease. The direct impact of stress causes problems in neuronal signaling in the brain which leads to emotional control, learning, and memory problems.^{5, 12, 13, 14} In an apt metaphor Groger et al. describe trauma as causing “scars” in the brain that impact future functioning.¹⁵ Chronic stress also causes changes to the immune system via dysregulation of proinflammatory cytokines. This physiological change negatively impacts multiple systems including vascular health.¹⁴ In addition to these systems-based changes, the long- term impact of stress also leads to dysfunction on the cellular level from telomere damage due to DNA methylation changes that alter gene expression in deleterious ways.^{15,16} Multiple other models exist to explain the impact of ACEs on adult health outcomes.^{5,17, 18,19, 20, 21, 22, 23, 24, 25} While different investigators propose different models, the extreme impact of childhood trauma is clear.

Despite such a clear connection and graded response between the ACEs and negative adult outcomes, inconsistency exists in outcomes between individuals who have similar ACE scores. Many researchers have looked into factors that explain these variable outcomes.² For example, the role of resilience has become a predominant explanation for why two individuals exposed to the same negative childhood environment could have different adult outcomes, although this notion is complicated by a direct negative impact of ACEs on resilience.^{5,11, 18} Vulnerability is another concept that can mediate outcomes often making the outcomes worse than similarly scored peers.¹⁹ Race and socioeconomic status fall under the concept of vulnerability for specific populations, and mediate outcomes for ACEs.^{20, 22} Vulnerability not only impacts the individual patient, but also

has effects on the societal level. Due to the variable impact of ACEs, and the more severe impact seen on vulnerable populations, a synergistic effect occurs that cause barriers for such these populations leads to worsening health disparities.⁹

The combination of all this data shows the broad impact of ACEs on an individual's health. For example, in the realm of compliance with treatment, this data shows a more complex picture than patients refusing to take responsibility for their health. Many unhealthy behaviors result directly from past trauma. Viewing these risky behaviors as a symptom of ACEs on an individual's body that further exacerbates their negative impact is a more helpful view than an attitude of blaming a patient. Providers who choose to address these behaviors by shaming a patient not only ignore these physiological underpinnings, they can also make the situation worse for a patient further diminishing their desire to participate in healthcare system from an already low baseline. Providers can also negatively affect a patient by possibly re-traumatizing them with actions like these.²¹ Thus, providers who choose to focus on compliance in patients with history of ACEs without understanding their impact can serve to worsen these patient's trust in the healthcare system and thus unwittingly worsen their health outcomes.

In this section, I have described the discovery of the impact of adverse childhood experiences on adult health outcomes by detailing work of Felitti and colleagues in the 1990s. I also detailed follow-up studies about the mechanism ACEs and their impact on the health of individuals and the healthcare system in general. To highlight the importance of understanding these effects, I concluded by showing how providers ignoring these factors that affect a patient physiologically and psychologically can negatively influence their interactions with patients and further worsen their health

outcomes. Due to this preponderance of evidence, many have started use ACEs scores as a screening tool in adult populations. In the next section, I describe the current state of screening for ACEs and some challenges to implementation.

CHAPTER 3

SCREENING FOR ACES: FEASIBILITY AND CHALLENGES

Many have advocated for the importance of screening for ACES and the implementation universal screening in primary care settings.²⁶ Multiple models validate the feasibility of screening in this setting. For example, Glowa et al. implemented a screening questionnaire across three primary care clinics. They found it did not interfere with the flow of the office visit and that patients felt that the questioning was appropriate in the context of their office visit.²⁷

Despite this promising data on feasibility, many providers still report hesitance to implement screening for ACEs despite knowing their importance. Part of the delay in implementation of ACE screening comes from the current unavailability of interventions for ACEs. In general, a screening test should meet certain criteria. The WHO defined these criteria in the 1960s. One of these guidelines states that “there should be an acceptable form of treatment for patients with recognizable disease.” In other words, options for further diagnosis and follow-up treatment should exist after a patient receives a screening test. Screening should not just be done for the sake of screening. Therefore, the utility of screening goes down with less robust interventions.

For ACEs screening, many providers do in fact cite not knowing how to use the information clinically.^{28,29} Even in the work by Glowa et al, this issue arises. Despite not interfering with clinical operations of the practice, no change to the care in visits or plans for follow-up visits occurred after the implementation of screening. While the study claims this as evidence of the feasibility of the screening strategy, it also points to the fact

that the screening lacks effectiveness in terms of changing the clinical management of patients.²⁷

In this section, I briefly described the desire and feasibility of providers screening adult patient populations for past experience of ACEs. I showed that in spite of this clear interest a lag in implementation remains. I discussed some reasons for why providers remain hesitant to screen for ACEs including ability to intervene upon them. In the next section I investigate the interventions currently available to determine the accuracy of this concern of providers.

