

## Client and Provider Discomfort With an Adverse Childhood Experiences Survey



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**Introduction:** Many service providers report concerns that questions about adverse events may upset clients. Studies indicate that most survey respondents answer sensitive questions without experiencing distress, although little is known about the prevalence or correlates of clients' discomfort when they are asked similar questions by direct care providers, such as home visitors.

**Methods:** This study used data collected between 2013 and 2018 from 1,678 clients and 161 providers in a network of home visiting programs in Wisconsin. Clients and home visitors completed an adverse childhood experience questionnaire that concludes by asking about discomfort with the questions. Analyses conducted in 2018 examined overall client discomfort and associations between discomfort and the endorsement of 10 distinct adverse childhood experiences. Multilevel regressions were performed to test whether client and provider factors were associated with client discomfort.

**Results:** More than 80% of clients were not at all or slightly uncomfortable with the adverse childhood experience questionnaire, and 3% reported extreme discomfort. Bivariate results showed that each adverse childhood experience, except parental divorce, was associated with greater discomfort; sexual abuse was the only adverse childhood experience associated with discomfort in a multivariate analysis. Multiple client variables were linked to increased discomfort, including higher adverse childhood experience scores ( $b=0.06$ , 95% CI=0.04, 0.08) and depression scores ( $b=0.01$ , 95% CI=0.00, 0.02). Home visitor discomfort was positively associated with client discomfort ( $b=0.16$ , 95% CI=0.01, 0.31).

**Conclusions:** Results indicated that most clients in home visiting programs tolerated an adverse childhood experience questionnaire well. The findings point to clients who may be more likely to report discomfort and highlight an important association between client and provider discomfort.

*Am J Prev Med 2019;57(2):e51–e58. © 2019 Published by Elsevier Inc. on behalf of American Journal of Preventive Medicine.*

### INTRODUCTION

Adverse childhood experiences (ACEs) are a common class of acute or recurring stressors that encompass multiple forms of child maltreatment and household dysfunction. More than half of U.S. adults have endured at least one ACE,<sup>1–3</sup> and the prevalence is even higher in low-income groups.<sup>4,5</sup> Research also has shown that greater exposure to ACEs increases the risk of morbidity and mortality across SES.<sup>6,7</sup> Although the public health implications are becoming increasingly clear,<sup>8</sup> the recommendations for preventing ACEs or mitigating their effects remain inconclusive.

There is a lack of consensus, for example, as to whether screening and assessment for ACE should be widely implemented.<sup>9</sup> Only a small minority of practicing physicians and medical residents ask patients about exposure to ACE or childhood trauma,<sup>10,11</sup> which may

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0749-3797/\$36.00

<https://doi.org/10.1016/j.amepre.2019.02.026>

be because of barriers, such as a general lack of professional awareness and training, the time and costs associated with screening, and the absence of corresponding treatment recommendations.<sup>10–13</sup> Although screening and assessment rates are often higher in other service sectors, such as child welfare, wide variations are observed despite the increasing availability of trauma-informed interventions.<sup>14</sup> Notably, health and human service providers often report concerns that sensitive questions may upset clients and disrupt provider–client relationships.<sup>11–13,15</sup>

Prior research has demonstrated that a small minority of survey research participants experience distress or embarrassment when asked survey questions about personal adversity and trauma.<sup>16–19</sup> However, few studies have examined patient and client discomfort with sensitive questions in direct care settings. One study of 127 mothers receiving child welfare services found that 79% reported little or no discomfort with a trauma screening that was administered by case planners; approximately 3% reported significant discomfort.<sup>20</sup>

Even less is known about individual and contextual factors that predict discomfort with sensitive questions. Prior research indicates that survey respondents with a trauma history are more likely than nonvictims to report discomfort,<sup>16–19,21</sup> and one study found that levels of upset among youth research participants did not vary by age or race/ethnicity of the respondent.<sup>22</sup> Otherwise, there are limited data on whether discomfort varies by demographic or other respondent characteristics.

Furthermore, the extent to which client discomfort is associated with provider characteristics is largely unknown. Many professionals are apprehensive about asking clients questions about adverse and traumatic experiences.<sup>10,13,15</sup> A significant percentage of providers have had similar experiences themselves,<sup>10,23,24</sup> and some evidence indicates that those providers are more likely to complete trauma screenings with their clients.<sup>10,11,25</sup> It is uncertain, however, if provider exposure to personal adversity is associated with client discomfort. To date, no studies have explored whether providers experience discomfort when answering the same sensitive questions that they ask their clients, or if there is a link between provider discomfort and client discomfort.

