

1 Systematic Review of the Global Implementation of Adverse Childhood Experiences Surveys

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29 **Abstract**

30 Adverse childhood experiences (ACEs) are common globally and have been found to be  
31 associated with a myriad of negative behavioral and health outcomes. An understanding of how  
32 ACEs are measured and through what survey mechanisms is not well documented. Peer  
33 reviewed and grey literature were searched for articles on adverse childhood experiences and  
34 articles from 1998 through November 2018 were included. Inclusion criteria were studies that  
35 administered a version of the ACE questionnaire on non-institutionalized adults 18 years and  
36 older. All study designs were included with the exposure of interest being self-reported ACEs.  
37 Studies that did not meet these criteria were excluded. A total of 712 studies, from 60 different  
38 countries were included and there were 87 different ACEs related surveys used. Over a third of  
39 the surveys were modified from their original versions. Majority of the articles included  
40 questions on physical/emotional abuse (93%), while sexual abuse questions were included in  
41 89% of the articles. Household dysfunction questions were included in 75% of the articles and  
42 neglect questions were included in 67% of the articles. Thirty-two percent of these studies were  
43 conducted in clinical settings while 68% were conducted in community settings. The Childhood  
44 Trauma Questionnaire was most commonly used in clinical settings and the Centers for Disease  
45 Control and Prevention ACE questionnaire in community settings. The variety of surveys used to  
46 measure ACEs may make it difficult for researchers and practitioners to choose which survey is  
47 best for a given setting and to compare findings across different populations.

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52 Key words: adverse childhood experiences, surveys, child maltreatment

53 **Introduction**

54 Adverse Childhood Experiences (ACEs) increase the risk of negative health outcomes in later  
55 life. Retrospective reports of exposures to multiple ACEs find that ACEs are strongly linked with  
56 sexual risk behaviors, sexually transmitted infections, drug use, problematic alcohol use,  
57 violence and suicide was observed (Hughes et al., 2017). Associations with ACEs have also been  
58 observed for other health risk behaviors such as physical inactivity and smoking, and chronic  
59 diseases like diabetes, cardiovascular disease, cancer, and liver or digestive diseases (Huang et  
60 al., 2015; Hughes et al., 2017). In the United States, up to 32% and 24% of psychiatric disorders  
61 in women and men respectively are attributable to having experienced any adverse childhood  
62 event; whereas up 50% and 33% of the proportion of suicide ideation and attempts in women and  
63 men respectively are linked to experiencing an adverse childhood event (Afifi et al., 2008).

64 Questionnaires or instruments for retrospective measurement of ACE in adults abound, including  
65 the Centers for Disease Control and Kaiser Permanente ACE study questionnaire (U.S Centers  
66 for Disease Control and Prevention, 2016), the state-level Behavioral Risk Factor Surveillance  
67 Study (BRFSS) ACE model (U.S Centers for Disease Control and Prevention, 2016), the World  
68 Health Organization’s ACE International Questionnaire (WHO ACE-IQ) (World Health  
69 Organization, 2018), and the Philadelphia ACE tool (The Philadelphia ACE project., 2018).

70 However, identification and comprehensive documentation of these instruments in various  
71 geographical and public health contexts to guide decision-making and further research on their  
72 validity and reliability is non-existent. The current systematic review will provide an overview of  
73 ACE instruments implemented globally, which could potentially inform researchers and other  
74 public health practitioners on the most appropriate questionnaire(s) to implement in their area of

75 focus and to ascertain whether additional work is needed to adapt extant questionnaire to their  
76 context.

