



Research Reactivity and Distress Protocols for Youth Trauma-related Research: A Scoping Review

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Article abstract

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Methods: A systematic scoping review was conducted in APA PsychInfo, CINAHL, Embase, and OVID Medline. 2 reviewers screened each article for 12 eligible studies. Quantitative and qualitative studies measuring maltreatment and trauma research responses were eligible. Youth were defined as individuals aged 10-19.

Results: No study utilized the ACEs questionnaire with research-related stress measures. Among those that included research reactivity measures, various forms of childhood and youth victimization were considered. The majority of participants did not report feeling upset, with many reporting benefits to participation. Information on protocols for managing distress was available for 11 studies, the most common being the provision of a resource helpsheet and/or referral system.

Implications: There is no indication of distress following ACEs-related research, with few studies measuring across the research experience. One study measured follow-up for distress and further action. Additional research may be indicated to assess the effectiveness of these protocols in this population with a follow-up assessment.

Research Reactivity and Distress Protocols for Youth Trauma-related Research: A Scoping Review

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Abstract

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Methods: A systematic scoping review was conducted in APA PsychInfo, CINAHL, Embase, and OVID Medline. 2 reviewers screened each article for 12 eligible studies. Quantitative and qualitative studies measuring maltreatment and trauma research responses were eligible. *Youth* were defined as individuals aged 10-19.

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Implications: There is no indication of distress following ACEs-related research, with few studies measuring across the research experience. One study measured follow-up for distress and further action. Additional research may be indicated to assess the effectiveness of these protocols in this population with a follow-up assessment.

Keywords: ACEs, research reactivity, clinical protocol, youth.

Introduction

Youth experiencing adverse contexts and experiences has been identified as an important area for developing health services (Dube, 2018; Giano et al., 2020). The World Health Organization (WHO) defines youth as persons between 10 and 19 years of age (WHO, n.d.), capturing the transitional ages from puberty to young adulthood. About 26% of the global population is under the age of 15 (Statistica, 2021). Developmentally, youth are on a trajectory of greater autonomy and decision-making capacity (Zimmer-Gembeck & Collins, 2008) at a time of risk for relationship violence and mental health problems (Kessler et al., 2005; Taquette & Monteiro, 2019). Globally, adolescents in low-income, urban communities were found to have high exposure to adversity, with 46% of participants reporting violence victimization and 38% experiencing emotional neglect (Blum et al., 2019).

Clinician-researchers, in particular, are presented with the issue of care parameters when childhood adversity is the domain of research inquiry. Depending on the circumstances, professionals may possess a legal duty of care, or another duty (such as in occupational policy), to act in the person's best interests, which may require referring a situation to welfare authorities or taking other precautionary action (Wekerle, 2013). Minors are not likely to fully understand the implications of their assent or consent as it relates to mandatory reporting law requirements, with the notion that early services may prevent victimization and promote resilience (Wekerle, 2013). Further, the majority of youth with adversity backgrounds have been shown to have poorer health practices (e.g., low routine check-ups; Alcalá et al., 2018; Black et al., 2016). Despite a surge in research on adversity, an under-consideration of the implications of such inquiry has been identified (Finkelhor, 2018; Kia-Keating et al., 2019; McLennan et al., 2020). In any investigation of trauma exposures, appropriate trauma-informed response is relevant (Racine et al., 2020). An area of research gap relative to the volume of adversity research is understanding the appropriate supportive approaches that have been undertaken in conducting such research. Anda and colleagues (2020) highlight that the presence or absence of ACEs cannot be taken to indicate risk or response at the individual level, as their connection to ill health was demonstrated at the population level. In a systematic review of reviews, evidence is inconclusive on a clear fit between trauma exposures (type, nature, and number of) and trauma-based interventions (Lorenc et al., 2020). Trauma- and Violence-Informed Care (TVIC) practice is built on the knowledge and understanding of the impacts of trauma and violence on health (Ponic et al., 2016). In addition to recognizing trauma event(s) exposure, it also addresses the effects of systemic, structural, and organizational violence (i.e., historical, intergenerational, cultural; Cullen et al., 2020; Oral et al., 2016; Public Health Agency of Canada, 2018). An important component is the need to ensure avoidance of re-traumatization or unintended risk of violence exposures, with an implicit assumption that there is an ongoing timeframe across the interaction. TVIC places psychological and physical safety as a priority goal (Isobel et al., 2021). Indeed, in Canada, systemic and structural violence, indeed “cultural genocide,” has been acknowledged in the Truth and Reconciliation Report on Indigenous-directed discrimination and abuse (Truth and Reconciliation Commission of Canada, 2015). It is important to recognize trauma as ongoing; to date, over 1,000 graves have been discovered at residential school sites in Canada (Deer, 2021). An estimated 1,200 sterilizations took place among Indigenous people between 1966 and 1976, affecting approximately 1,150 women and 50 men or persons of undocumented sex (Stote, 2022). Intergenerational trauma is a factor to be considered for Indigenous youth participation in trauma-informed research.

The right of the victim's voice in research as a component of self-determination has been argued, although perhaps less clearly for youth (Becker-Blease & Freyd, 2006; Kosher & Ben-Arieh, 2020). The United Nations Convention on the Rights of the Child (UNCRC; United Nations, 1989) states that children and adolescents have the right to express their views and participate in all matters that affect them. The UNCRC similarly guarantees cultural participation, such that, as applied to research, appropriate methodologies (e.g., qualitative interviews, visual-based approaches), are considered (United Nations, 1989). However, informed consent for legal minors is accomplished typically through youth assent or consent, depending on the jurisdictional guidance. The former is based on the assumption that guardians will make decisions to protect their child's best interest (Brassard et al., 2020; Field et al., 2004). In a research context, the potential impact of participation is an empirical question. Actions towards youth must promote their sense of dignity and worth, respecting their human rights and fundamental freedoms (Bargeman et al., 2021). As previously defined by Liebenberg and Joubert (2019), resilience is “an interactive developmental process involving the agency, or inner capability of individuals, to call on their personal assets, engage with others and look for external resources to successfully transform adversity into opportunities to learn and thrive.” A positive research experience for youth participants may act as a potential resilience experience and contribute to developing a positive meaning-making framework (Liebenberg & Joubert, 2019). Concerns about potential harms have led researchers to implement specified plans to measure and respond to distress that may arise (Yeater & Miller, 2014).

ACEs prevalence among youth

Exposure to one type of adverse event (e.g., ACEs; Felitti et al., 1998) increases the likelihood of exposure to others (Su et al., 2015). Youth from service systems have higher endorsements of adversities (Freeman, 2014). A systematic review on ACEs and pediatric health outcomes found that exposure to ACEs can alter the stress response and cortisol release and is associated with cognitive delays, asthma, infections, somatic complaints, and sleep disruptions (Oh et al., 2018). A US national survey found that increased exposure to ACEs is associated with poor adolescent health and emotional well-being, with each additional ACE increasing the odds of poor health and emotional problems by 9% and 32%, respectively (Balistreri & Alvira-Hammond, 2016). Certain groups of youth have experienced higher-than-average levels of ACEs, including youth who are system-involved, i.e., child welfare (McCrae et al., 2019); juvenile justice (Baglivio et al., 2014; Weber & Lynch, 2021); mental health (Finkelhor et al., 2021), as well as cultural groups, such as Indigenous youth (Ames et al., 2015; BigFoot et al., 2018; Freeman & Ammerman, 2021; Richards et al., 2021; Smith et al., 2021), and other youth of colour (Freeny et al., 2021). Given the probabilistic detection of increased health risk, the question arises as to what type of post-research participation referrals and protocols are required.

