Chapter 13

Survivors of Child Maltreatment: A Historical Review of Global Health and Research

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Abstract

Based on an extensive literature review, this chapter outlines key developments in global health and research during the last century with focus on the emergence of violence and child maltreatment as international public health priorities. Violence has been known to humans for millennia, but only in the late 1990s was it recognised as a global public health issue. Every year, an estimated 1 billion children are exposed to trauma, loss, abuse and neglect. Child maltreatment takes a social and economic toll on countries. Research initiated in 1985 found child maltreatment to be associated with increased disease, disability and premature death in adult survivors. The global availability of data on child maltreatment is, however, sporadic with low validity and reliability. Few global experts have consulted and involved the survivors of child maltreatment, as the experts by experience, in their attempts to provide a more comprehensive picture of reality. Youth and adult survivors of child maltreatment are often traumatised by the experience, and it is important to use trauma-informed approaches to prevent re-traumatisation. Participatory and inclusive research on child maltreatment is only in its infancy. There is a need for more inclusive research, designed by survivors for survivors, hereby strengthening local capacity building and informing policymakers from the bottom up. This chapter reviews lessons learnt and provides recommendations for how to enhance the participation and inclusion of the experts by experience in research on child maltreatment.

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Introduction

Globally, more than 452 million children living in conflict-affected areas are exposed to trauma and loss, the impact of which range from resilience to disease, disability and death (Save the Children, 2021; Stoddard, 2014). Every day, even more children are exposed to violence by the very people responsible for their safety and upbringing: parents, family, care facilities, schools, the social system, siblings, peers and others. Violence is a major public health problem. Every year, an estimated 1 billion children from 2 to 14 years old are victims of violence (World Health Organization [WHO], 2020). Violence in the home, with an estimated prevalence of 22% (Stoltenborgh et al., 2013), is predominant among children from 2 to 14 years old, Youth often have multiple exposures in and outside the home (Hillis et al., 2016). The global prevalence of child sexual abuse (CSA) is estimated at 11.8% (Stoltenborgh et al., 2011). A meta-analysis in Nordic countries revealed a prevalence of CSA from 3%–23% for boys and 11%–36% for girls (Kloppen et al., 2016).

Traumatic childhood experiences are important societal problems with far-reaching health and socioeconomic consequences. Abuse, violence and neglect in early infancy and childhood (child maltreatment) enhance the risk of attachment disorders, substance abuse and mental health problems, such as anxiety, depression, suicidal behaviour, personality and attention deficit disorders, post-traumatic stress disorder (PTSD), psychosis and bipolar II (Black, 2011; Leeb et al., 2011; Norman et al., 2012). Child maltreatment is further associated with increased risk of cardiovascular, liver and chronic lung diseases; cancer; stroke; injuries and disabilities (Bellis et al., 2014; Chiang et al., 2018; Danese et al., 2009; Felitti et al., 1998).

The health and social consequences of violence take an economic toll on countries. The provision of treatment, mental health services, emergency care, criminal justice responses and safety places represents some direct costs associated with violence. A wide range of indirect costs also occurs. Survivors of violence are more likely to experience problems affecting quality of life and school and job performance. Other indirect costs include those related to lost productivity because of premature death; long-term disability; disruptions to daily life because of fears for personal safety and disincentives related to investment and tourism. In 2004, the estimated direct and indirect economic costs of violence were equivalent to 0.4% of gross domestic product in Thailand, 1.2% in Brazil and 4% in Jamaica (WHO, 2008). In the United States, the total lifetime economic burden resulting from new cases of fatal and nonfatal child maltreatment is approximately $124 billion annually (in 2010 dollars; Fang et al., 2012).

Violence has been associated with humanity for millennia, but only since the late 1990s has it truly been recognised as a global public health problem and research priority (WHO, 1996). Survivors of violence, including children, youth

and adults exposed to child maltreatment, are experts by experience. So how do we better integrate these experts in our research on child maltreatment?