77 The aims of the review were: 1) determine where ACE questionnaires have been implemented  
78 globally, 2) determine what versions of ACE questionnaires have been used and how those  
79 questionnaires have differed, 3) the types of settings the ACE questionnaires were used (clinical  
80 or community), whether the ACE questionnaires was modified for implementation, and if  
81 modified, the explanations that were provided. The overall goal of this review was to provide  
82 comprehensive documentation of ACE instruments utilized in various geographical and public  
83 health contexts to guide decision-making and further research on their validity and reliability

#### 84 **Methods**

85 The systematic review protocol was registered with PROSPERO, the international prospective  
86 registrar of systematic reviews, in November 2018. Both the peer reviewed and grey literature  
87 were searched for English language only articles from October 26, 2018 to November 12, 2018.  
88 Articles published from 1998 through November 2018 were eligible for inclusion. A keyword  
89 search using adverse childhood experiences as free text was completed. Searches were conducted  
90 in the following databases: MEDLINE, EMBASE, CINAHL, PyschINFO, ERIC, ProQuest and  
91 Social Science Index. Grey literature searches included databases of dissertation abstracts;  
92 websites of the following organizations - ACEs connections, National Center for Trauma-  
93 Informed Care and Alternatives to Seclusion and Restraint (NCTIC), The Philadelphia ACE  
94 project; abstract books of the following organizations - International Society for the Prevention  
95 of Child Abuse and Neglect, Sexual Violence Research Initiative, Association for the Treatment  
96 of Sexual Abusers. Moreover, additional searches will be conducted to identify grey literature

97 from the Google search Engine. Further, reference lists of identified literature were screened, and  
98 relevant articles were retrieved and included in the study.

99 All study designs were included. Included studies must have administered a version of the ACE  
100 questionnaire on non-institutionalized adults 18 years and older. The exposure of interest was  
101 self-reported ACEs. Studies conducted in any location globally provided the ACE questionnaires  
102 were administered by the principal investigators. Studies that did not meet these criteria were  
103 excluded.

104 After the search procedure, identified studies were loaded into Mendeley referencing software  
105 and duplicates were deleted. Two members of the systematic review team independently  
106 screened the titles and abstracts of all identified studies for inclusion into the review. Articles  
107 that are unrelated to the review or did not meet the inclusion criteria based on the title and  
108 abstract were eliminated. The full text of articles with sufficient information in the title or  
109 abstract were extracted to determine whether the inclusion criteria were met. Ineligible articles  
110 were excluded. Disagreements among the screeners were discussed and consensus was reached  
111 based on the opinion of a third reviewer. After screening was concluded, all full text articles  
112 were downloaded, and their reference lists were reviewed to identify eligible articles. Two  
113 reviewers extracted the following information into a standardized pre-piloted form created for  
114 the purposes of this study: Article name, date, journal and authors; name of ACE survey used,  
115 location of the study, the study setting (clinical vs community), the types of ACE questions  
116 (household dysfunction, abuse, bullying, community violence, others), the version of the ACE  
117 survey (Kaiser Permanente, BRFSS, WHO ACE-IQ, others), whether the survey was modified,  
118 and the reasons for modification. Disagreements between the reviewers were discussed and a

119 final decision was determined by the reviewers. If needed, a third reviewer was consulted to  
120 finalize the review.

121 Qualitative synthesis of the systematic review findings was completed. A narrative synthesis was  
122 presented structured around the geographic location and setting (community or clinical) of ACE  
123 questionnaire implementation, the types of ACE questions (household dysfunction, abuse,  
124 bullying, community violence, others), the version of the ACE survey (Kaiser Permanente,  
125 BRFSS, WHO ACE-IQ, others), whether the survey was modified, and the reasons for  
126 modification. Results was categorized by the following sub-groups: ACE surveys, country,  
127 setting (clinical or community), type of ACE questions and survey modification. Assessment of  
128 individual study quality for the risk of bias was not of concern in this review because the  
129 methods employed within individual studies did not influence the review questions, which were  
130 to identify the ACE questionnaire and version used in individual studies, the implementation  
131 setting, and the reasons for modification of the instrument, if applicable.