The importance of collecting empirical data on potential benefits and harms for participants in trauma-related research has been identified to inform these clinical protocols (Jaffe et al., 2015). Previous studies in adult populations have found that asking ACEs questions is associated with distress in a small proportion of participants: although some emotional reactivity was evoked, participants reported positive sentiments about discussing their experiences in a safe and controlled setting (Becker-Blease & Freyd, 2006; Jaffe et al., 2015; McClinton Appollis et al., 2015). While the risk-benefit ratio for this type of research is not unfavourable in adult populations (McClinton Appollis et al., 2015), limited information is available on youth populations. The specific objectives of this scoping review are to explore the existing literature to address the following questions:

1. Among youth with adversity and/or trauma events exposure, what is known in terms of general reactivity to research study participation?
2. Among studies, what protocols are identified for managing distress and reactivity to research study participation?

Method

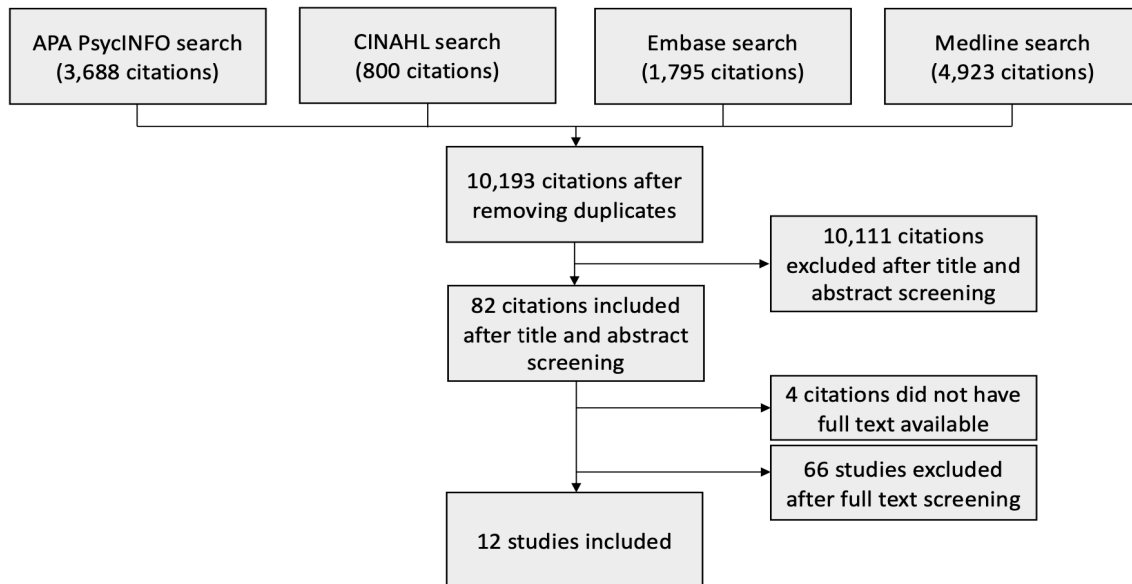
Identifying relevant studies

We followed Arksey and O'Malley's (2005) methodology framework for this review to summarize current findings in the field of ACEs research and participant reactivity and identify potential gaps to guide further research. The final search on PsycINFO, Embase, Medline, and CINAHL databases was conducted on December 28, 2020. The search strategy was developed in collaboration with an academic librarian and included terms related to youth, adolescents, and the violence/trauma indicators used in the ACEs questionnaire (family mental illness, domestic abuse, intimate partner violence, ACEs, child abuse, child trauma, child neglect), as well as terms related to the research response (clinical protocol, distress protocol, research participation, and research reactivity).

Study selection

The inclusion criteria for articles included the following: (i) peer-reviewed, quantitative, or qualitative data publications that included research ethics approval; (ii) in English; (iii) with youth participants (10 to 18 years old, inclusive); and (iv) a focus on adversity/trauma items, or use of the ACEs questionnaire. Only articles in English published after 1998 were included, given that the first article on ACEs was published in 1998 (Felitti et al., 1998). The exclusion criteria included (i) non-original studies, including dissertations, thesis, book chapters, personal communication, audio files, images, case reports, or reviews. Articles were first screened by title and abstract, followed by full-text screening (Figure 1). In both screening phases, each article was evaluated by two independent authors, and any conflicts were resolved by consensus. Information extracted from eligible studies included the year of publication, country, the purpose of the study, participant demographics (i.e., age and sex/gender), sample size, study design, method of recruitment, method of conducting research, characteristics of ACEs studied, participant reactions to study, protocol in handling research reactivity, and suggestions for protocols in future studies. Two independent authors completed data extraction for each study, and conflicting information was reviewed to reach a consensus. In total, 12 studies met eligibility criteria and were included.

Figure 1. PRISMA flow diagram of the literature review process



Results

A summary of the results found from each paper can be found in Table 1.

Study Characteristics

The participant populations of the studies were from two main categories: (1) school studies; and (2) service system studies. Six studies sampled from a population of school-attending adolescents (Chu et al., 2008; Edwards et al., 2016; Fagerlund & Ellonen, 2016; Finkelhor et al., 2014; McClinton Appollis et al., 2020; Zajac et al., 2011), four studies drew from system-involved adolescents, in child welfare or mental health (Chu & Deprince, 2013; Devries et al., 2015; Skar et al., 2019; Waechter et al., 2019), and one study drew participants from both populations (Guerra & Pereda, 2015). Walsh and colleagues (2016) additionally investigated adolescents who were victims of childhood sexual abuse material (CSAM). Youth were recruited in various countries (US, Canada, Uganda, South Africa, Finland); however, no research study focused on trauma-specific groups, such as Indigenous youth.

Research reactivity tapped three areas: (1) level of youth upset, (2) youth perceptions of benefits, and (3) youth regrets regarding participation. All 12 studies reported that the majority of participants did not experience substantial distress. Among the eight studies that examined participants' perceptions of benefits (Chu et al., 2008; Chu & Deprince, 2013; Devries et al., 2015; Edwards et al., 2016; Fagerlund & Ellonen, 2016; Guerra & Pereda, 2015; McClinton Appollis et al., 2020; Walsh et al., 2016), all reported some benefits to research participation. Of the five studies that measured regrets to participation, the majority of adolescents did not report regrets (Edwards et al., 2016; Finkelhor et al., 2014; McClinton Appollis et al., 2020; Waechter et al., 2019; Walsh et al., 2016). Of the 12 studies, 11 mentioned protocols to address potential distress or concerning disclosures from participants (Chu et al., 2008; Chu & Deprince, 2013; Devries et al., 2015; Edwards et al., 2016; Fagerlund & Ellonen, 2016; Finkelhor et al., 2014; Guerra & Pereda, 2015; McClinton Appollis et al., 2020; Waechter et al., 2019; Walsh et al., 2016; Zajac et al., 2011).