Global Research on Violence, Child Health, Abuse and Neglect

In 1962, C. H. Kempe recognised the importance of child abuse and neglect. He established an international working group, and in 1977, he founded the International Society for the Prevention of Child Abuse and Neglect (ISPCAN) 'to promote opportunities, facilities and organisations which will enable the children of all nations to develop physically, mentally and socially in a normal manner . . . and in particular, to promote the protection of every child, in every country against all forms of cruelty and exploitation' (Kempe et al., 1962).

Kempe was ahead of his time. Although violence had long been known to humanity, only during the 1980s did it move from being a criminal justice issue to a public health problem (Winett, 1998).

In 1996, the World Health Assembly declared violence a major public health issue and called for promotion of research in the area (WHO, 1996). In 2002, the *World Health Report on Violence and Health* described different types of violence including child abuse and neglect, the size of the problem, risks and preventive efforts (WHO, 2002).

In 2006, the *World Report on Violence against Children* provided a comprehensive global scenario of the problem: 'Throughout the study, children's voices were listened to, heard and respected' (Pinheiro, 2006, p. XIX).

In 2009, the United Nations appointed a special representative to conduct a global survey on violence against children, published in 2013 (Office of the Special Representative of the Secretary General on Violence against Children, 2013).

In 2014, the *Global Status Report on Violence Prevention* found most of the 133 countries included in the survey to lack data on violence. Only 41% of the countries had done national surveys (60% in Europe) and prevention programmes were only implemented in a third of the countries. Laws existed in 80% of the countries but were only enforced in 57% of them. Safe places were available in half the countries (WHO, 2014).

In 2015, a global report on the prevalence of violence against children emphasised the need for more reliable and comprehensive data (UNICEF, 2015).

In 2016, global actors developed 'INSPIRE: Seven Strategies for Ending Violence against Children' in support of the globally defined 2030 sustainable development goals to (1) End abuse, exploitation, trafficking and all forms of violence against and torture of children; (2) Eliminate 'violence against women, and girls; and reduce (3) all forms of violence and related death rates' (WHO, 2016). In 2020, the *Global Status Report on Preventing Violence against Children* found 80% of countries had a partial action plan in line with INSPIRE, but only 21% had quantitative baselines and target indicators to monitor the effect. Implementation of preventive strategies was low (WHO, 2020).

Early Research on Adult Survivors of Child Maltreatment

In 1985, Judith Herman and Bessel van Der Kolk observed that many patients diagnosed with borderline personality disorder (BPD) reported maltreatment in childhood. To uncover the possible relationship between trauma and BPD, they developed the Trauma Antecedents Questionnaire (see http://www.trauma-center.org) and obtained a trauma history from 55 outpatients. The questionnaire gently approached the issue of childhood relationships and trauma, considering that most traumatised persons feel shame about past trauma. The study found that 81% of patients with BPD reported severe histories of child abuse including sexual abuse or neglect, usually before the age of seven (Herman et al., 1989). These researchers approached the team revising the *Diagnostic and Statistical Manual of Mental Disorders* (DSM; third edition), proposing that people with severe childhood abuse or neglect be diagnosed as having complex PTSD. To gain more information and compare different groups of traumatised individuals, an additional study including 525 adult patients occurred at five sites across the United States. The three groups of focus were: (1) adults with histories of childhood abuse, (2) recent survivors of domestic violence and (3) survivors of natural disaster. Adults who had been abused as children had problems concentrating, complained of being on the edge and reported feelings of self-loathing. They had trouble with intimate relationships and memory and often engaged in self-destructive behaviours. These symptoms were relatively rare in adult disaster survivors. The DSM (fourth edition) PTSD workgroup suggested survivors of interpersonal trauma be diagnosed as having 'complex PTSD', but the diagnosis did not appear in the final version of the fourth edition of the DSM (van der Kolk, 2015). PTSD for children aged 6 years and younger was recognised in the fifth edition of the DSM, along with the somewhat broader 'trauma and stressor-related disorders' (Luxenburg et al., 2001). The 11th version of International Classifications of Diseases includes the diagnosis of complex PTSD (see https://icd.who.int).