CHAPTER 4

INTERVENTIONS FOR ACES CURRENTLY AVAILABLE

Many have attempted to create interventions for ACEs. Some state that the act of providing screening for trauma, and by extension for ACEs, is itself a therapeutic intervention. Purkey et al., for example, postulate a therapeutic effect to simply acknowledging trauma and helping patients understand that it may have led to some of their current coping mechanisms. They believe this therapeutic effect exists without further intervention from the provider.²⁴ Beyond screening itself, other interventions currently available for those with past exposure to ACEs fall into a few categories: psychotherapy, resilience-focused, and community-focused. These interventions have shown mixed benefits.

Korotana et al. wrote a detailed review of the psychotherapeutic interventions available in 2016.⁶ Many of the trials specific to ACEs have investigated the utility of cognitive behavioral therapy (CBT) and its variants. CBT is a well-known, intensive psychotherapy used for broad range of conditions including depression disorders, anxiety disorders, eating disorders, etc. In terms of ACEs, CBT mainly provides symptom management for specifically mental health related symptoms, not physical health symptoms. For example, one study of a variant of CBT, cognitive behavioral analysis system of psychotherapy (CABSP), found CABSP superior to the antidepressant tested for management of depression in patients with adverse experiences in childhood.^{30,35} In their review Korotana et al. found CBT to be the most promising option for improving functioning of patients who had experienced ACEs. They also detail other attempts at psychotherapies. Examples include other traditional therapeutic options like prolonged

exposure therapy, mindfulness-based therapy, and interpersonal therapy. Studies have also assessed newer more somatic based interventions such eye movement desensitization and reprocessing. All of these options require an extensive time commitment from patients and providers. They also demand sufficient access to a mental health practitioner.

Beyond Korotana et al's review other evidence has shown the efficacy of psychotherapies. For example, a phase II clinical trial in the United Kingdom tested emotional regulation in a small group of patients and saw promising results from this cohort.¹⁸ This study found “moderate to large improvements in emotional regulation skills, psychological resilience, mental health, specific facets of quality of life, and physical health problems” in its study participants. Additionally, studies have seen the efficacy of structured mindfulness as an intervention, though primarily tested in youth.⁷

Resilience has also proved a potential option for intervening upon the negative effects of ACEs. Resilience plays a role in mediating the different outcomes seen by individuals with exposure to similar numbers of ACEs. Rutter defines resilience broadly as “reduced vulnerability to environmental risk experiences ... or a relatively good outcome despite risk experiences.”³¹ With this definition in mind, many interventions have hoped that increasing an individual's resiliency would subsequently fortify them against the adverse effects of ACEs and help to prevent the negative outcomes.

The Trauma-Resiliency model attempts to use resiliency in this way. Grabbe and Miller-Karas detail this model in their 2018 study.⁵ It focuses on “somatic mindfulness of physical sensations associated with positive internal resources.” In other words, this model teaches individuals skills that allow them to shift uncomfortable feelings that may be associated with a traumatic memory to more pleasant “sensations of well-being”.⁵ This

method purports to create “more resilient neural pathways” as individuals use these learned skills in their daily lives. Despite the promising description of this therapy in the article, no trials have determined the clinical effect of the therapy on individuals yet. For now, it remains a promising theoretical model.

The Empower Resilience intervention also aims to increase an individual’s resilience to buffer the past effects of trauma. This model provides a psycho-educational intervention that focuses on coping and social support. In contrast to the Trauma-Resiliency model, a study tested Empower Resilience’s theoretical framework on a patient population. It used this framework to create a four-week intervention for a small group of college-aged women who had past experiences of trauma.¹¹ This study tested resilience scores in controls and the individuals who had gone through the intervention. It also looked at risk behaviors, like smoking and recreational drug use, and health promoting behaviors like level of physical activity. Unfortunately, after intervention investigators saw no statistically significant change in resiliency scores in these participants. Those in the intervention, however, did increase their amount of physical activity in a statistically significant manner. The investigators also collected qualitative data that reported improvement in areas like sleep, mindfulness, and relaxation.

The Restorative Integral Support model provides yet another example of the many interventions relating resilience and trauma. It looks at helping an individual recover from the consequences of ACEs by mobilizing resilience through social affiliations. In one example, it attempted to work specifically with those experiencing homelessness.³³ A specific homeless shelter in Penultima California called COTS used this model to further improve their programming. This paper reports that COTS integrated the model in a cost-

effective manner, however, it does not elaborate on the outcomes of the individuals within the program.

To summarize, resilience can theoretically mediate the negative effects of ACEs. Multiple investigators have used this theory to create interventions to change clinical outcomes. These interventions remain in the preliminary phases either purely in the theoretical stage or tested in small groups. Continued investigation of this promising area should be pursued to determine its ultimate impact on ACEs outcomes.