Table 1. Data Extraction Chart of Studies

Study & Country of Origin	Participant Population	Method of Conducting Research	Characteristics of ACEs	Participants' reactions	Protocol	Suggested Protocol(s)
Chu et al., 2013 United States	- 180 female mid-adolescents aged 12-19 (M _{age} 15.85) - Current or past involvement in the child welfare system	- Reactivity was measured secondary to participation in one of two intervention groups - Trauma history was assessed using the validated Traumatic Events Screening Inventory (TESI) - Child Version via one-on-one interviews - PTSD symptomatology was assessed using the validated Trauma Symptom Checklist for Children (TSCC) - Reactivity was assessed at four periods using the validated Response to Research Participation Questionnaire (RRPQ) via one-on-one interviews - Cost-benefit score was calculated by subtracting the negative appraisal scores from positive scores - Approved by the university institutional review board	- Childhood interpersonal trauma exposure (teen dating violence, injuries, domestic violence, community violence, accidents, physical and sexual victimization)	- Participants reported positive cost-benefit ratios after research sessions across four timepoints - Retention rates remained consistent at each interview time point - Symptom severity and perceptions of participation did not predict retention	- Used consent quizzes to assess participant's understanding of the consent/assent information - At end of the first interview, participants were offered a newsletter that provided referrals to community agencies dealing with health and violence issues	N/A
Chu et al., 2008 United States	- 181 early adolescents 7-12 with their parents (M _{age} 9.98) - 86 females, 6 unknown genders - From local Denver metropolitan area	- Participants completed questionnaires about their behaviour and their parent's parenting practices, then completed lab tasks in sessions 1 and 2 to assess cognitive performance - Trauma history was provided by parents with the validated UCLA PTSD Index - Reactivity was assessed after completion of both studies using the validated Response to Research Participation Questionnaire for Children (RRPQ-C) in a one-on-one interview - Cost-benefit score was calculated by subtracting the negative appraisal scores from positive scores - Approved by the university institutional review board	- Interpersonal trauma (e.g., sexual abuse, physical abuse, witnessing domestic violence, witnessing community violence) - Non-interpersonal (e.g., motor vehicle accidents, medical traumas, etc.)	- Participants reported positive cost-benefit ratios, with no significant difference between trauma exposure groups - 6.1% made one or more negative appraisals of the research process, but for most, positive items were still rated higher than negative items - 1.6% reported negative cost-benefit ratios; however, this was due to boredom rather than emotional distress - no significant association was found between sex and reactivity	- Used consent quizzes to assess participant's understanding of the consent/assent information - Participants were asked to talk about a pleasant event with the experimenter before leaving	- Encourage systematic assessment of research reactivity - Encourage the use of consent quizzes to assess early adolescent's understanding of the consent/ assent information
Devries et al., 2015	- 40 adolescents aged 12-14 years	- Conducted as part of the larger "Good Schools Study"	- Asked about specific acts of	- Most participants expressed relief to be able to discuss their experiences and did	- Study-employed counsellor available after completing the	- Encourage future protocols to include

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Uganda	(M _{age} NA) - 18 boys, 22 girls - From Ugandan primary schools referred to a community agency through the study	- Data on violence and mental health were gathered via face-to-face interviews - Trauma history was assessed using the validated International Society for the Prevention of Child Abuse and Neglect Child Abuse Screening Tool-Child (ICAST-C), and validated items from the WHO Multi-Country Study on Women's Health and Domestic Violence against Women - Reactivity was assessed in select participants who were referred after interviews via one-on-one interviews about their experiences in the research and referral process - Approved by the Ministry of Education and Sports and District Education Officer ¹	violence (e.g., "Hit you with a stick? Caned you? Kicked you?")	not see the interview as traumatic event - Adolescents valued being asked about their problems and expressed relief to be able to talk to someone about their experiences - One participant said that the interview had caused her to recall the pain of the original abuse - Several others mentioned that they felt "bad then good" at the interview - Several participants mentioned feeling scared about their information being passed on	initial interview survey - Comprehensive referral protocol offered specific pathways of action based on severity and timeframe of disclosure - Decisions regarding disclosures were made in line with laws of Uganda and structure of local child protection systems - 3.8% of the 529 referred participants were followed up on, requiring the research team to intervene and employ the study counsellor to take charge of follow ups - Drawing on the WHO Study, interviews were scripted to end on a positive note by focusing on child's strengths	precise definitions and referral pathways, and be developed considering local legal and practice environments - When services are not well developed, alternative strategies to support participants should be agree upon and detailed
Edwards et al., 2016 United States	- 204 mid-adolescents aged 13-18 (M _{age} 15.56) - 117 males, 85 females, 2 identified as other - High school adolescents in New England area	- Participants completed a survey in gender-specific groups, with multiple choice and open-ended questions, and participated in focus groups - Trauma history was assessed using a 2-item survey from the validated Youth Risk Behaviour Surveillance Survey (YRBS) - Reactivity was assessed using researcher-created questions tapping feelings of upset, benefits, and regrets to participation - Approved by the university institutional review board	- Dating violence (DV): physical, sexual, emotional abuse	- Victims of sexual DV reported being upset more than non-victims - 1.5% regretted their participation, 6% reported being upset because of their participation - 49% reported personal benefits - Of participants reporting upset, 58.3% reported personal benefits - 90.9% of physical DV history, 80% of sexual DV history participants did not report upset feelings and 36.4% and 60% reported benefits respectively - No significant difference between sexes was found	- All facilitators had previous experience related to DV - All facilitators were trained on the current protocols prior to facilitating a focus group - Students received local referral and debriefing information and - An advocate from a local crisis center was with the research team during all data collection procedures.	- Encourage the implementation of information on research reactivity in consent forms prior to participation - Encourage implementation of information on commonly upsetting aspects of research during debriefing and tailoring self-care tips to these concerns
Fagerlund et al., 2016 Finland	- Two age cohorts of adolescents aged 12 (n = 4745) and	- Conducted in a group setting on school computers via an online survey - Trauma history was assessed using the	- Sexual victimization analyzed using four	- The most common feeling about answering the survey was neutral, but slightly positive (50% non-victimized, 43%	- Participants entered the survey via a webpage which offered extra tasks for those who finished	- Encourage the systematic assessment of