This manuscript adds to the sparse literature on client responses to sensitive questions in direct care settings by assessing levels of discomfort with an ACE questionnaire reported by women receiving home visiting services. Analyses examine whether client discomfort ratings are associated with the number and type of ACE reported as well as select client characteristics. Further, this study assesses home visiting providers' discomfort responding to ACE questions and examines whether client

discomfort is associated with provider discomfort and ACE scores. In sum, this analysis uses data from a statewide home visiting program to investigate the following research questions:

1. What levels of discomfort do clients and providers of home visiting programs report upon completing an ACE questionnaire?
2. Do clients' discomfort with the questionnaire vary by the number and type of ACE they report as well as their age, race/ethnicity, education, and mental health status?
3. Controlling for client-level measures, are client discomfort ratings associated with provider ACE scores and provider discomfort ratings?

## METHODS

### Study Population

This was a study of clients and service providers in Wisconsin's Family Foundations Home Visiting (FFHV) Program, a statewide network of agencies that support pregnant women and parents with young children. All FFHV agencies receive federal funding from the Maternal Infant and Early Childhood Home Visiting Program, which currently allocates \$400 million per year nationwide to evidence-based home visiting.<sup>26</sup> States, territories, and tribes dedicate Maternal Infant and Early Childhood Home Visiting Program dollars to serving families who meet certain risk criteria, such as household poverty. Approximately 98% of client households served by the FFHV Program are low-income, as defined by eligibility for means-tested benefits or incomes <200% of the poverty line.<sup>27</sup>

Access to client data, which were collected by home visiting staff and recorded in a state public health database, was granted by the Wisconsin Department of Children and Families pursuant to a data sharing agreement. In addition to client data, the study analyzes data collected from 161 FFHV home visitors through an online survey accessed between November 2015 and January 2018. These data were matched with archival records by client name and service agency. The study procedures were approved by the IRB at the University of Wisconsin-Milwaukee (protocol 14.286).

### Measures

Home visiting clients and providers were asked to complete the Childhood Experiences Survey (CES), an ACE assessment tool that has been analyzed and described previously.<sup>27</sup> Client and provider responses to the CES were used to code 10 dichotomous ACE variables: physical abuse, sexual abuse, emotional abuse, physical neglect, emotional neglect, household substance abuse, household mental illness, household crime, domestic violence, and divorce/separation. The 10 indicators were summed to produce a total ACE score (range, 0–10) for both clients and providers. The data also were used to create a variable indicating whether a client declined to answer at least 1 ACE question, which is a potential correlate of client discomfort. After a series of ACE questions, clients and providers responded to a final CES question

that assesses discomfort: *Overall, how uncomfortable did you feel answering the questions on this survey?* Response options ranged from (1) not at all to (5) extremely.

Client age was recorded at the time when the CES was completed. Client race/ethnicity was coded into 5 categories, including 1 Hispanic and 4 non-Hispanic groups: African American, American Indian, white, and other race/ethnicity. Educational attainment was a dichotomous variable indicating if clients had any postsecondary education. Home visitors administered the Edinburgh Postnatal Depression Scale, a widely used screen for depressive symptoms that includes 10 brief Likert-type scale items (range, 0–30).<sup>28</sup> The Edinburgh Postnatal Depression Scale has been shown to have acceptable internal consistency reliability, sensitivity, and specificity in diverse samples of women during the antenatal and postpartum periods.<sup>28–30</sup>

### Statistical Analysis

To describe the study measures, means or percentages were calculated. Independent *t*-tests and chi-squared tests were conducted to determine if there were bivariate differences in client discomfort by ACE type. A multivariate analysis was conducted to compare least squares means (i.e., population marginal means) of client discomfort by ACE type while controlling for other ACE types and client age, race/ethnicity, education status, and depression score. Because the data were nested, meaning that 1 home visitor could have multiple clients, this multivariate analysis was performed using a multilevel approach that accounted for providers' total ACE scores and discomfort ratings in the second level of the model. Another set of multilevel multivariate regressions were performed to estimate whether client and staff characteristics were associated with client discomfort with the ACE questionnaire. Two separate models were fitted. The first model tested relationships between client discomfort and client-level predictors. Building on the first model, a second multilevel model tested whether client discomfort was associated with client-level indicators as well as home visitors' ACE scores and discomfort with the ACE questionnaire. Linear models were used to analyze total discomfort scores, whereas a logistic distribution was used to analyze the dichotomous outcome of any discomfort. All regression analyses were conducted in December 2018 using SAS, version 9.4.<sup>31</sup>