In addition to resilience focused strategies to combat the effects of ACEs, many investigators have attempted community-based strategies. Hall et al.'s study in Washington State shows the importance of community capacity and its possible effect of decreasing ACEs prevalence.³³ External reviewers determined the community capacity rating of the different areas examined in this study using a standard scale. This scale included criteria like community strategic leadership and focus on inter-related problems. After collecting this data, they compared communities by the ACE scores of the individuals living within them. They found that factors like funding that increased community capacity also showed decreased ACE scores of community members. Interestingly, these findings point to the primary prevention that interventions focused on adults can accomplish. It notes a reduction of the number of ACEs in coming generations in areas with increased community capacity. It shows that intervening on ACEs can affect not only the patients who have experienced them but also may prevent exposure of children in their community to ACEs.

In this section I have shown that, in contrast to the opinion of many providers seen in the last section, multiple different interventions to prevent the deleterious

outcomes of ACEs do exist. Many factors can explain the disconnect between their availability and their utilization by providers. For example, many of these interventions remain in their infancy, often with a more theoretical focus or emphasis on symptom management may explain. Additionally, most interventions still require more research to understand their impacts on patients and their clinical outcomes. Finally, multiple problems exist with the current interventions that limit their utility and feasibility to implement. In the following section I will discuss these limitations and challenges.

CHAPTER 5

CHALLENGES OF CURRENT INTERVENTIONS

The amount of time necessary for many current interventions both per session and total serves as a major challenge to their feasibility. For example, the CASBP therapy, which showed promise for symptom management, typically involves sixteen or more individual sessions on a weekly basis.³⁴ All other examples of psychotherapy interventions and the resiliency-focused and community-focused interventions also all require a large investment of time. They take place over the course of weeks to months and require frequent interactions with a provider. This time requirement shows that these interventions may lack feasibility in a primary care setting. In primary care, brief interventions provide the most impact due to limited time and resources available for each patient.⁶

As psychotherapies have shown the most promise in terms of clinical effect on patients who have experienced ACEs, understanding the utility of these therapies within a primary care setting is especially important. Due to their time requirements, these interventions do not seem to fit well in the current structure of primary care. Referrals to other providers could provide a solution. Referrals, however, have their own set of challenges. Kates et al. go into some of these issues citing long wait times to obtain an appointment, suboptimal communication between mental health services and primary care providers, and antagonism from behavioral health providers when primary care providers initiate mental health services.³⁶

In order to overcome this hurdle many have advocated for the integration of behavioral health services into primary care practices. Kates et al. did this in multiple

family medicine offices over the course of 16 years in a town in Ontario. They found that access to mental healthcare increased, especially in communities in which it had previously been underutilized. They also found decreased stigma to seeking care and, as expected, decreased waiting time. This solution appears to circumvent the challenges of referring primary care patients to behavioral health providers.³⁶ Later data, however, has shown that even when mental health services become integrated into primary care practices with effective improvement in access and increased use of services, patients still fail to experience improvement of symptoms.³⁷

All current therapies have mainly focus on symptom relief and improvement in functioning in areas including social and emotional domains. This scope causes an additional issue with the current therapies because they lack data on physiologic changes after interventions and do not assess changes in disease burden or other measurements of patient physical health. While a patient's day to day functional status should be considered, without a physiological focus, interventions do not address effects on physical health of ACEs that contribute to a great deal of morbidity. These mental health focused interventions may still provide valuable means of changing physical health parameters for patients, but studies have not yet investigated them in the context of ACEs.⁶

In this section I examined some of the challenges that continue to discourage providers from implementing the interventions currently available for ACEs into their regular practice. Due to these challenges and others, multiple ethical considerations around screening for ACEs arise. In the following section I will discuss the key ethical concerns about ACEs screening.

CHAPTER 6

ETHICAL CONSIDERATION OF SCREENING FOR ACES

In his 2017 article, Finkelhor discusses the general ethics of screening for ACES and questions whether screening programs are ethical.³⁸ He lists many broad critiques such as the fact that few interventions exist and those that do - behavioral health interventions - are more general than would be expected from another screening test. He also points out that screening on its own can carry consequences, including patient's discomfort and stigma. Others like Garg et al. and Perrin have made similar arguments to Finkelhor.^{39,40} While I acknowledge many of their arguments, I believe investigating the ethics of screening for ACES more specifically through the lens of the principles of urban bioethics will further clarify a provider's ethical obligation with respect to screening. In the following section, I will investigate screening for ACES from the lens of the five major principles of urban bioethics: nonmaleficence, beneficence, social justice, solidarity, and agency.

When considering nonmaleficence, providers must look at the negatives of screening for ACES and determine if these negative results can cause harm to patients. Some negatives come inherently from the act of screening such as the potential to be retraumatized through having to recall and conceivably relive painful experiences of past trauma.²¹ Other sources of possible harm come from the after effects of labelling a patient as someone with a high ACE score. The two main post-screening consequences are bias and stigma.