Adverse Childhood Experiences Research

In 1985, Vincent Felitti observed that some of the people in a Kaiser Permanente clinic for extreme overweight rapidly regained the weight they lost. Interviews with 286 extremely obese persons attending the clinic showed that a large percentage had been exposed to child abuse (Felitti, 2019). Although the data were interesting, the study population was small and nonrepresentative of the general population. The Centers for Disease Control and Prevention (2022), therefore, suggested a larger study. It took three years to design the retrospective cohort Adverse Childhood Experiences (ACE) Study, implemented from 1995 to 1997 at Kaiser Permanente with support from the Centers for Disease Control and Prevention. The study aimed to determine the prevalence of ACEs in the general population and how ACE affect adults later in life. The data collection was done in two waves.

In total, 26,000 adults who received an annual comprehensive medical examination were asked to join. Baseline survey data on health behaviours, health status and exposure to ACEs were collected from 17,337 adults who agreed to participate. Most respondents were White (74.8%); 11.2% were Hispanic and 54% were female. Nearly 40% had attended college or beyond. The study mainly included financially secure, middle-aged people with good medical insurance.

The ACE questions, which referred to the respondents' first 18 years of life, included 10 categories: abuse (emotional, physical, sexual); household challenges (mother treated violently; household members with mental illness, substance abuse or sent to prison; or parents separated or divorced) and neglect (emotional or physical). The ACE score was used as a measure of cumulative exposure to traumatic stress during childhood, with 0 being no exposure and 10 being the highest exposure. Two-thirds had an ACE score of 1 or more.

In the first ACE study published in 1998, a questionnaire was mailed to 13,494 adults; 70.5% (9,508) responded. Logistic regression was used to adjust for demographic factors regarding the association between ACE score (0–7) and risk factors for the leading causes of disease, disability and death in adult life. More than half of the respondents reported at least one ACE, and one-fourth reported two or more ACEs. People with four or more ACEs, compared to those with none, had 4 to 12 times the risk of alcoholism, drug abuse, depression and suicide attempt. They also had two to four times higher odds of smoking, poor self-rated health, more than 50 sexual partners, and sexually transmitted diseases and 1.4 to 1.6 times higher odds of physical inactivity and severe obesity. The ACE score showed a graded relationship with the presence of ischaemic heart, liver and lung disease; cancer and skeletal fractures in adults. The ACE score was interrelated, and people with multiple ACEs were likely to have multiple health risk factors later in life (Felitti et al., 1998).

The original ACE study was the first of its kind to find a strong graded relationship between ACEs and multiple risk factors for several leading causes of disease, disability and death in adults. Follow-up studies and papers continue to appear, mostly from the United States and mainly confirming and expanding on the initial findings (Chapman et al., 2004, 2011; Hillis et al., 2001, 2004; Oral et al., 2016; Whitfield et al., 2005).

A 2009 analysis of the ACE data for 17,337 adults found that 1,539 had died by 31 December 2006. The crude death rate was 91.0 per 1,000; the age-adjusted rate was 54.7 per 1,000. People with six or more ACEs died nearly 20 years earlier than people without ACEs (Brown et al., 2009).

A 2013 ACE study including four adult male offender groups ($N = 151$; nonsexual child abuse, domestic violence, sexual abuse and stalking) reported nearly four times as many ACEs compared to a normative adult male sample. Perpetrators of sexual offences and child abuse were more likely to report CSA than other offender types (Reavis et al., 2013).

A 2014 ACE study found that 47 female sexual offenders, compared to women in the general population, had more than three times the odds of CSA, emotional neglect, verbal neglect and having an incarcerated family member. Half of the offenders had experienced CSA. Only 20% had no ACEs, compared to 35% of the

general female population, and 41% had four or more ACEs, compared to 15% of the general female population (Levenson et al., 2015).

Another 2014 ACE study found that 670 male sexual offenders, compared with men in the general population, had more than three times the odds of CSA, emotional neglect and coming from a broken home (homes where mum and dad split or divorced); twice the odds of physical abuse; and 13 times the odds of verbal abuse. Nearly half had an ACE score of 4 or more. Only 16% had no ACEs. Multiple forms of maltreatment often co-occurred with other household dysfunctions, suggesting that many sex offenders were raised in a turbulent social environment (Levenson et al., 2016).