## RESULTS

The sample included 1,678 women who were aged >16 years and had completed an ACE assessment with a home visitor between September 2013 and June 2018. Of all the participants, 44.6% were white, non-Hispanic; 20.9%, Hispanic; 19.3%, non-Hispanic African American; 10%, non-Hispanic American Indian; and 5.2%, of other race/ethnicity. The mean age of participants was 24.4 years (SD=6.0), and 26.8% had some postsecondary education. As shown in Table 1, the mean level of client discomfort was 1.7 (SD=1.1). Discomfort with the ACE questionnaire was reported by  $\cong$ 36% of the 103 respondents; 17.6% were slightly uncomfortable, 9.5% moderately uncomfortable, 6.0% very uncomfortable,

**Table 1.** Sample Characteristics of FFHV Program Clients and Providers

Characteristics	n (%)
<b>Client variables</b>	
Age, years, mean (SD)	24.4 (6.0)
<b>Race/ethnicity</b>	
African American	324 (19.3)
American Indian	167 (10.0)
White	749 (44.6)
Hispanic	350 (20.9)
Other race/ethnicity	88 (5.2)
Any postsecondary education	449 (26.8)
Total depression score, mean (SD)	8.6 (6.1)
Declined an ACE question	66 (4.0)
Total ACE score, mean (SD)	3.3 (2.6)
Mean discomfort with ACE questions, mean (SD)	1.7 (1.1)
Any discomfort with ACE questions <sup>a</sup>	610 (36.4)
Slightly uncomfortable	295 (17.6)
Moderately uncomfortable	160 (9.5)
Very uncomfortable	101 (6.0)
Extremely uncomfortable	54 (3.2)
<b>Provider variables</b>	
Total ACE score, mean (SD)	2.4 (2.2)
Mean discomfort with ACE questions, mean (SD)	1.8 (1.1)
Any discomfort with ACE questions	66 (41.0)
Slightly uncomfortable	31 (19.3)
Moderately uncomfortable	18 (11.2)
Very uncomfortable	11 (6.8)
Extremely uncomfortable	6 (3.7)

<sup>a</sup>The percentages of discomfort categories do not total the percentage of any discomfort because of rounding error.

ACE, adverse childhood experience; FFHV, Family Foundations Home Visiting.

and 3.2% extremely uncomfortable. Home visitors' mean discomfort was 1.8 (SD=1.1)—slightly higher than their clients' ratings. Approximately 41% of home visitors reported any discomfort; 19.3% were slightly uncomfortable, 11.2% were moderately uncomfortable, 6.8% were very uncomfortable, and 3.7% were extremely uncomfortable.

Except for parental divorce, endorsement of each ACE was associated with higher mean ratings of client discomfort (Table 2). When discomfort was dichotomized (any versus none), all ACE types were associated with significantly higher discomfort. The percentage of women who reported any discomfort ranged from a low of 39.4% among those who experienced parental divorce to a high of 54.1% among those who experienced emotional neglect. Multivariate multilevel analyses showed that, controlling for other ACE and confounding variables, self-reported sexual abuse was significantly associated with greater discomfort ( $p<0.001$ ).