Bias exists in multiple areas of medicine when a provider arrives at a diagnosis or a treatment plan using faulty information. Bias can result from misinterpretation of

objective information like when a provider anchors to a specific symptom to make a diagnosis while ignoring others, or it can come from unconscious assumptions such as a provider interpreting a person's pain tolerance differently due to their gender or their race.⁴² For patients with past experience of trauma, bias occurs when providers make assumptions about what their interaction with a patient before meeting the patient. Providers often assume that such patients are more "difficult" than others and will anticipate an unpleasant interaction before actually having one.²⁴ The anticipation of a negative interaction often makes providers more rushed and less patient while collecting clinical information. If they attribute a patient's complaint about symptoms to their "difficult" nature rather than a symptom of a physiological process, they may miss important diagnostic clues that could help ease a patient's symptoms. When patients experience bias of this sort on a regular basis it can translate into stigma in a medical environment.

Stigma has many definitions. Eliason states that stigma "is the process of making a group of people outsiders, 'deviant', and thus, less deserving of basic human right."³ It involves many things including "labelling, ... prejudice, and discrimination" and within a power differential "is exercised to the detriment of members of a social group."⁴³ Stigma can operate in similar ways to ACEs both by encouraging unhealthy behaviors in order to cope with the unpleasant feelings and by creating physiological changes in an individual's body.⁴ Stigma around a screening test such as ACEs screening can also negatively impact a patient's well-being in many ways. For example, patients can fear a diagnosis due to the stigma associated with it and thus avoid seeking care for a treatable condition, as seen with mental health disorders and sexually transmitted infections.⁴⁴

Once a patient receives a diagnosis, stigma can also create harm due to an individual experiencing a changed sense of their social identity, specifically feeling devalued within a certain social context.²⁵

Within the context of healthcare, stigma already exists for patients with history of trauma due to provider bias. Green et al. interviewed women in primary care and social service settings about multiple topics including trauma and found that those who had experienced trauma in the past described negative interactions with providers such as feeling overlooked or receiving rude treatment.⁴⁵ These interactions with providers exist before the presence of a formal label in these patients' records. An official label like an ACE score may serve to exacerbate such negative interactions and put a further strain on the relationship.

Finally, stigma operates differently across different communities and cultures. As mental health providers perform most of the current interventions for ACEs, communities with a stigma against mental healthcare, such as ethnic and racial minority communities, can face an additional stigma of ACEs on top of what others with and ACEs score experience.⁴⁶ Ironically, this differential amount of stigma further serves to increase health disparities that ACEs screening hopes to diminish.

While providers need to consider all of these negative factors when thinking about ACEs screening for the lens of nonmaleficence, they should also consider the harms that ACEs can cause a patient without treatment. Deciding to not screen for ACEs due to the fear of stigmatization or future bias in interactions may prevent these negative interactions from occurring, but it does not address the harm patients experience from negative interactions with the healthcare system that can re-traumatize them. Avoiding

ACEs screening also does nothing to decrease the known harm that ACEs have on an individual in terms of health outcomes. Providers considering ACEs screening should of course continue to advocate for appropriate interventions that can help diminish the impact of ACEs on health outcomes in their adult patients, however, waiting to implement screening until these interventions become available does not fulfill the obligation to nonmaleficence. In the current context, while interventions continue to improve, providers still have an obligation to begin screening for ACEs due to their known negative health effects. In this process, they can start to more fully understand they effect of trauma on their patients and begin to diminish possibilities for re-traumatization in the healthcare setting. They should also continue to train themselves and their staff to decrease the stigma and bias that can come from ACEs screening in order to further protect their patients.

Beneficence in bioethics denotes performing actions that will positively benefit a patient. While ACEs clearly have a negative impact on patients and their future health, the actual act of screening does not as clearly have a positive impact. In fact, changes in physiological systems begin soon after the individual experiences trauma and persist despite differences in environment between different patients.¹⁹ Additionally, some also question the utility of ACEs themselves as a screening tool. Geronimus et al., for example, propose different life experiences and “weathering” that occurs due to factors like race, sex, and sexual orientation as an alternative model to ACEs.²⁰ Thus, trying to capture data about an individual’s outcomes from an overly-simplistic score may not yield detailed enough data to do good for the patient. Due to findings like these and the continued uncertainty of the impact of screening on an individual patient, I will detail

other positive outcomes that could come from screening for and treating ACEs by showing that the risk of ACEs not only impacts the individual but others around them.

ACEs have different incidence and impact on different communities depending on race, socioeconomic status, sexual orientation, and other factors. As ACEs predispose individuals to poorer health outcomes, they thus can increase health disparities in these groups that already have other barriers limiting their capacity to live their healthiest life. Screening for ACEs has been theorized to help reduce these health disparities.⁹

Dube notes an additional benefit and further urgency of screening for ACEs in adults. ACEs screening works for the adults with an ACEs score as tertiary prevention, i.e. preventing worse outcomes for patients already affected by the condition. For others, however, ACEs screening can also serve as primary and secondary prevention.