¹ In replacement of a research ethics board

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	15 years (n = 3107) (M _{age} 13.19) - 48% males - Finnish school students	Finnish Child Victim Survey (FCVS), a self-report survey of youth's experiences of violence on a broad range - Reactivity was assessed by requesting respondents to write free-text comments based on the question "How did you feel about answering these questions?" - Followed ethics guidelines set by Finnish Advisory Board on Research Integrity and United Nations Convention on the Rights of the Child ²	types of victimization: by adults, by peers, online victimization, and victimization in the context of organized free-time activities	victimized) - 20% of respondents regarded answering the survey as negative and/or confusing - Victimized participants reported higher rates of negative responses (19% of non-victimized individuals, 23% of victimized) - Feelings of relief were more frequent among participants with a history of sexual victimization than their non-victimized peers. - Differences in reactions between victimized and non-victimized participants were statistically significant - No significant difference between sexes was reported, however females more frequently reported negative emotions as well as relief	early, so nobody could see how long it took for everyone else to answer - The webpage also included the contact information of support organizations	research reactivity - Encourage future research design to utilize more open-ended questioning regarding reactivity
Finkelhor et al., 2014 United States	- 2312 adolescents aged 10-17 (M _{age} NA) - Adolescents from randomly selected households nationally	- Interviews conducted over the phone with one interviewer - Trauma history was assessed using the enhanced version of the validated Juvenile Victimization Questionnaire (JVQ) to measure 54 childhood victimizations - Mental health symptomatology was assessed using the validated TSCC - Reactivity was assessed using a set of researcher-developed debriefing questions tapping the importance of research, regrets to participation, and the presence and degree of upset. - Approved by university institutional review board	- JVQ included: experience of conventional crime, physical assault, maltreatment, peer victimization, sexual victimization, witnessing violence in the home and community	- 4.6% reported being upset by the survey - Of these, 26% said the questions were not very upsetting, 49% said a little upsetting, 9% said pretty upsetting, 17% said a lot upsetting - Among participants who reported upset, 95.3% reported that they still would have participated - 0.3% were both upset by the survey and would not participate again, with only one citing the nature of the questions as why they would not participate - Of the 57 who said they would not participate again, 64% cited the length of the survey - Higher levels of mental health symptomatology was significantly associated with higher levels of upset - No significant differences between sexes were found	- Survey had a procedure for identifying participants reporting high-risk experiences: child maltreatment, sexual assaults, or suicidal ideation - Interviewers registered concern about participants whom they felt might be in danger - Both types of cases were evaluated as whether they merited a call back to the participant by the study crisis counselor - Interviewers offered a toll-free number to all participants that provided further information and assisted with referral to local services if desired - 17.3% of participants were flagged for evaluation, with 2% deemed serious to merit clinician follow-up	- Encourage future research to incorporate similar protocols of providing information on services and monitoring at-risk participants
Guerra & Pereda, 2015 Chile	- 114 early adolescents aged 12-17 (M _{age} 14.01)	- Instruments administered in a single session in a private room for the sexually abused group by their	- Child sexual abuse (implied to be from previous reports)	- Question 1: abused group reported significantly less unpleasant emotions than control; victims had M score of 1.43	- To minimize potential adverse effects, a pilot study conducted with 10 adolescents who had	- Encourage systematic assessment of

² In replacement of a research ethics board

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Study & Country of Origin	Participant Population	Method of Conducting Research	Characteristics of ACEs	Participants' reactions	Protocol	Suggested Protocol(s)
	<ul style="list-style-type: none"> - 86.8% females - Victims of childhood sexual abuse in psychotherapy care - Non abused adolescents from local schools 	<ul style="list-style-type: none"> psychotherapists - Participants without a reported history had instruments administered in a class session done in groups - Trauma history and symptomatology assessed using self-report scales: Generalized Self-Efficacy Scale; Youth Coping Scale adaptation; Multidimensional Scale of Perceived Social Support; Child Post-Traumatic Stress Symptoms Scales adaptation; Child Depression Scale and State Anxiety Scale adaptations - Reactivity assessed using questions about emotional impact: 1) "were the questions unpleasant to answer?" (1 'not at all' to 5 'a lot'), 2) "how did you feel while answering the questions?" (verbal responses) - Approved by the university institutional review board 		<ul style="list-style-type: none"> of displeasure ("not at all"), while controls had M score of 1.88 - Question 2: responses grouped into five categories - 1st: "feeling good after thinking about it" had responses from 61.1% - 2nd: "feeling good, but disconnected", had 14.1% - 3rd: "feeling so-so, but supported by the study", had 5.6% - 4th: "feeling not so well" had 9.3% - 5th: "feeling bad" had 9.3% - Significant correlation between discomfort and severity of trauma symptoms (from 0.35-0.49, $p < 0.01$) - Females showed significantly stronger unpleasant emotions and discomfort compared to males in the abused group 	<ul style="list-style-type: none"> been victims of sexual abuse - Based on these results, two questions from the Youth Coping Scale were excluded as they were considered invasive/inadequate for highly traumatized populations ("describe the problem you are having" and "did you think about how this situation could improve your life?") - To avoid contact with unknown researchers, psychotherapists administered the instruments - Followed a protocol including guidelines for a support session for victims after answering - Interviews ended on a positive note to induce pleasant emotions 	<ul style="list-style-type: none"> research reactivity - Encourage assessment of instruments in causing discomfort using pilot studies - Encourage administering instruments in a private setting
McClinton Appollis et al., 2020 South Africa	<ul style="list-style-type: none"> - 3264 early adolescents aged 12-15 (M_{age} 13.55) - 60% females, 37.5% males, and 2.5% had no response - Random sample of high school students in the Western Cape Town Province 	<ul style="list-style-type: none"> - Instruments were administered using a written questionnaire in a classroom setting consisting of 227 questions and a survey at the end about perceived harms - Trauma history was assessed using adapted validated measures from the WHO Multi-Country Study on Women's Health and Domestic Violence against Women - Reactivity was assessed at the end of the survey, with five questions about perceived benefits, two questions about perceived harms, and one question about regrets with a 2-point scale (yes = 1, no = 0) - Approved by the university institutional review board 	<ul style="list-style-type: none"> - Verbal intimate partner violence (IPV), physical IPV, sexual IPV, verbal abuse, physical abuse, sexual abuse at home or at school 	<ul style="list-style-type: none"> - Most participants reported benefits (70.3%), with significantly more females than males - > 25% of participants reported harms, with significantly more males than females - Most participants who reported harms also reported benefits (76.4%) - 14% of participants reported regrets from participating, with no significant differences between sexes - 35.7% reported a negative impact (either harms or regrets) - Of these, 70.9% also reported benefits 	<ul style="list-style-type: none"> - Participants informed of the questions' sensitive nature, and if they need to talk, research staff will stay behind - Referral system to assessment and counselling services built into the project - Only trained fieldworkers remained in classrooms/arranged rooms so distance was sufficient to ensure confidentiality - Support services card containing relevant contact numbers of sexual and reproductive health clinics, social and mental health services, and police stations in their region given at the end - Space provided at the end of the questionnaire to inform if they were in a difficult situation and needed help - Four referrals were made based on active cases of trauma 	N/A