**Table 2.** Client Discomfort by ACE Category

ACE category/endorsement	Any discomfort n (%)	Total discomfort	
		Model 1, mean (SD)	Model 2, mean (SE)
Physical abuse			
Yes	<b>302 (47.1)</b>	<b>1.8 (1.1)</b>	1.7 (0.04)
No	<b>282 (28.5)</b>	<b>1.6 (1.0)</b>	1.6 (0.06)
Sexual abuse			
Yes	<b>202 (46.8)</b>	<b>1.9 (1.2)</b>	<b>1.8 (0.04)</b>
No	<b>367 (30.9)</b>	<b>1.6 (1.0)</b>	<b>1.6 (0.06)</b>
Emotional abuse			
Yes	<b>221 (48.4)</b>	<b>1.9 (1.1)</b>	1.7 (0.04)
No	<b>385 (31.8)</b>	<b>1.6 (1.0)</b>	1.6 (0.07)
Physical neglect			
Yes	<b>92 (49.2)</b>	<b>1.9 (1.1)</b>	1.7 (0.04)
No	<b>516 (34.7)</b>	<b>1.7 (1.1)</b>	1.6 (0.10)
Emotional neglect			
Yes	<b>157 (54.1)</b>	<b>2.0 (1.2)</b>	1.8 (0.09)
No	<b>450 (32.6)</b>	<b>1.6 (1.0)</b>	1.6 (0.04)
Household alcohol/Drug abuse			
Yes	<b>366 (43.6)</b>	<b>1.8 (1.1)</b>	1.7 (0.05)
No	<b>236 (28.6)</b>	<b>1.5 (1.0)</b>	1.6 (0.05)
Household mental illness			
Yes	<b>322 (45.4)</b>	<b>1.8 (1.1)</b>	1.7 (0.05)
No	<b>258 (28.9)</b>	<b>1.5 (1.0)</b>	1.6 (0.05)
Household crime			
Yes	<b>267 (42.7)</b>	<b>1.8 (1.1)</b>	1.7 (0.05)
No	<b>317 (31.6)</b>	<b>1.6 (1.0)</b>	1.6 (0.04)
Domestic violence			
Yes	<b>278 (45.6)</b>	<b>1.8 (1.1)</b>	1.7 (0.06)
No	<b>285 (29.3)</b>	<b>1.6 (1.0)</b>	1.6 (0.04)
Parental divorce			
Yes	<b>296 (39.4)</b>	1.7 (1.0)	1.7 (0.05)
No	<b>305 (33.4)</b>	1.7 (1.1)	1.6 (0.05)

Note: Boldface indicates statistical significance ( $p < 0.01$ ). Model 1 results are from bivariate analyses. Model 2 results are from a multivariate multi-level analysis including all ACE indicators and controlling for client age, race/ethnicity, education status, and depression score as well as provider total ACE score and discomfort.

ACE, adverse childhood experience.

Table 3 displays results of multilevel linear and logistic regression analyses. Clients' total ACE scores were significantly associated with their mean discomfort ratings ( $b=0.06$ , 95% CI=0.04, 0.08) and their likelihood of reporting any discomfort (OR=1.18, 95% CI=1.13, 1.23). Clients who declined to answer at least 1 ACE question also had higher mean discomfort scores ( $b=0.68$ , 95% CI=0.43, 0.94), and they were more likely to report any discomfort (OR=5.59, 95% CI=3.13, 9.99). Compared with non-Hispanic whites, American Indians had higher mean discomfort levels ( $b=0.27$ , 95% CI=0.06, 0.48) and Hispanics were less likely to report any discomfort (OR=0.68, 95% CI=0.50, 0.91). Client depression scores were positively associated with higher mean discomfort ( $b=0.01$ , 95% CI=0.00, 0.02) and any discomfort

(OR=1.02, 95% CI=1.01, 1.04). Age and postsecondary education were not related to client discomfort.

A second set of multilevel analyses tested associations between client discomfort and select staff indicators, controlling for other client-level factors. Results showed that home visitors' ACE scores were not associated with client discomfort. However, any home visitor discomfort with the ACE questionnaire was associated with higher mean client discomfort ( $b=0.16$ , 95% CI=0.01, 0.31) and any client discomfort (OR=1.44, 95% CI=1.15, 1.82).

## DISCUSSION

This is one of the first studies of client discomfort with an ACE questionnaire in a direct care setting. More than