A 2014 study in eight Eastern European countries including 10,696 young adults (18–25 years, 59.7% women) found increased risk of health-harming behaviours, with Odds Ratios (OR) varying (or ranging) from 1.68 CI [1.36–2.15] for physical inactivity to 48.53 CI [31.98–76.65] for attempted suicide among those reporting four or more ACEs compared to those without ACEs. (Bellis et al., 2014).

Other Relevant Studies

A 2010 meta-analysis including 59 studies compared male adolescent sex offenders (n = 3,855) with male adolescents with no sex offences (n = 13,393) in antisocial tendencies, childhood abuse, exposure to violence, family problems, interpersonal problems, sexuality, psychopathology and cognitive abilities. Ranked by effect size, the largest group difference occurred for atypical sexual interests, followed by sexual abuse history, criminal history, antisocial associations and finally, substance abuse (Seto & Lalumière, 2010).

A 2013 systemic literature review including 65 publications found child abuse, substance abuse and parental divorce to be frequent risk factors for poor mental health in adulthood. Emotional, sexual and physical child abuse were key risk factors for depression. CSA and family violence were the greatest risk factors for anxiety disorders. Family violence and physical neglect were strongly correlated with substance abuse (De Venter et al., 2013).

A 2015 systematic literature review of the relationship between ACEs and sleep disturbances, with a focus on adult women, identified 30 publications (28 retrospective studies) with heterogeneity in the types of ACEs and sleep outcomes measured. Most (n = 25) of the retrospective studies documented statistically significant associations between the number of ACEs and sleep disorders. This association was verified by two prospective studies. Further, the associations between family conflict at ages 7–15 years and insomnia at age 18 years (OR = 1.4, CI [1.2–1.7]) and between CSA and sleep disturbances 10 years later in adult women ($\beta = 0.24$, $p < 0.05$). were statistically significant (Kajeepeta et al., 2015).

A 2016 cross-sectional survey including 318 people receiving community mental health care found 63% of men and 71% of women reported childhood maltreatment. About 46% of men and 67% of women reported domestic violence and 22% of men and 62% of women reported sexual violence, both in adulthood.

Overall, people with mental health issues and experiences of childhood maltreatment were two to five times more likely to report domestic and sexual violence in adulthood (Anderson et al., 2016).

A 2016 prospective longitudinal study following 332 persons (52.4% male) from childhood (18 months–6 years old) to adulthood (31–41 years old) looked at parent-reported physical and emotional abuse and child-reported sexual abuse. Adult outcomes included three groups: (1) low risk of substance abuse, depression and anxiety; (2) moderate substance abuse risk and mild depression and anxiety and (3) moderate substance abuse risk and moderate to high depression and anxiety. Physical abuse increased adolescent depression but not the adult outcome groups. Children exposed to severe emotional abuse had higher risk of comorbid substance abuse, depression and anxiety into their mid-30s. Sexual and physical abuse had more proximal effects on adolescent alcohol use and depression, which then influenced the risk of adulthood problems (Skinner et al., 2016).

A 2017 study including a national sample of 2,244 young Swedish adults with at least one ACE found that physical assault, neglect and witnessing violence as a child were significantly associated with adult criminal behaviour, but not experiences of property, verbal or sexual victimisation (Howell et al., 2017).

Studies With a Focus on CSA Survivors

A European study from November 2015 to October 2021 included 6,000 survivors of CSA who shared their experiences as part of an independent inquiry. Out of the 6,000 survivors, the 5,440 accounts analysed at the point of writing, 1 in 10 talked about an experience of CSA for the first time. Around two-thirds did not tell anybody about the CSA at the time it happened. Around 88% described an impact on their mental health, with more than a third reporting depression and 45% indicating an illness or condition that affected their day-to-day life (Berrymans Lace Mawer, 2021).