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Study & Country of Origin	Participant Population	Method of Conducting Research	Characteristics of ACEs	Participants' reactions	Protocol	Suggested Protocol(s)
Skar et al., 2019 Norway	- 10,157 early adolescents aged 6-18 (M _{age} 13) - 1001 participants did not provide info about age - 5230 females (55%), 489 did not provide info about sex - Adolescents in mental healthcare clinics	- Instruments were administered using a self-report or an interview - Trauma history was assessed using a screening inventory from the Norwegian Centre for Violence and Traumatic Stress Studies, including 15 traumatic events; participants responded yes, no or pass (coded as yes) - PTSD symptomatology was assessed using the validated Child and Adolescent Trauma Screen (CATS) - Reactivity was assessed using the 1 st item of a reaction questionnaire from a previous study on trauma screening: "did you find it upsetting or stressful to answer these questions?", using a visual analog scale from 1 to 7 (1-2 is no or minimal upset, 3-5 is moderate upset and 6-7 is high upset) - Approved by the Norwegian Regional Committee for Medical and Health Research Ethics	- Threat-related events, including child abuse, sexual abuse, family and community violence, natural disasters, serious unintentional injuries, sudden or violent loss of loved ones, and war	- Most participants did not find the trauma screening upsetting, with 68.4% reporting no or low levels of upset - 31.2% of participants who had been exposed to trauma and 12.0% of unexposed participants reported moderate levels of upset - 5.2% of participants who had been exposed to trauma and 1.5% of unexposed participants reported high levels of upset - Exposure to sexual abuse was significantly associated with higher levels of upset than other traumas - Female sex was significantly associated with higher levels of upset - Higher levels of PTSD symptoms were significantly associated with higher levels of upset	N/A	- Encourage validation of participant and discussion on any ongoing trauma after conducting interviews
Waechter et al., 2019 Canada	- 382 mid-adolescents aged < 18 (M _{age} 15.8) - 46% boys - Adolescents receiving child protective services (CPS) care in a major urban centre	- Data from a larger cohort called Maltreatment and Adolescent Pathways (MAP) - Participants completed batteries of assessments across time points; most (80%) completed these privately at home - Trauma history was assessed via the validated Childhood Trauma Questionnaire (CTQ) - PTSD symptomatology was assessed via the validated TSCC - Reactivity was assessed with six researcher-developed questions using a 7-point [0 (not at all) to 6 (a lot)] scale. - Questions were: 1) "How interesting?", 2) "How distressing?", 3) "How clear?", 4) "Did you gain something?", 5) "Questionnaire upsetting?", 6) "Still would have agreed?" - Approved by the university institutional review boards	- Emotional neglect, physical neglect, sexual abuse, physical abuse, and emotional abuse	- Participants with more current trauma symptom severity reported more distress and upset because of the study - Participants above the clinical cut-off (at least one item on the TSCC) found the study significantly more distressing and upsetting but also more interesting than those below the cut-off - Participants who reported at least one form of extreme child maltreatment found the study significantly more distressing than those below the cut-off but also found it more interesting, the questions to be clearer, and more likely to report that they would still have agreed to participate knowing what was involved than to those below the cut-off - Mean scores for each group indicated favourable responses to research in all domains (< 3 concerning negative aspects, > 3 concerning positive aspects)	- The research assistants had project-supplied cell phones and were also instructed to call the project manager and/or PI for support. - Participants received a help sheet that listed local resources and 24-h help lines at the end of each session. - Clinicians involved for follow-up referrals	- Encourage implementation of support systems for distressed participants during and post participation - Encourage implementation of allied health professionals in studies

Research Reactivity and Distress Protocols for Youth Trauma-related Research: A Scoping Review

Study & Country of Origin	Participant Population	Method of Conducting Research	Characteristics of ACEs	Participants' reactions	Protocol	Suggested Protocol(s)
				- Significant positive correlation between reactivity and perceived benefits of participating (from .231-.383, $p < 0.001$)		
Walsh et al., 2016 United States	- 11 adolescents aged 13-17 (M _{age} NA) - Adolescents who had forensic interviews at Children's Advocacy Centers	- One-on-one telephone interviews lasting approximately 10-15 minutes - Reactivity was assessed by asking questions about the importance of participating in the research, how upsetting the questions were in the survey, and whether they would have still agreed to participate knowing what was involved - Approved by the university institutional review board	- Victims of child sexual abuse including those portrayed in sexual abuse images and those who were not photographed	- Most participants felt it was very important to participate in research, and reported not being upset by the questions - 83% of participants found the research very important, with 18% finding it more than a little important - 100% did not find it at all upsetting - 100% would still agree to participate knowing the survey content	- They offered toll-free phone numbers for support services	- Encourage implementation of support systems for distressed participants during and post-participation
Zajac et al., 2011 United States	- 3614 adolescents aged 12-17 (M _{age} NA) - 1849 males, 1760 females - Participants from randomly selected households nationally	- One-on-one telephone interviews - Trauma history was assessed using specific interview questions - Mental health symptomatology was assessed using validated measures from previous studies - Reactivity was assessed at the end of the interview, using the following four questions: "Were any of the questions emotionally upsetting to you?", "Are you still feeling emotionally upset?", "If you would like to talk to someone about how you are feeling, would you like me to have someone call you?", "Do you need to talk with a counselor, or can I have someone call you?" - Approved by the university institutional review board	- Physical assault and abuse, sexual assault, witnessed community and parental violence, and other potentially traumatic events such as motor vehicle accidents and natural disasters	- 5.7% reported that some questions had been emotionally upsetting to them - 0.2% reported still feeling upset by the end of the interview - < 0.1% wished to speak to a counselor - < 0.1% required immediate contact with a counselor - Participants with trauma history reported significantly higher rates of distress than the unexposed group - Females reported significantly higher rates of distress than males - Participants positive for mental health symptomatology reported significantly higher rates of distress	- To increase likelihood of open answers, interviewers asked if they were in a private situation where they could answer freely, and planned to call back if they were not - Participants were asked if they wanted to speak to a counselor after participating - Referral system to speak to a counsellor built into the questions	- Encourage systematic assessment of research reactivity - Encourage assessment of which aspects of instruments elicited reactivity

Participant Demographics (Age, Sex and/or Gender, Country of Origin)

Studies varied in sample size, ranging from 11 to 10,157 adolescents (Skar et al., 2019; Walsh et al., 2016). Of the 12 studies, 11 studies provided information on the age ranges of participants (Chu et al., 2008; Chu & Deprince, 2013; Devries et al., 2015; Edwards et al., 2016; Fagerlund & Ellonen, 2016; Finkelhor et al., 2014; Guerra & Pereda, 2015; McClinton Appollis et al., 2020; Skar et al., 2019; Waechter et al., 2019; Walsh et al., 2016; Zajac et al., 2011). Eight studies had available data on mean ages, in which participants ranged from 9.98 to 15.85 years old (Chu et al., 2008; Chu & Deprince, 2013; Edwards et al., 2016; Fagerlund & Ellonen, 2016; Guerra & Pereda, 2015; McClinton Appollis et al., 2020; Skar et al., 2019; Waechter et al., 2019). Nine studies included information about the sex and or gender of participants (Chu et al., 2008; Chu & Deprince, 2013; Devries et al., 2015; Edwards et al., 2016; Fagerlund & Ellonen, 2016; Guerra & Pereda, 2015; McClinton Appollis et al., 2020; Skar et al., 2019; Zajac et al., 2011). Two studies examined nearly all-female samples (Chu et al., 2013; Guerra & Pereda, 2015).