**Table 3.** Client Discomfort Regressed on Client and Provider Characteristics

Characteristics	Total discomfort, b (95% CI)	Any discomfort, OR (95% CI)	Total discomfort, b (95% CI)	Any discomfort, OR (95% CI)
<b>Client characteristics</b>				
Age	0.00 (−0.01, 0.01)	1.01 (0.99, 1.02)	0.00 (−0.01, 0.01)	1.01 (0.99, 1.03)
<b>Race/ethnicity</b>				
African American	0.05 (−0.10, 0.20)	0.89 (0.67, 1.19)	0.04 (−0.11, 0.19)	0.86 (0.65, 1.15)
American Indian	<b>0.27* (0.06, 0.48)</b>	1.32 (0.92, 1.87)	<b>0.24* (0.03, 0.45)</b>	1.23 (0.86, 1.77)
Hispanic	−0.09 (−0.23, 0.05)	<b>0.68* (0.50, 0.91)</b>	−0.10 (−0.24, 0.05)	<b>0.67* (0.50, 0.89)</b>
Other	−0.07 (−0.31, 0.16)	0.79 (0.48, 1.31)	−0.09 (−0.33, 0.14)	0.73 (0.44, 1.21)
Any post-secondary education	0.03 (−0.08, 0.15)	1.08 (0.85, 1.38)	0.04 (−0.08, 0.15)	1.10 (0.86, 1.40)
Total depression score	<b>0.01* (≈0.00, 0.02)</b>	<b>1.02* (1.01, 1.04)</b>	<b>0.01* (≈0.00, 0.02)</b>	<b>1.02* (1.01, 1.04)</b>
Declined an ACE question	<b>0.68** (0.43, 0.94)</b>	<b>5.59** (3.13, 9.99)</b>	<b>0.69** (0.43, 0.94)</b>	<b>5.85** (3.26, 10.50)</b>
Total ACE score	<b>0.06** (0.04, 0.08)</b>	<b>1.18** (1.13, 1.23)</b>	<b>0.06** (0.04, 0.08)</b>	<b>1.18** (1.13, 1.23)</b>
<b>Provider characteristics</b>				
Total ACE score	—	—	0.00 (−0.03, 0.03)	0.98 (0.93, 1.04)
Any discomfort	—	—	<b>0.16* (0.01, 0.31)</b>	<b>1.44* (1.15, 1.82)</b>

Note: Boldface indicates statistical significance (\* $p < 0.05$ , \*\* $p < 0.01$ ). All estimated coefficients are unstandardized. ACE, adverse childhood experience.

80% of 1,678 low-income women reported that they were not at all or slightly uncomfortable completing a brief ACE assessment with their home visitors, whereas 3% reported extreme discomfort. The results are comparable to a smaller study of mothers receiving child welfare services.<sup>20</sup> Taken together, the findings suggest that it is not uncommon for clients to experience some discomfort when answering questions about ACE but that major discomfort is atypical. The results reinforce prior studies indicating that a large majority of survey research subjects can answer sensitive questions without experiencing distress.<sup>16–19</sup>

Bivariate analyses showed that, except for parental divorce, endorsement of each ACE was associated with significantly greater discomfort. In line with the reported results of a previous study,<sup>22</sup> discomfort did not vary widely across items. ACEs that were linked to the highest mean discomfort on a 5-point scale were all forms of child maltreatment: emotional neglect (2.0), physical neglect (1.9), emotional abuse (1.9), and sexual abuse (1.9). However, multivariate analyses showed that clients with a sexual abuse history reported significantly higher rates of discomfort. The results reinforce research indicating that sexual abuse questions may be particularly likely to induce feelings of discomfort or shame.<sup>32</sup>

Multilevel regression analyses were performed to investigate whether client discomfort with the ACE questionnaire was associated with certain client and staff characteristics. Compared with those who completed the full assessment, the 4% of clients who declined at least 1 question also had greater discomfort. The findings lend credence to studies that have used item response rates as a proxy for the acceptability or tolerability of ACE questions.<sup>33,34</sup> In addition, higher client ACE scores were linked to greater discomfort. Studies have consistently shown that trauma victims are more likely than nonvictims to be distressed by sensitive survey questions.<sup>16–19,21</sup> By contrast, clients of home visiting programs reported lower levels of discomfort than their providers, despite having higher average ACE scores. The results imply that factors other than exposure to adversity influence discomfort with ACE questions.

There was some evidence of racial/ethnic variation in discomfort. Compared with non-Hispanic whites, American Indians reported more discomfort whereas Hispanics reported less discomfort. The observed group differences may be partly attributable to other factors associated with race/ethnicity, although the analyses controlled for potential confounders, such as client ACE scores. Additionally, the sample was restricted to low-income women in Wisconsin who received home visiting services, which limits some unobserved heterogeneity. Further research into discomfort with ACE

questions across racial, ethnic, and cultural lines is warranted.