A 2017 study included 484 adult CSA survivors (86% female) treated by the Danish Victims Foundation (http://www.offerfonden.dk) over an 18-month period. The exclusion criteria were (1) intoxication, (2) psychotic disorder, (3) self-harm and (4) treatment elsewhere. The mean age was 36.1 years (range: 18–70). Most participants (91%) had experienced CSA before the age of 15, committed by a person at least 5 years older and occurring an average of 23.5 years ago. The average age that abuse started was 6.6 years, and it lasted for an average of 6.9 years. About 8.5% had experienced abuse once, 22% 2 to 5 times, 21.4% 6 to 15 times, 22% 16 to 50 times and 26.4% 51 or more times. Twenty-five percent had been sexually abused by more than one person. Multiple abusive acts were associated with anxiety, somatoform disorder, drug dependence, PTSD and major depression. The co-occurrence of CSA and childhood physical abuse was associated with increased risk of alcohol dependence (OR = 2.89). The presence of more than one abuser in childhood increased the risk of PTSD, major depression, anxiety, somatoform, dysthymia and thought and delusional disorders by two to four times. Women were more likely to be diagnosed with a

somatoform disorder, whereas men were more likely to be diagnosed with dysthymia and substance dependence (Elklit et al., 2017).

Moving Towards More Participatory and Inclusive Research

In most of the research reviewed here, the researchers determined the research focus, design and process, whereas the study population was a passive target.

In participatory research, the target population becomes involved as a partner to varying degrees: manipulation, tokenism, consulted and informed, assigned but informed, externally initiated and shared decisions with the target group, initiated by the target group and shared decisions with the external partner, and initiated and directed by the target group. Participatory research enables informed research because the people who have experienced child maltreatment contribute to knowledge sharing and production on the topic.

Most current globally initiated child health research rarely reaches beyond consulted and informed.

An example from the category of 'externally initiated and shared decisions with the target group' is a study from 2001 that used focus groups and thematic analysis to learn what children and adolescent CSA survivors believed counselling and therapy should entail to help them and how others (e.g. parents, social workers, law enforcement and siblings) might have helped them better (Nelson-Gardell, 2001).

In January 2021, the Council of Europe created a handbook for children's participation, developed with the participation of children and including nine basic requirements for effective and ethical participation: (1) transparent and informative, (2) voluntary, (3) respectful, (4) relevant, (5) child-friendly, (6) inclusive, (7) supported by training for adults, (8) safe and sensitive to risk and (9) accountable (Council of Europe, 2021).

Save the Children, which has decades of experiences in 'rights-based approaches', has developed two manuals for research with children, youth and adults.

The first, *Children in Focus: A Manual for Participatory Research with Children* (Boyden & Ennew, 1997), provides practical and ethical guidance on how to conduct research with children including participation, child-centred and conventional research methods and child-focused research tools. The manual was developed based on broad cooperation with children, youth and adults in Bangladesh, Ethiopia, India, Nepal, Pakistan, Sri Lanka and Uganda. Some of the methods were field tested in Kenya (Boyden & Ennew, 1997).

The second, *A Kit of Tools for Participatory Research and Evaluation with Children, Young People, Adults: Compilation of Tools Used during a Thematic Evaluation and Documentation on Children's Participation in Armed Conflict, Post Conflict and Peace Building* (Save the Children, 2008), is based on practical experiences from Bosnia-Herzegovina, Guatemala, Nepal and Uganda. A key feature is its use of formative dialogue research and child-friendly tools to allow for active involvement of children as advisors, peer researchers, active

respondents, development workers, peace agents and documenters (Save the Children, 2008).

Save the Children has moved towards more inclusive research (from child- or youth-initiated with shared decisions with adults to child- or youth-initiated and directed).

Inclusive research is a term originally established in the early twenty-first century alongside the closure of large institutions for people with learning disabilities (Buchanan & Walmsley, 2006). Inclusive research is illustrative of changing ideas about people with disabilities from incompetent and burdensome 'objects of charity' to people with rights and potential to learn and contribute. Inclusive research is part of a wider rights movement, known by the slogan 'Nothing about us without us'. It has been adopted in work with children, young people and others (Welshman & Walmsley, 2006).