Individuals who have adverse experiences in childhood have an increased risk of “next-generation child maltreatment” causing ACEs to occur intergenerationally with a cyclic nature.¹¹ By addressing the harm that ACEs have caused for an adult, members of future generations from the same family may avoid such experiences.⁴¹ On an individual level, through effectively identifying individuals with these risk factors, providers could offer appropriate counseling, therapy, and possibly interventions for other members of the household to try to avoid this cycle of harm. Such actions would allow this screening to serve as primary prevention as well. Additionally, on a community level, the fact that interventions for community capacity that modify the incidence of ACEs within communities already exist shows that providers and politicians currently have a way to start working towards this goal.³⁴ Thus, by looking at ACEs beyond the focus of an

individual and instead looking at the health of a community can help disprove the idea that currently no effective interventions exist for ACEs.

Thus, in considering the obligation of beneficence, a provider must consider the increasingly large quantity of data showing that ACEs have a significant and broad impact on adult health. They must also realize that the impact of ACEs not only extends to the individual patient but may affect how that patient interacts with their children and other individuals around them. They can also serve to further exacerbate health disparities in groups that already experience them. In this context, a provider can view ACEs as an issue of public health. In matters of public health, beneficence must be considered at a population level instead of just for an individual patient. Examples include mandatory reporting for sexually transmitted infections even despite a patient's wishes not to disclose their status to a partner or reporting of seizure activity to the government which could result in suspension of a patient's driver's license. In both of these examples, a provider's actions affect a patient neutrally or possibly even negatively, however, on a societal level they lead to decreased morbidity and/or mortality due to decreased spread of infectious disease and decreased risk to other drivers of accidental vehicular collision. For ACEs, providers should also consider their obligation of beneficence in this manner. Deciding not to screen for ACEs because of unclear positive impact to the individual patient or concern of screening's possible negative impact to the individual causes providers to miss the opportunity to start to diminish the impact of ACEs on the health of the general population. In order to fulfil their obligation to beneficence with the current information, providers should advocate for continued development of treatment strategies for ACEs while also beginning to implement

screening. In doing so, they commit to limiting new exposures of individuals around their patient to ACEs.

An individual patient taking on risk in order to achieve benefit for another patient can be justified by the principle of solidarity. This principle helps reconcile the seemingly contradictory obligations of beneficence and non-maleficence by asking individuals to take on a cost to themselves to help others around them. Even if a patient does not receive direct benefit or knowingly takes on a degree of harm, others in society can receive benefits from ACEs screening on a broad scale and thus fulfill this ethical obligation. The principle of solidarity especially relates to ACEs due to their ability to contribute to health disparities. When providers consider ACEs screening for a view of public health and encourage those with access to healthcare from both over-represented and under-represented groups to complete ACEs screening, a reduction on a societal level of ACEs may occur and can help to decrease their effect. This societal change can impact even to those who do not have access to healthcare to undergo screening. When viewed on a societal level, continued implementation of screening can thus serve to decrease the health disparities caused by ACEs even as other disparities in access continue to exist. The principle of solidarity obligates providers to work towards relieving these disparities even if a cost exists to certain patients for doing so.

Justice is the next classic principle of bioethics to consider. Justice relates to the equal distribution of resources across society. A screening tool like ACEs suffers from inequitable distribution of access to primary care among different segments of the United States. As Duke et. al point out, screening during preventative visits in pediatric

populations likely does not reach those as impacted by ACEs who do not have access to preventative care in the first place.⁴⁷ The same sentiment can be applied to adult patients.

Justice, however, only serves as a general background for the discussion of ACEs. Providers should consider social justice to fully understand the complexity of the topic and to more fully allow screening to serve their patients. As with solidarity, social justice considers existing and historical disparities to move beyond looking for a solely equal distribution of resources and attempts to reach an equitable distribution. The social justice lens makes the problematic nature of the current state of screening and intervention for ACEs apparent.

The mental health focus of current options for intervention creates further disparities when providers attempt to interventions for those with high ACE scores. As noted by Maura and Weisman de Mamani in a metareview, in the United States ethnic/racial minorities have less access to mental health services.⁴⁸ They also receive differential care when they do receive mental health care. Their care differs in ways like the amount of time a physician spends with them, the diagnoses given to them, and many other areas. This study also showed lower rates of outpatient follow-up with racial and ethnic/minorities for mental health services. Others have validated that ethnic minorities have less access to care and discuss various barriers including stigma, cultural feeling about mental health services, lack of culturally competent services, geographic availability of services etc.^{37, 46, 49, 50} These disparities exist even when adjusting for mental health status.^{49, 51} Additionally, even among patients who seek out treatment, there is a disparity in services given, so disparities cannot solely be explained by interest in resources.⁵² In other words, multiple factors contribute to differential care received by

ethnic minorities within the mental healthcare system. Thus, relying on the mental providers to intervene upon the effects of ACEs can further worsen the disparities caused by ACEs. These disparities apply other demographic group of society as well, including those of low socioeconomic status and sexual orientation minorities.^{53, 54, 55}

In addition to issues of access, stigma plays into the concept of social justice as well. Due to the behavioral health nature of many ACEs interventions, communities in which mental health services are stigmatized face a further barrier of accessing them, and also face a further burden of treatment. Gary points out the added stigma of racism for specific ethnic minorities that comes from within and outside the healthcare system, a kind of double stigma.⁵⁴ Factors like these cause even greater disparities in access to mental health resources and thus intervention for ACEs.