## 132 **Results**

### 133 *Search Results*

134 A total of 6,928 publications were retrieved from the initial search. This included 566  
135 documents from Psych info, 5674 documents from Medline, 398 documents from CINAHL, 100  
136 documents from Sociological abstracts, 32 documents from ERIC, and 158 from ProQuest  
137 Dissertations and Theses Global. 6551 articles were screened after removing unrelated articles  
138 and duplicates. 1165 articles were selected for full-text review and 453 articles were excluded.  
139 Reasons for exclusion include studies without the explicit name of ACE questionnaires and

140 studies using minors. The final selection consisted of 712 articles. The PRISMA flow diagram of  
141 the process is depicted in Figure 1.

### 142 *Overview of Selected Articles*

143 The included 712 articles had 87 different surveys and 60 countries were represented as shown in  
144 Table 1. Thirty-two percent of these studies were conducted in clinical settings while 68% were  
145 conducted in community settings. Thirty-four percent of the surveys were modified. Majority of  
146 the articles included questions on physical/emotional abuse (93%), sexual abuse questions were  
147 included in 89% of the articles, household dysfunction questions were included in 75% of the  
148 articles, neglect questions were included in 67% of the articles. The least represented questions  
149 were peer victimization (32%), witnessing community violence (31%) and dating violence  
150 (27%). The names of all surveys represented are shown in Table 2. Reasons for modification  
151 included cultural adaptation, language, study focus, coverage of broader items, deficient  
152 psychometric properties of various sub-scales of questionnaires, adult recall versions, etc.

### 153 *Overview of Prevalent ACE questionnaires*

154 Surveys that were utilized in at least 10 articles were further analyzed (Tables 3a and 3b). The  
155 most common questionnaire used in 19% of the articles was the Childhood Trauma  
156 Questionnaire (19%) and this has been utilized mostly in the United States (US), and also in  
157 Germany, United Kingdom (UK), Turkey, Netherlands, Italy, e.t c in both clinical and  
158 community settings equally (50%). In studies that utilized the Childhood Trauma Questionnaire,  
159 most questions included neglect (84%), physical/emotional abuse (96%), dating violence (74%)  
160 and sexual abuse (95%) and 68% of studies modified their surveys. The second most common  
161 questionnaire was the Kaiser Permanente ACE Questionnaires (18%) and this has been utilized

162 mostly in the United States (US), and also in Germany, Canada, Ireland and United Kingdom  
163 mostly in community settings (55%). In studies that utilized the Kaiser Permanente ACE  
164 Questionnaire, most questions included physical/emotional abuse (89%), sexual abuse (87%),  
165 household dysfunction (86%) and 35% of studies modified their surveys.

166 The BRFSS questionnaire was utilized in 8% of the included studies and this has been utilized  
167 mostly in the United States (US), and also in UK in mostly community settings (82%). In  
168 studies that utilized the BRFSS questionnaire, most questions included peer victimization (98%),  
169 physical/emotional abuse (95%), and household dysfunction (93%) and 70% of studies modified  
170 their surveys. The conflict tactic scale questionnaire was utilized in 7% of the included studies  
171 and this has been utilized mostly in the United States (US), and also in South Korea, Japan, etc.  
172 in mostly community settings (82%). In studies that utilized the conflict tactic scale, all  
173 questions included physical/ emotional abuse and 89% of studies included questions on sexual  
174 abuse and household dysfunction while 74% of studies modified their surveys.

175 There were 19 studies that utilized the WHO ACE-IQ and this questionnaire was used mostly in  
176 Kenya for six of those studies mostly in community settings (79%). In studies that utilized the  
177 WHO ACE-IQ, all questions included household dysfunction and 89% of studies included  
178 questions on sexual abuse, peer victimization and witnessing community violence while 95% of  
179 studies modified their surveys. Other surveys utilized in this review are shown in table 3b. These  
180 surveys include the Early Trauma Inventory, the Risky Family Questionnaire, the Trauma  
181 History Questionnaire, the WHO CIDI and Wyatt Sex History Questionnaire.