Inclusive research changes the hierarchy of traditional research configurations, which view professional researchers as expert and commentators on the lives of those positioned as the subjects of research. Inclusive research privileges insider accounts from experts by experience and results in less rigid hierarchies and a sense of research as a shared journey.

Inclusive research (1) is owned by lay people; (2) furthers the interests of lay people, with researchers on their side; (3) is collaborative; (4) enables lay people to exercise control over the process and outcomes and (5) produces outputs that are accessible (Walmsley & Johnson, 2003). A manual for inclusive research has been developed by Jönköping University in Sweden based on an Australian manual for inclusive research practice with the autism community (CHILD, n.d.).

Key Findings, Discussion, Conclusions and Recommendations

Violence is a major public health problem. Every year, an estimated 1 billion children from 2 to 14 years old are victims to violence. Child maltreatment is an important societal problem with far-reaching health and socioeconomic consequences that take an economic toll on countries throughout the world.

The global availability of data on child maltreatment is sporadic, with low validity and reliability, and cost-effective evidence-based interventions remain to be identified (World Health Organisation, 2016). Few global experts have consulted and involved the survivors of child maltreatment in an attempt to provide a more comprehensive picture of reality and guide priority setting and strategy development. But changes might be on the way; during the production of the *World Report on Violence against Children*, children were 'listened to, heard and respected' (Pinheiro, 2006, p. XIX), and the Committee of European Ministers embarked on a more consultative process involving children when it developed a recent strategy to advance the protection and promotion of the rights of the child across Europe (Council of Europe, 2022).

However, regarding research on child maltreatment, inclusion is only in its infancy. This literature review did not identify research studies designed by survivors for survivors. However, a few intervention projects exist, mainly aiming to

help female survivors of violence. Knowledge about and interventions for men and people of other genders are limited. This review identified one promising project, 'Survivors & Mates Support Network (SAMSN)', founded in Australia in 2010 by men for male CSA survivors. The project runs support groups for men who have been sexually assaulted as young boys or adolescents. It includes men of different cultural, religious and sexual orientation but has no research component (https://www.samsn.org.au/get-to-know-us/).

Researchers like Kempe, Herman, Bessel, and Felitti and others have made valuable contributions to our present knowledge about childhood maltreatment and initiated the development of research tools for measurement of ACEs and structured interviews (http://www.traumacenter.org; Luxenburg et al., 2001). But we still have far to go.

We need to improve the present research tools to enhance our measurement accuracy and move our research questions from 'What is wrong with you?' toward a more curious and inclusive 'What happened to you?' (Winfrey & Bruce, 2021).

We need to see survivors of child maltreatment as experts by experience to be included in research and empowered to initiate research by them for them.

Present research on child maltreatment has mainly been done on survivors, who are invited to participate in already designed projects. To be inclusive in design, future projects need to be designed, implemented, analysed and disseminated by survivors of child maltreatment in close cooperation with researchers. Likewise, all national and international strategies, plans and policies aiming to address maltreatment need to start with the true experts: the survivors of child maltreatment.

Youth and adult survivors of child maltreatment are often traumatised by the experience. Therefore, it is important that all research including survivors of childhood maltreatment follow the principles of trauma-informed approaches to prevent retraumatisation and enhance capacity building: (1) promote a sense of safety, (2) approach decisions with transparency and enhance trustworthiness, (3) develop and strengthen peer support, (4) ensure collaboration and mutuality to contribute to healing during the process, (5) embrace survivor-centred approaches that empower the survivors and give them a voice and choice and (6) ensure efforts are culturally, historically and gender sensitive and free of prejudices based on bias and stereotypes (SAMHSA's Concept of Trauma and Guidance for a Trauma-Informed Approach).

There is a need for more trauma-informed, inclusive research initiated by survivors for survivors of childhood maltreatment – research that strengthens local research capacity building and inform policymakers from the bottom up, including experts by experience.

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