Finally, diverting resources from other areas that need investigation in primary care may result from initiating a new screening for ACEs. This unintended consequence could further serve to create disparities. From the context of social justice, healthcare systems with many resources would not feel the strain as much as under-resourced systems. In other words, in trying to provide equitable care among all members of society to honor the principle of social justice, screening for ACEs could unknowingly work to further worsen disparities in other areas that received diminished resources as a result.

The obligation for social justice allows a provider to consider these sorts of contextual issues and move beyond the abstract idea of equally dividing access to ACEs screening and intervention after screening. A provider must consider the inequitable distribution of mental health services when thinking about interventions for their patients of certain races, socioeconomic statuses, or sexual orientations. They must also consider

the stigma an individual may already experience in their community around a mental health intervention. Keeping these factors at the forefront of a medical decision will fulfill this bioethical obligation and will also provide more effective patient care and therefore hopefully improve outcomes.

Finally, with respect to the classic principle of autonomy, the considerations with ACEs are similar to those of other screening test. Patients offered these tests should know the benefits and downsides of screening. As seen in the previous sections, while screening has many potential benefits, harms also exist from it. Providers need to weigh the possibility of stigma and re-traumatization against the possible therapeutic effect of screening and the positive effects screening can have on others due to the cyclic nature of ACEs. The provider should also educate the patient on the idea of solidarity and the possibility of decreasing health disparities for other even if it means the patient needs to take on some risk of their own. Before offering the screening, providers should be able to explain these risks and benefits in a way a patient can understand to allow them to make a personal decision about their willingness to be screened.

It is also important, however, for providers to give patients the option to opt in or out of screening. ACEs already lead to disparities in health outcomes by factors like race and socioeconomic status while existing in a system with inequitable distribution of interventions. Thus, if providers decide which patients they believe will be interested in screening and which will not they may subconsciously further this inequitable distribution. Providers are therefore obligated to explain the risks and benefits while also offering this screening to their patients in a consistent manner allowing the patients to make a final decision about screening.

To further honor autonomy, and provider must consider the principle of agency. In general, to do so a provider must assess an individual's capacity to make a decision by considering factors like health literacy and access to healthcare. For ACEs screening, providers must specifically accommodate for past negative experiences with providers that many who have experience trauma have had. A patient who has already experienced the stigma of trauma from healthcare providers may balk at the prospect of a new screening test of any sort. This offer to a patient who has experienced trauma may feel like an inappropriate surveillance of history they had not expected to share. Providers should not assume that a patient will always reject the offer to complete ACEs screening, even if they do so the first time it comes up. Providers can continue to offer education about the screening in order to allow the patient to make a fully informed decision. They also need to demonstrate to patients how this information will be used by themselves and by their staff and show specific strategies by which they will protect this information. Through this process, they can work towards building trust in a relationship with a clinical provider for patients who have not received this sort of positive benefit in the past. In other words, providers need to consider a patient's previous interactions with the healthcare establishment and how those factors may influence their ability to fully engage with this medical decision. They must then work with the patient to fully understand their desires for their health and how ACEs screening may fit into those desires.

In this section, I discussed screening for ACEs from the prescriptive of non-maleficence, beneficence, social justice, solidarity, and agency. I began with an argument by Finkelhor which states the current state of ACEs screening is not ethical. I showed, however, that with further investigation from the lens of urban bioethical principles that

ACEs screening is in fact an ethical obligation. The principles of urban bioethics allow for more consideration of contextual factors compared to the classic principles of bioethics which can help explain our differing conclusions. Much of what Finkelhor and others conclude comes from looking only at the individual effect of screening and not the application of ACEs in a public health context. I showed in the discussion of beneficence and solidarity the limited nature of this view of screening. These authors also do not take into account how the current state of interactions between providers and patients who have experienced trauma already causes the stigma and bias for which they are concerned. This fact and the fact that ACEs continue to cause such negative health outcomes in adult populations further speak to the urgency and obligation for implementing broad screening for ACEs, as I discussed in the section about nonmaleficence. In the following section, I will conclude my argument by discussing strategies that can help providers implement ethically appropriate screening in order to fulfil this obligation.

CHAPTER 7

STRATEGIES TO EFFECTIVELY IMPLEMENT SCREENING

I believe screening for ACEs does more good than harm due to the complex nature of ACEs' influence on adult health. As with any screening protocol, a provider has an ethical obligation to explain the negatives that can come from screening and educate their patients on these possible harms. On top of this basic obligation, I believe the following considerations can help diminish some of the ethical tension within ACEs screening and in doing so maximize the benefit while limiting the harms to patients.