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184 **Discussion**

185 To our knowledge, this is the first study to assess ACE survey use in various contexts to  
186 determine the best choice of questionnaire for use in future research. Even though childhood  
187 maltreatment was studied prior to the original ACEs study by Felitti et al., that specific study  
188 highlighted the link between ACEs and adult health outcomes, and has since garnered much  
189 more attention possibly because the economic burden of these traumas was highlighted  
190 (Finkelhor, 2018; McLennan et al., 2020). Since then, stakeholders have made efforts to assess  
191 the prevalence and effects of ACEs to determine and attenuate the associated effects thus  
192 reducing economic burden and increasing individual's health (Finkelhor, 2018). Researchers  
193 have typically assessed ACEs through patient retrospective self-report, often through  
194 questionnaires or epidemiological studies (McLennan et al., 2020).

195 The current study found that the Childhood Trauma Questionnaire (CTQ), CDC Kaiser  
196 Permanente ACE Study Questionnaire, CDC Behavioral Risk Factor Surveillance System  
197 (BRFSS) ACEs Module, and the Conflict Tactics Scale (CTS), and Adverse Childhood  
198 Experiences International Questionnaire (ACE-IQ) were used in 55% of the included studies and  
199 no other questionnaire was utilized in more than 3% of the included studies. The CTQ was  
200 utilized mostly in clinical settings (n = 65) and the CDC Kaiser Permanente ACE Study  
201 Questionnaire was administered most frequently in community settings (n = 71).

202 The Childhood Trauma Questionnaire is a 28-item questionnaire that assesses five categories of  
203 childhood adversity: emotional abuse, physical abuse, sexual abuse, emotional neglect, and  
204 physical neglect (Scher et al., 2001). Although it was originally intended to assess childhood  
205 maltreatment in male patients who abuse drugs, it was later tested on community samples.

206 However, the questionnaire has a higher reliability among clinical populations compared to  
207 community populations (Burgermeister, 2007; Scher et al., 2001).

208 The CDC Kaiser Permanente ACE Study Questionnaire was initially designed for use in a  
209 clinical setting; questionnaires were delivered in two waves to patients at a health maintenance  
210 organization in Southern California (Felitti et al., 1998). The wave I questionnaire consisted of  
211 17 items that assessed childhood psychological, physical, and sexual abuse as well as household  
212 dysfunction (Felitti et al., 1998). The study's second wave included eleven additional items; five  
213 items each assessing emotional and physical neglect as well as one item about parental divorce  
214 (Anda et al., 2009). Researchers should be aware that the choice for selecting items for some  
215 existing questionnaires based upon the original ACE study, such as the ACE Scale, appear to be  
216 arbitrary rather than evidence based and omits more predictive childhood experiences (Finkelhor  
217 et al., 2015).

218 The Behavioral Risk Factor Surveillance System is a national survey administered to residents of  
219 the United States that gathers data about individuals predictive behaviors and health outcomes  
220 (*CDC - About the Behavioral Risk Factor Surveillance System (BRFSS)*, n.d.). In 2009, the  
221 BRFSS added an optional 11 item ACE module based upon the CDC Kaiser Permanente ACE  
222 Study Questionnaire that assesses household dysfunction, physical abuse, and sexual abuse (Ford  
223 et al., 2014).

224 The Conflict Tactics Scale was created through a research program with the University of New  
225 Hampshire and asks about verbal and nonverbal conflicts between family members including  
226 between the respondent and each family member as well as between non-respondent family  
227 members (Straus, 1979). The outcomes include verbal abuse, physical abuse, as well as  
228 witnessing domestic violence (Straus, 1979).