Study methods

Methods of measuring adversity and/or trauma exposure varied across studies. No study measured both the traditional ACEs questionnaire and reactivity to research. Validated questionnaires were used in seven studies, and were administered through a variety of methods, including face-to-face interviews, phone calls, and written questionnaires (Chu et al., 2008; Chu & Deprince, 2013; Devries et al., 2015; Edwards et al., 2016; Finkelhor et al., 2014; McClinton Appollis et al., 2020; Waechter et al., 2019). Only one of the seven studies (i.e., McClinton Appollis et al. 2020) administered these instruments in a group setting. Examples of victimization questionnaires included the Juvenile Victimization Questionnaire (Finkelhor et al., 2014) and the Traumatic Events Screening Inventory-Child Version (Chu & Deprince, 2013). All 12 studies examined sexual abuse, nine studies examined physical abuse (Chu et al., 2008; Chu & Deprince, 2013; Devries et al., 2015; Edwards et al., 2016; Finkelhor et al., 2014; McClinton Appollis et al., 2020; Skar et al., 2019; Waechter et al., 2019; Zajac et al., 2011), six studies examined emotional/psychological abuse (Edwards et al., 2016; Finkelhor et al., 2014; McClinton Appollis et al., 2020; Skar et al., 2019; Waechter et al., 2019; Zajac et al., 2011), five studies examined witnessing domestic/family violence (Chu et al., 2008; Chu & Deprince, 2013; Finkelhor et al., 2014; Skar et al., 2019; Zajac et al., 2011), five studies examined witnessing community violence (Chu et al., 2008; Chu & Deprince, 2013; Finkelhor et al., 2014; Skar et al., 2019; Zajac et al., 2011), four studies examined non-interpersonal traumas (i.e., accidents or natural disasters; Chu et al., 2008; Chu & Deprince, 2013; Skar et al., 2019; Zajac et al., 2011), two studies examined adolescent intimate partner violence (IPV; Chu & Deprince, 2013; Edwards et al., 2016), and one study examined neglect (Waechter et al., 2019).

Five studies measured trauma exposure using tools that were either designed by the researchers or were based on previously developed tools that did not have information regarding validity (Fagerlund & Ellonen, 2016; Guerra & Pereda, 2015; Skar et al., 2019; Walsh et al., 2016; Zajac et al., 2011). Methods of administering these instruments included interviews, phone calls, and written questionnaires.

Reactivity to research also used varied measurements. Two studies used published questionnaires to assess reactivity, both of which used a version of the Response to Research Participation Questionnaire (RRPQ; Chu et al., 2008; Chu & Deprince, 2013). The 10 other studies used measures that were either designed by researchers or were based on previously developed tools; these did not typically report psychometric properties (i.e., test-retest measurement, validity, etc.). Three studies that used a telephone interview (Finkelhor et al., 2014; Walsh et al., 2016; Zajac et al., 2011), three used an in-person interview (Devries et al., 2015; Edwards et al., 2016; Guerra & Pereda, 2015), and four used self-report questionnaires (McClinton Appollis et al., 2020; Waechter et al., 2019; Skar et al., 2019; Fagerlund & Ellonen, 2016). Additionally, six studies also evaluated the symptomatology of different mental health disorders, most commonly post-traumatic stress disorder (PTSD; Chu & Deprince, 2013; Finkelhor et al., 2014; Guerra & Pereda, 2015; Skar et al., 2019; Waechter et al., 2019; Zajac et al., 2011). All of these studies utilized validated questionnaires, with the Trauma Symptom Checklist for Children (TSCC) being the most common (Chu & Deprince, 2013; Finkelhor et al., 2014; Waechter et al., 2019).

Participation Reactivity

Negative perceptions from participants constituted a minority of reactions to research participation. Methods used to report reactivity varied between studies. Of the 12 studies, 11 utilized some form of quantitative measure to report findings. In contrast, the study by Devries et al. (2015) relied solely on qualitative results from participant interviews, with the majority expressing positive effects and only one citing a negative response. Quantitative reporting

was primarily done via Likert scales measuring reactivity and/or the frequency of certain responses (e.g., interest in the study, fatigue, or distress levels). Of the four studies that reported averaged scores (Chu et al., 2008; Chu & Deprince, 2013; Guerra & Pereda, 2015; Waechter et al., 2019), results supported positive perceptions of participation and showed minimal negative reactions. Two studies additionally calculated a cost-benefit score based on the scales utilized, in which the majority of participants demonstrated a favourable ratio (Chu et al., 2008; Chu & Deprince, 2013). Waechter et al. (2016) similarly found a positive association between reactivity and reported benefits. Negative responses, distress, or regret, ranged from the highest in the McClinton Appollis et al. (2020) study with 35.7% of participants and the lowest at 0% in the Walsh et al. (2016) study. However, most of the studies that reported frequencies (five of the nine studies) had <10% of participants reporting any negative reaction to research participation (Chu et al., 2008; Edwards et al., 2016; Finkelhor et al., 2014; Walsh et al., 2016; Zajac et al., 2011). Positive/neutral attitudes or perceived benefits towards the research constituted a large proportion of responses. In the McClinton Appollis et al. (2020) study, of those reporting negative reactions, 70.9% also reported benefits of participating.

Five studies considered the relationship between mental health symptomatology and research reactions (Finkelhor et al., 2014; Guerra & Pereda, 2015; Skar et al., 2019; Waechter et al., 2019; Zajac et al., 2011). All studies found a positive association between symptom severity and negative reactions. Additionally, Waechter et al. (2019) found a positive association between symptom severity and perceived benefits. In the seven studies that compared youth with a history of ACEs with a control or a less trauma-exposed group (Chu et al., 2008; Edwards et al., 2016; Fagerlund & Ellonen, 2016; Guerra & Pereda, 2015; Waechter et al., 2019; Zajac et al., 2011), five found that those with a history of abuse experienced more negative emotions than those with lower trauma scores or controls. However, the study by Guerra and Pereda (2015) found the opposite, with abused participants reporting significantly fewer unpleasant emotions, and the study by Chu et al. (2008) reported no significant differences in cost-benefit scores between groups. The Fagerlund and Ellonen (2016) study found that participants with adversity were also more likely to feel “relief” after participating; however, further details were not provided. Two studies attempted to examine reactivity between different types of traumas (Edwards et al., 2016; Zajac et al., 2011). Both studies found that sexual abuse history was associated with greater feelings of upset compared to other forms of trauma and when compared to controls.