First, shifting screening from an etic perspective to an emic one will allow it to become more patient-centered. Most screening tests in the medical field take the etic approach looking to diagnose a disease. The greater utility of ACEs screening, as Dube argues, comes from an emic perspective in which providers are looking for a “new perspective to understanding the human experience.”⁴¹ Rather than providing a piece of data that will determine the path to take at a decision point in a clinical algorithm, an emic focus allows for ACEs screening to give the provider a fuller perspective on their patient's context as an individual outside of their disease. It attempts to more fully understand their experience of their illness. Others have validated this this patient-centered focus while attempting interventions for trauma and ACEs. Kates et al., while integrating mental health services into primary care clinics, note that they obtained their most important and innovative changes from direct patient input. With the goal of “understanding the individual's health journey” this team collected specific data on patient experience including “input from satisfaction questionnaires, focus groups, and [a] ‘shadowing’ exercise.”³⁶ Other authors have detailed ways of getting specific patient

input as well. Doornbos et al. used community base participatory research to determine what specific resources a group of urban, underserved, and ethnically diverse women would like to see to improve their access to mental health services.⁵⁶ Strategies like these can all help providers achieve this emic perspective within ACEs screening.

Resilience can paint a fuller picture of a patient's individual experience as well. Understanding a patient's resilience can make the results of an ACE screening even more relevant to a provider. The ACE score on its own only provides a limited view of how past trauma affects a patient in the future. Resilience and other factors serve to mitigate the effect of trauma on health outcomes and has been a focus for screening and interventions of its own.¹⁹ Dube advocates for assessing a patient's resilience in tandem with screening for ACEs to help achieve the emic perspective for which she advocates.⁴¹ Additionally, Rutter notes that negative experiences can have a steeling effect allowing those individuals to respond more effectively to future adversity and stress.³¹ Other factors may also play in to this mitigation. Effective interventions of resilience already exist that can occur outside of the clinical and mental health contexts.^{5,11,33} These interventions appeal to providers because, unlike the fixed past experiences that ACE screening describes, a patient's resilience can fluctuate. Thus, interventions on resilience can affect disease progression and the outcomes individuals with past trauma experience.²⁴ These interventions can occur in many contexts making them more largely available. This increased availability can help diminish the issues of access seen currently with mental health interventions for ACEs. Thus, resilience provides a known factor that can currently be intervened on. With the knowledge of the negative effects of ACEs on adult health, providers have an ethical obligation to attempt to intervene as long as the

consequences of such intervention are tolerable to the patient with which they are working.

Finally, to further encourage a culture of healthcare professionals that understand the impact of childhood trauma on patients' health, professional education should incorporate more of this knowledge into their curricula. Many of the articles I found addressing patient experiences with trauma and the creation of appropriate interventions came from non-physician perspectives such as PhDs, RNs, and social workers. Enhanced education in medical student curriculum is particularly important to the mindset of future physicians. As seen in studies like those by Strait and Bolman, effective and time-efficient approaches exist that can change students' outlook on ACEs and their willingness to investigate them in their future careers.³²

These three goals – an emic perspective, consideration of mitigating factors like resilience, and education of trainees – all can be further enhanced by trauma-informed care. Trauma-informed care does not provide a specific intervention to ACEs, however, the environment created by this style of clinical practice complements these goals. Thus, my final recommendation to diminish ethical concerns surrounding ACEs screening is implementing trauma-informed care in clinics concurrently with an ACEs screening program. To understand how trauma-informed care helps achieve these goals, I will give a brief overview of trauma-informed care then address each goal specifically.

Trauma-informed care is a philosophy of healthcare that acknowledges that everyone, from patients to providers, has experience with trauma. It focuses on training of providers and other clinical staff, rather than patients. It seeks to change their actions and the ways in which they interact with patients who have experienced trauma, and

suggests that it is beneficial to acknowledge this trauma to better understand its repercussions in an individual's life. Through this acknowledgement, it states that individuals can more effectively and appropriately interact with others who have experienced trauma.

Various authors have proposed principles that allow clinics to be more trauma-informed. Purkey et al enumerate general principles that focus on ways to acknowledge a patient's past trauma and ways to verify that patients are not retraumatized in their interactions with healthcare. They emphasize the holistic nature of this strategy and the importance of its application to the entire organization from providers to receptionists.²⁴ This approach to care can help improve interactions between providers and their patients who have experienced trauma.

From the patient perspective, this model acknowledges that past trauma creates unique needs and risks when interacting with institutions like healthcare centers, such as the risk of re-traumatization.²⁸ It also views the behavior of those who have experienced ACEs as "normal reactions to an abnormal experience."²¹ This philosophy of care also encourages attention to subtle cues from patients which can help providers decrease hostility towards their "difficult" patients. This understanding of patient behavior prevents from undue criticism of valid responses to trauma. In this way it protects against re-traumatization and promotes healing. Due to the wide range of facets of trauma-informed care, it can also more broadly address the needs of patients with ACEs. For example, Purkey et al. discuss its utility for working with patients who have experience societal abuse due to factors like race, gender identity, sexual orientation, etc.²⁴ In other words, many positive impacts can come out of trauma-informed care for patients, but

these impacts are not limited to patients. Providers can also get positive impacts from trauma-informed care.