229 The World Health Organization (WHO), in conjunction with the United States Centers for  
230 Disease Control, created the 29 items ACE-IQ as a tool for researchers to use to assess ACE  
231 prevalence and correlation to adulthood outcomes in low and middle income countries that are  
232 underrepresented in this field of study (“WHO | ACE Global Research Network,” 2014; “WHO |  
233 Adverse Childhood Experiences International Questionnaire (ACE-IQ),” 2018). This  
234 questionnaire is more robust than those previously discussed and not only assesses physical,  
235 emotional, and sexual abuse and neglect but also includes items concerning peer victimization,  
236 observing community violence, and collective violence (“WHO | Adverse Childhood  
237 Experiences International Questionnaire (ACE-IQ),” 2018). There are proposed methods to  
238 modify the ACE-IQ for cultural competence and it has been shown to be appropriate in multiple  
239 settings (Ho et al., 2019; Kidman et al., 2019; Quinn et al., 2018).

240 It is important to note both the time period these surveys were created and the age of the  
241 respondents of the newer tools such as the original ACE Study. As parental divorce has become  
242 more common, its effects on children growing up have diminished (Finkelhor et al., 2015).  
243 Furthermore, aside from the ACE-IQ, the standard versions of the previously mentioned surveys  
244 do not include peer victimization and none of them assesses childhood poverty both of which  
245 have been linked to negative adulthood outcomes (Aber et al., 1997; Copeland et al., 2013).  
246 Additional concerns about the use of surveys to score ACEs include the lack of consideration for  
247 mediating factors as well as the assumption that different individuals are affected similarly by  
248 maltreatments (*Take the ACE Quiz – And Learn What It Does and Doesn't Mean - Center on the*  
249 *Developing Child at Harvard University, n.d.*).

250 While 55 countries were represented in the current analysis, and less than half were developed  
251 countries as defined by the United Nations (*World Economic Situation and Prospects -*

252 *Statistical Annex*, 2019), the vast majority of research was conducted in developed countries,  
253 with the United States assessing ACEs far more than any other country. This is consistent with  
254 previous research indicating childhood maltreatment is underassessed in developing countries  
255 and that data is inconsistent (Veenema et al., 2015) Even though reported rates of some ACEs in  
256 developing countries are high, rates of traumas such as sexual abuse can be underreported and  
257 difficult to research because of stigmatization (Ramiro et al., 2010; Veenema et al., 2015).

258 A concern with assessment tools that are utilized in a variety of settings is cultural competence.  
259 This includes acknowledging how and why a tool was created including the target audience,  
260 present or potential issues between cultures, as well as solutions (Kumaş-Tan et al., 2007).

261 Findings from this study indicate that primary reasons for survey modification included  
262 adaptation for language and cultural settings.

263 Selecting appropriate survey tools is needed to develop appropriate strategies to improve  
264 outcomes in children. However, majority of the surveys utilized in low- and middle-income  
265 countries were developed in Western contexts and are often adapted to capture important aspects  
266 of the child's development and environment within cross cultural contexts. When comparing  
267 responses among populations that vary in language and culture, the comparability of such  
268 responses is a concern particularly when these assessments are based on verbal reports of  
269 sampled population and it would be important to demonstrate that characteristics such as cultural  
270 values, education and language do not influence the quality of assessment (Fischer, Morris, &  
271 Martines, 2014). Even though standard surveys from Western countries may have been validated  
272 within their settings, applying these surveys to non-Western contexts is associated with  
273 limitations such as interpretation of scores and feasibility in resource-constrained settings  
274 (Fischer et al., 2014).

275 In some articles studied, no appropriate tools were available and new items had to be created.  
276 This usually requires understanding the domain being measured and cultural references but can  
277 still be problematic. Developing survey items is a process that involves engaging individual  
278 representatives of the population within focus groups and decisions regarding participation,  
279 transcription and analysis of the information are relevant factors in this process (Sabanathan,  
280 Wills, & Gladstone, 2015). Screening tools are beneficial when utilized with known applicability  
281 in the target population.