Seven studies also aimed to analyze the relationship between sex and reactivity, which showed varying results as well (Chu et al., 2008; Edwards et al., 2016; Fagerlund & Ellonen, 2016; Finkelhor et al., 2014; Guerra & Pereda, 2015; McClinton Appollis et al., 2020; Skar et al., 2019; Zajac et al., 2011). Three studies showed no significant differences in reactions between male and female participants (Edwards et al., 2016; Fagerlund & Ellonen, 2016; Finkelhor et al., 2014). Three other studies found that females reported significantly more negative reactions than males (Guerra & Pereda, 2015; Skar et al., 2019; Zajac et al., 2011). McClinton Appollis et al. (2020) found that significantly more females than males reported benefits, while significantly more males than females reported upset.

Research Distress Mitigation Protocols

Among the 11 studies that referred to protocols (Chu et al., 2008; Chu & Deprince, 2013; Devries et al., 2015; Edwards et al., 2016; Fagerlund & Ellonen, 2016; Finkelhor et al., 2014; Guerra & Pereda, 2015; McClinton Appollis et al., 2020; Waechter et al., 2019; Walsh et al., 2016; Zajac et al., 2011), the most common method, used by nine studies, was some form of referral system (Chu & Deprince, 2013; Devries et al., 2015; Edwards et al., 2016; Fagerlund & Ellonen, 2016; Finkelhor et al., 2014; McClinton Appollis et al., 2020; Waechter et al., 2019; Walsh et al., 2016; Zajac et al., 2011). Four studies offered counselling (Devries et al., 2015; Finkelhor et al., 2014; McClinton Appollis et al., 2020; Zajac et al., 2011), three structured their interviews to end on a positive note (Chu et al., 2008; Devries et al., 2015; Guerra & Pereda, 2015), two utilized specially trained interviewers (Edwards et al., 2016; Guerra & Pereda, 2015), two had detailed consent procedures (Chu et al., 2008; Chu & Deprince, 2013), and one conducted a pilot study to identify changes to be made in their instruments used (Guerra & Pereda, 2015). Both Chu et al. (2008) and Chu and Deprince’s (2013) studies used an interactive consent quiz to evaluate youths’ understanding of the consent process. Five studies employed some integrated protocol for referring adolescents based on any distress disclosures or observations during the study (Devries et al., 2015; Finkelhor et al., 2014; McClinton Appollis et al., 2020; Waechter et al., 2019; Zajac et al., 2011); six studies provided youth with an information sheet (Chu et al., 2008; Edwards et al., 2016; Fagerlund & Ellonen, 2016; McClinton Appollis et al., 2020; Waechter et al., 2019; Walsh et al., 2016). In the studies using specialized interviewers, Edwards et al. (2016) required facilitators to have prior experience working with relationship violence. Guerra and Pereda (2015) utilized the participants’ psychotherapists as the data collectors (i.e., administer questions), with the rationale of minimizing contact with the unfamiliar researchers.

Only four studies provided detailed information regarding the usage of their protocols (Devries et al., 2015; Finkelhor et al., 2014; McClinton Appollis et al., 2020; Zajac et al., 2011). In the Devries et al. (2015) article, they employed a referral protocol that was based upon children's disclosures of violence and categorized into "urgent", "serious but less urgent", and "serious but non-urgent". Working with the child protection system hierarchy in Uganda, research teams would either directly contact local non-governmental organization (NGO) services for less urgent cases, or directly place the child in the care of the Community Development Office and allow the local government systems to handle decision making for more serious cases. They outlined that 529 adolescents utilized their referral protocol but with a follow-up rate of 3.8% for child protective services to contact the child. Details on the scheduling and frequency of these follow-ups were not provided. Due to this, researchers themselves had to intervene and employ their own study counsellor to aid in managing follow-ups. Finkelhor et al. (2014) reported that 17.3% of participants were flagged for in-study evaluation, and 2% were later flagged for clinician follow-up. McClinton Appollis et al. (2020) reported that four participants were referred to local services due to active trauma. Zajac et al. (2011), describes that < 0.1% of participants required a counsellor. Apart from Devries et al. (2015), no other studies followed up on adolescents' use over time of any help resources or referrals.

Study recommendations on protocols

It was clear that no study had as its sole focus the detailed evaluation of research reactivity and the need for, access to, and use of clinical protocols. Studies, therefore, were active in making recommendations for the study of youth distress, participation, and cost/benefit analysis. Ten studies outlined future considerations (Chu et al., 2008; Devries et al., 2015; Edwards et al., 2016; Fagerlund & Ellonen, 2016; Finkelhor et al., 2014; Guerra & Pereda, 2015; Skar et al., 2019; Waechter et al., 2019; Walsh et al., 2016; Zajac et al., 2011). Four studies encouraged the continued use of instruments that measured distress about research participation (Chu et al., 2008; Fagerlund & Ellonen, 2016; Guerra & Pereda, 2015; Zajac et al., 2011). Fagerlund and Ellonen (2016) further indicated the importance of incorporating questions that allow "free text" answers to generate a greater range of youth responses than prescribed self-ratings. Along similar lines, Guerra and Perada (2015) suggested the continued use of pilot studies to examine which aspects of certain instruments were most distressing before conducting research. Five studies mentioned the need for referral protocols to support services in place for research regarding sensitive topics with youth (Devries et al., 2015; Finkelhor et al., 2014; Skar et al., 2019; Waechter et al., 2019; Walsh et al., 2016), including building in alternate service opportunities where trauma-based services are not well developed. Waechter et al. (2019) also advocated for the continued involvement of other allied health professionals across research phases, such as a service-based research advisory committee. In this Maltreatment and Adolescent Pathways study, the research questionnaire queried resilience and positive experiences, in addition to traumatic experiences and symptoms. Improvements to the consent and debriefing process were suggested by three studies (Chu et al., 2008; Edwards et al., 2016; Skar et al., 2019). Chu et al. (2008) encouraged the continued usage of consent quizzes. The provision of information regarding research reactivity in the consent form may be important for the validation of participant experience tips (Edwards et al., 2016; Skar et al., 2019).

Discussion

Despite the prevalence of research on childhood adversity, health, and mental health in youth, there is surprisingly little research considering the participation process from a youth perspective. This aspect of rights and ethics has generally been an add-on to larger studies with vulnerable populations or studies involving sensitive victimization questions. No study had this question as to its primary focus. This scoping review considered 12 studies from the peer-review literature that research ethics committees had vetted. Most utilized quantitative approaches to measuring youth distress post-participation and some pre- and post-participation. While distress was a concern in several of the included studies, this review found that responses to research participation were generally positive, which is consistent with similar reviews conducted on adult-only or combined adult and adolescent populations (Becker-Blease & Freyd, 2006; Appollis et al., 2015). Only one study measured participant reactivity at multiple time points, suggesting that this may be an untapped opportunity to examine the occurrence of and change in distress over time. Most studies found that participating in research had benefits, with youth citing the opportunity to discuss their experiences as positive. The general trend suggests that participants who had experienced adversity and/or more severe mental health symptoms may be more likely to report negative reactions than other participants. One study found that such youth were also more likely to report being more interested in the research and to still have agreed to participate in the study after knowing what was involved (Waechter et al., 2019). It has been suggested that emotional reactivity may result from increased engagement with the research (Newman & Kaloupek, 2004), indicating that the