Providers more effectively serve their patients when they acknowledge their past experiences of trauma, but also preserve their own well-being in doing so. Shifting the provider perspective from one of dealing with a difficult patient to working with a complex individual whose actions can be partially understood by their past experiences with trauma can help providers avoid their own burnout. Additionally, in order to protect providers from vicarious trauma or re-traumatization when they hear about past experiences of trauma, trauma-informed care programs emphasize the importance self-care and empathy.⁷ This model of care thus teaches providers to more rationally, calmly, and empathetically work with their patients who have experienced trauma and serves to diminish provider distress from working with these patients.

Trauma-informed care helps to advance the emic perspective of ACEs screening by offering another way to accommodate for the context of patients' lives within a healthcare practice.⁸ Providers who have taken the time to understand the impact of trauma on their own lives can feel an allegiance for their patients with ACE scores. They can see how individuals with extreme levels or amounts trauma are even more affected by past trauma than they are themselves. Context like this allows providers to avoid stigmatizing patients with histories of trauma. Increased understanding of patient context can also diminish stereotypes of what a patient with an ACE score will act like and avoid the temptation to write off patients as difficult. Thus, trauma-informed care sets up an environment in which providers already have a comprehensive view of trauma. This baseline understanding allows them to interpret the results of an ACEs screening test in a

more emic perspective and diminishes the possible stigmatization and bias that could occur if providers used an etic view.

Due to trauma-informed care's broad, non-specific nature, it also serves to supplement ACEs screening in accommodating for mitigating factors. Factors like weathering and resilience or race and socioeconomic status are not accounted for in an ACEs screen. Interventions that look to address only the impact of ACEs may leave out some positive and negative effects of these factors. Rather than acting as a screening tool or a targeted intervention, trauma-informed care works to shift the general culture of a clinical environment. It can thus also provide a background on which providers can use the ACE score more effectively to serve their patients. As the culture of a clinic or institutions changes, some of these mitigating factors may subtly be addressed or bolstered without specifically intervening upon them. The ACE score therefore can just focus on childhood trauma without needing to modify all other factors that impact it.

Finally, trauma-informed care involves a cultural shift for all healthcare providers involved. It requires education of not only trainees but of everyone who interacts with a patient. Many have looked at specific ways to train providers and students. Green et al. for example developed a continuing medical education curriculum with the goal of educating primary care providers to become more comfortable with trauma-informed care. They did not specifically screen for trauma, but rather gave techniques to optimize interactions between providers and patients who had experienced trauma. They tested this curriculum with standardized patients and reported more patient-centered interactions after the intervention.⁸ Strait and Bolman took a different route by having trainees consider their own personal trauma and its effects on them to see if this would influence

their willingness to screen their future patients for trauma. They found that trainees more frequently understood the importance of an ACE score for their patients after they assessed their own score.³² Finally, Palfrey et al. offered a one-day training session and looked at a provider's willingness to implement trauma-informed care before and after. They found an increased confidence in the providers who had attended the workshop and willingness to implement such principles within their own practice. They also followed up with the providers a year later. Many had taken steps to integrate new services into their practices that could further serve their patients who had experienced trauma.²⁸ These studies and models show that many options exist to train providers on trauma-informed care. Greater understanding of trauma provided by trauma-informed care education can serve to make staff understand instruments like the ACE score more effectively without additional education. It allows providers to collect this data without stigma or bias. It also increases empathy for patients with high ACE scores as providers have a greater understanding of what that trauma entails and the impacts of it on behaviors and health outcomes.

In this section, I discussed some strategies that allow ACEs screening to become more patient-centric and that can help shift the culture of medical providers with respect to trauma. I also discussed how trauma-informed care synergistically works with these strategies to help prevent ACE scores from becoming a source of stigmatization and helps to increase empathy of providers to those who have experience trauma.

CHAPTER 8

CONCLUSION

In conclusion, adverse childhood experiences play a significant yet variable role on the health of individuals who have experienced them. While providers cannot predict outcomes precisely for each individual, on a population level ACEs have a massive negative impact. Many interventions for ACEs exist, however, issues with access and questions about effects on health outcomes remain with these interventions. These factors and others create many ethical questions surrounding the screening of ACEs. In this paper, I have shown that despite these ethical questions and issues, when providers look at ACEs screening from the lens of the principles of urban bioethics, their obligation to work towards relieving the effect of ACEs on the health outcomes of their adult patients becomes clear. Providers can focus on interventions that build resilience and advocate for a shift in medical culture to be more trauma-informed. A shift in culture of this sort can lead to increased understanding of a patient's lifestyle choices, less antagonistic treatment of patients by providers, improved trust between patients and providers, and reduced re-traumatization in healthcare settings. In creating this change of culture, providers will start to diminish the effects of childhood trauma on adult patients. They will also help to limit exposure of future generations to trauma and start to diminish the health disparities caused by these exposures to trauma. While continuing to refine the field of intervention on the effects of ACEs, providers must start more widely implementing the screening of ACEs. They cannot wait to allow them to continue to damage patients and those around them.

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