282 Measuring ACEs in low- and middle-income countries with standard surveys for large scale  
283 surveys or evaluations can be costly and difficult and their validity in such circumstances is  
284 unknown. The knowledge of the structure, psychometric properties and limitations of surveys are  
285 typically restricted to specialists and in practice, health workers from different backgrounds  
286 administer and interpret survey results (Rubio-Codina, Araujo, Attanasio, Muñoz, & Grantham-  
287 McGregor, 2016). Many surveys administered in the US and in European countries do not  
288 demonstrate similar strong psychometric properties in different settings (Knauer, Kariger,  
289 Jakiela, Ozier, & Fernald, 2019). Future research should investigate understanding the structure  
290 and psychometric properties of these surveys to interpret findings appropriately.

### 291 **Strengths and Limitations:**

292 As outlined in the study protocol and the Prisma checklist for reporting, this analysis did not  
293 have a risk of bias. The number of times a survey was utilized could be inflated due to the  
294 number of articles that were secondary analyses of existing data using data from the Original  
295 ACE study or BRFSS. For example, the Original ACE Study by Felitti et al., has garnered much  
296 attention to the study of ACEs and a growing body of research, including articles reviewed for

297 the current study, are based upon secondary analysis of data from the Original ACE Study  
298 (McLennan et al., 2020).

299 Several factors may have resulted in the omission of ACE questionnaires and affected the  
300 accuracy of the present analysis. Examples of these are: researchers including articles based upon  
301 the abstract but data extractors not being able to locate the complete text for analysis, literature  
302 not stating which ACEs survey was utilized or not including the survey in the article, articles  
303 only reporting the total number of ACEs as opposed to the types and number of ACE questions  
304 they asked participants, articles stating that an existing tool was modified but not stating which  
305 modifications made, as well as not stating if the survey was or was not modified. Another factor  
306 that affects the assessed prevalence of ACEs, through any mechanism, is that some individuals  
307 may not be ready to disclose their ACEs at the time a survey is administered (Read et al., 2007).  
308 The reliability and risk of under reporting of ACEs, particularly physical abuse, has been  
309 previously established (McKinney et al., 2009; Pinto et al., 2014; Wielaard et al., 2018).  
310 (Goldstein et al., 2017)

311 Alternatively, the decreasing cooperation of the general population of developed countries with  
312 data gatherers presents problems for many researchers (Groves, 2011; Rindfuss et al., n.d.). A  
313 key strength of this analysis is that it not only included ACE assessment in community and  
314 clinical settings including psychiatric, hospital, primary care, academic, and cross-sectional  
315 samples. This study also included data acquired globally, rather than only in developed countries,  
316 which allowed for a more robust review.

317 **Recommendations/Conclusions:**

318 The current analysis shows that CTQ is used more in clinical settings, which is consistent with  
319 its reliability. The CDC Kaiser Permanente ACE Study questionnaire is more often used in  
320 community settings. The majority of research on ACEs used a survey mechanism that assessed  
321 physical abuse, sexual abuse, and neglect but only about a third of the included articles that  
322 assessed peer victimization even though it has strong correlation to adult mental health.  
323 Investigators should also consider including items about childhood poverty because of its effect  
324 upon development and adulthood outcomes. While it was used less frequently than the other  
325 tools explored in this discussion, the ACE-IQ assess a broader range of childhood traumas with  
326 existing guidelines for modifications and established reliability and could be a valuable tool for  
327 researchers.

328 Because ACEs can affect individuals differently and for the sake of transparency, researchers  
329 should present assessed ACE prevalence individually instead of solely in aggregate. If  
330 researchers choose to modify an existing questionnaire survey or administered or, at minimum,  
331 the modified items should be presented with their findings. Researchers should be mindful of the  
332 reason for inclusion or exclusion or particular ACEs as cultural context changes and the effects  
333 vary. Future research should examine the necessary tradeoffs when selecting survey tools for  
334 evaluating policies and programs as well as strategies for triangulating evidence to enable  
335 comprehension of early childhood exposures and outcomes within a global context.

336

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