Client depression scores also were positively associated with discomfort ratings. Cognitive distortions that manifest as negative perceptions are common symptoms of depression. Clients with higher depressive symptom scores may be prone to negativity biases that increase their likelihood of reporting discomfort. Pending replication, the results have implications not only for how discomfort is interpreted but also for screening and assessment guidelines with depressed clients and other vulnerable populations. Recognizing the potential role of trauma in the etiology and remediation of depression and other disorders, mental health practice guidelines in the U.S. and abroad have called for the inclusion of questions about recent and past traumatic events.<sup>35–37</sup>

This study makes an original contribution by analyzing the connection between provider and client discomfort. Results showed that home visitors' discomfort ratings were slightly higher on average than their clients' ratings and that clients reported greater discomfort if they were served by a home visitor who reported any discomfort. It should be emphasized that this study did not measure how uncomfortable home visitors were with administering the ACE assessment. Nevertheless, it is plausible that home visitors who were less comfortable responding to ACE questions were also less comfortable asking ACE questions. Providers who experience discomfort during the assessment process may use verbal and nonverbal cues that prompt greater client discomfort, in which case it may be possible to mitigate client discomfort by enhancing provider interviewing skills through education and training.

The study findings also add to research on the prevalence and consequences of ACE, which helps to raise awareness of the need for large-scale prevention and intervention strategies. One framework that serves as a guide in this area is trauma-informed care, which calls for systemwide awareness of trauma and its effects.<sup>38</sup> Although it has been hailed as a paradigm shift in the field,<sup>39</sup> trauma-informed care also has been criticized for lacking specific practice recommendations.<sup>40</sup> In response, scholars have begun to articulate how trauma-informed care principles manifest as practice elements, such as screening and assessment.<sup>41</sup> However, in most service sectors, screening and assessing for ACE remain the exception rather than the rule. Results from this study suggest that service providers may not ask about ACE in part because of their own discomfort.<sup>11–13,15</sup>

### Limitations

The findings should be interpreted in light of the analysis omitting factors that might influence client

discomfort ratings, including traumatic events in adulthood and other mental health disorders. In addition, all participants were low-income women receiving long-term home visiting services, and it is uncertain whether the findings generalize to other client populations and service contexts. Most FFHV home visitors introduce the CES after completing multiple home visits, which may give them an opportunity to establish rapport and trust before asking about ACE. Client discomfort could vary in milieu such as medical and clinical settings, where provider–client interactions are shorter and less frequent and where the timing of assessment differs. The correspondence between provider and client discomfort also warrants further investigation. The causal direction of client and provider discomfort in this study is uncertain because of the cross-sectional design. Moreover, providers' feelings of discomfort upon completing the ACE questionnaire may not match their feelings while administering the questionnaire. Future research should focus on factors that influence provider discomfort and investigate whether provider discomfort asking sensitive questions is associated with client discomfort answering sensitive questions.

### CONCLUSIONS

This is the first study to show that there is an association between provider and client discomfort with an ACE questionnaire. The findings suggest that it may be possible to minimize client discomfort by ensuring that assessors are at ease with questions about ACE. It may be helpful for providers to learn that research participants typically respond to sensitive survey questions without experiencing major distress.<sup>16–19</sup> This study contributes to the literature by demonstrating that most clients can respond to ACE questions in a direct practice setting without extreme discomfort.

Future research should examine the risks and benefits of asking clients about ACE and other traumatic events. One systematic review concluded that the risk–benefit ratio of sensitive research is not unfavorable,<sup>42</sup> although it is unknown whether the findings apply to screening and assessment in direct care. There also is a need for longitudinal investigations into the long-term effects of immediate discomfort, as there is some evidence that negative feelings dissipate quickly.<sup>43,44</sup> Moreover, many individuals report positive feelings, such as relief or gratitude, after being asked about their trauma histories.<sup>43,45</sup> These findings suggest that discomfort cannot be simply interpreted as an adverse outcome and that providers should not rule out the use of ACE questionnaires based solely on the potential for client discomfort.

## ACKNOWLEDGMENTS

This work was supported by funding from the Maternal, Infant, and Early Childhood Home Visiting Grant Program, U.S. HHS, Health Resources and Services Administration (Awards: X10MC311790100, X10MC295120100).

No financial disclosures were reported by the authors of this paper.

## SUPPLEMENTAL MATERIAL

Supplemental materials associated with this article can be found in the online version at <https://doi.org/10.1016/j.amepre.2019.02.026>.

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