measure of reactivity alone would not be informative from the perspective of youth's right to participation. This would likely extend to higher trauma groups and may benefit from considering cultural traditions. For example, for Indigenous youth, cultural support may be important, in addition to more traditional helpline resources, including traditional medicines (e.g., cedar tea), smudging with Sage or Sweetgrass, and community representative to provide such support (e.g., Auntie, Elder; Venugopal et al., 2021). Avoiding this type of research based solely on the potential risks as perceived by research ethics boards may be a form of "protectionism" in which persons with lived experiences are not given the opportunity to contribute to advancing knowledge in this field (Friesen et al., 2017). When assessing the acceptability of sensitive questions in an adult population, almost all respondents felt that questions about childhood maltreatment were important to ask (Fortier et al., 2020). A core principle of research ethics prescribes that the likely benefit of the research must justify any risks of harm or discomfort to participants (Beauchamp & Childress, 2019). When specific groups are considered, the role of the community research advisory is important (Billan et al., 2020). The limited research in this area clearly points to the understanding of research as both an opportunity for risk and resilience. Empirical evidence on costs, as well as benefits, remains an important research goal. While limited relevant studies were identified, the tentative understanding is that clear, high clinical distress may be present, but for a small minority of a sample. No clear measurement approach emerged, with studies using either the Response to Research Participation Questionnaire (Kassam-Adams & Newman, 2002) or study-developed reflection items tapping discomfort and whether their decision to participate would have changed having experienced the research study. While all studies provided information about the nature and risks of participating in the research during the consenting process, two studies specifically administered "consent quizzes" (Chu et al., 2008; Chu & Deprince, 2013). Investigators found that these quizzes were effective as a standard to assess understanding of consent/assent information. The administration of these items also varied widely, ranging from face-to-face or telephone interviews to virtual or in-person questionnaires. These various approaches should be further investigated to ensure that these instruments are reliable and do not introduce additional distress.

The seven studies incorporating sex into their analysis came to varying conclusions about the relationship between participant sex and distress. Three studies did not find a significant difference between sexes, three found that females reported more distress, and one found that females reported less distress and more benefits. The latter was the only study that also analysed the relationship between sex and research participation benefits, indicating that this may be a gap area for further research. Further studies on how gender norms can influence benefits and harms are important in tailoring protocols to better support these participants. In response to stressful situations, females are more likely to use emotion-focused coping and seek social support, potentially allowing female participants to find greater value in sharing their experiences through research participation (Green & Diaz, 2008; Renk & Creasey, 2003). On the other hand, masculinity norms may result in additional stigma for male participants (Renk & Creasey, 2003).

There is an overarching need to address specific youth groups with elevated adversity to assess for differential impacts in distress as well as empowerment. Two studies included in this review represented special populations but only focused on child welfare system-involved youth. Previous studies found that both LGBTQ+ adults and youth reported higher rates of childhood adversity and increased levels of emotional distress as compared to the general population (Clements-Nolle et al., 2018; Elze, 2019; Merrick et al., 2018; Russell & Fish, 2016; Craig et al., 2020). Indigenous youth are another population at risk of high adversity and mental health and related issues that should be further investigated (Hop Wo et al., 2020) in terms of experiences with research participation. Histories of unethical research practices (e.g., nutritional experiments, vaccine trials, etc.) committed against Indigenous populations may exacerbate research reactivity and distress among youth, thereby increasing the need for protocols (Hyett et al., 2018), and a heightened sensitivity for researchers to craft trauma-and-violence informed research experiences. The present scoping study highlights the nascent area of this research and the need to be prioritized when sensitive questions are being investigated with vulnerable populations that need a higher consideration for preventing marginalization, a query without clear clinical protocols, and longitudinal considerations of research reactivity.

Recommendations for future protocols

A more recent publication outlined some recommendations for developing protocols to mitigate distress in childhood adversity/trauma event research, focusing on design features to minimize distress, and protocols to respond to participants who became distressed (Matthews et al., 2022). Some examples included: using validated, non-aversive instruments; sequencing and framing questions in a way that minimizes distress; employing professional interviewers; using local samples to test research instruments; ensuring participants are aware of their rights; and providing information about support agencies (Mathews et al., 2022). Elements of these were utilized in the included studies;

however, none of the studies included all the elements. Recommendations for future protocols emphasize the importance of the informed consent process for this kind of research. Overall, it is important for participants to be assured of the confidential nature of the research, and that their participation should be completely voluntary, with a particular focus on their rights to withdraw consent at any time and to choose not to answer questions. Two of the included studies reported success using “consent quizzes” to assess participant understanding of this information (Chu et al., 2008; Chu & Deprince, 2013).

In developing protocols to mitigate reactivity, precise definitions should be utilized to outline a clear referral pathway consistent with the local legal and practice environment (Devries et al., 2015; Mathews et al., 2022). These protocols should involve a stepped approach that addresses varying levels of distress, and training should be provided to all interviewers to ensure that they are able to recognize distress and implement protocols (Mathews et al., 2022). Developing protocols for this type of research is further complicated by the fact that the participants are minors who may also be disclosing information that warrants legal action. Researchers can collaborate with local child protective services to create protocols for reporting child welfare concerns, and it is extremely important that they are clearly specified and understood by the research team (Becker-Blease & Freyd, 2006). Information on incidents reported seems important to include in study publications. Future studies should consider clearly outlining the conditions that necessitate referral, the subsequent pathways of referral, and reporting data on the use of referrals and follow-ups.

Limitations

Variability in methods (in-person or telephone interview formats versus Likert-type rating questions) may have influenced the extent to which experimenter demand bias (i.e., cues that make the participant conform to perceived expectations from the researcher) may have created varying contexts for social desirability responding. This is especially relevant for youth samples sensitive to adults or authority figures (e.g., university researchers). Our inclusion and exclusion criteria also introduced potential bias in our results, as only English-language, peer-reviewed, published literature was selected. Due to the likelihood of published material containing reports and studies with positive outcomes, there is a risk of bias in the results analysed. There is also the possibility that this review may have missed some relevant studies due to our search strategy, the inherent broad focus of scoping reviews, database selection (i.e., some databases that were not searched may have identified additional relevant studies), exclusion of the grey literature from the search, and time-of-search limits.

Implications

This scoping review was conducted to explore the existing literature on research reactivity in youth with adversity and/or trauma event exposure. In accordance with similar studies conducted in adult populations, the included studies in this review suggest that participating in research is generally not found to be harmful to most adolescent studies. Studies did not define research participation as a potential resilience experience with relevant measurement, although youth did describe that the opportunity to respond to victimization questions could be experienced as a positive. Only one study examined the occurrence of and change in distress throughout the research experience, where distress reduction may be an indicator of resilience. Future research, taking both a risk and resilience perspective, may be fruitful in addressing the acceptability of such research among youth and exploring ways to enhance research participation as a positive experience.

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Conflict of interest

The authors have no conflict of interest to disclose.

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