Research with children exposed to disasters

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Abstract

A number of logistical issues complicate the conduct of child disaster research. Like studies of adults, much of the child research has used a single cross-sectional assessment of non-representative samples, it fails to consider pre-disaster contribution to post-disaster problems, and it leaps to unwarranted causal conclusions from results providing mere associations. Despite concern about the accuracy of parental report and concern about children's understanding of certain terms, most child studies have used a single source of information – either the children themselves or their parents. As the field matures, greater attention to the sophistication of research methods and design will increase our understanding of children in the context of disasters. Copyright © 2008 John Wiley & Sons, Ltd.

Key words: child disaster research, child studies, disaster, disaster research

Introduction

Disasters are by nature overwhelming, creating confusion and chaos and raising numerous concerns and questions as people try to make sense of their experiences. The disaster setting is not intuitively conducive to conducting research (North et al., 2002) and, except among seasoned disaster researchers, research is commonly not a consideration until after the disaster has passed, often not until well after. While disaster survivors and communities may wish to contribute to future knowledge, especially knowledge that might help potential future victims, they are likely to be focused on practical concerns. Disaster research with children is further hampered by developmental and social considerations which influence children's reactions and recovery and which affect the consent process and study methods and procedures. Kessler and colleagues (Kessler, Keane, Ursano, Mokdad and Zaslavsky, this issue) have described key issues and challenges in disaster mental health research. Much of their discussion is applicable to research related to children which raises additional concerns that further complicate the timely implementation of field work. In this article, we address

issues associated with crafting research questions, identifying and accessing samples, designing protocols, and selecting assessment tools for use in child disaster research.

Ethics and consent

Ethical concerns about the vulnerability of children are reflected in the informed consent process. Children cannot legally provide informed consent; rather, their parents must give permission for their participation with children themselves providing assent [Institute of Medicine (IOM), 2004]. Despite their lack of legal capacity to provide consent, children should be included in the consent process to the extent possible (IOM, 2004). As they mature, their participation in this process can and should increase. This has the advantage of giving them opportunities to learn about the study, express concerns, and ask questions (IOM, 2004).

The consent process itself can not only be cumbersome, it can prevent studies from being conducted or decrease participation rates. For example, because the goal was to identify children in need of evaluation and

possible treatment, passive consent was allowed in the school-based assessment of Oklahoma City school children after the 1995 bombing (North et al., 2002). Passive consent, instituted by the school district's superintendent because of concern about compliance and participation with an active consent process, is no longer likely to pass institutional review board scrutiny. Thus, researchers must be prepared to address the low response rates commonly associated with full informed consent – parental permission and child assent.

Identifying issues and framing questions

Preliminary to the implementation of research are the critical tasks of identifying the research questions and populations of interest. Children are especially vulnerable to the effects of disasters with reactions that span the continuum from distress and transient emotional and behavioral reactions to impaired functioning and enduring psychopathology (Norris et al., 2002). Well-designed research is needed to establish the extent of clinically-relevant outcomes, explore resilience and recovery, explicate family and social influences, and determine effectiveness and efficacy of services and interventions. Theoretically-driven research should be based on thoughtful review of the existing literature on child development, the family and social factors that influence children emotionally, and children's reactions to disasters. Too often disaster research is driven by accessibility of samples (Norris, 2006) with insufficient thought to theory or the novel issues that would increase knowledge in meaningful ways. Thus, careful attention to the literature and the specific issues raised in the context of a particular disaster are essential to framing the questions to be addressed in any study. Research serves a number of purposes. It can be used to document reactions and need, monitor recovery and the effects of post-event conditions, and evaluate the effectiveness of services and interventions. The research questions and purpose of assessment should guide the choice of populations and samples and the study methods and design.

Samples and sampling

Choosing the appropriate population to study depends in part on the issues of concern and the questions being asked, and conversely, specific populations raise distinct issues and generate distinct questions. Choice of a population for study may be based on a number of factors. For example, researchers may select a study

population based on some specific characteristic such as demographics (e.g. age or ethnicity of the child), family structure (e.g. children of divorce), cultural heritage, geographic location, type and severity of disaster exposure, or source (e.g. schools, daycare settings) (North and Norris, 2006).

Researchers use sampling to examine a smaller group or number of children in a population from which they can draw conclusions about the larger population. Ideally the process involves a sample that is representative of the population, but this is not always feasible. Important issues associated with sampling include the types of samples and sampling approaches as well as access to appropriate populations and recruitment strategies.

Types of samples and sampling approaches

Norris (2006) identified five sampling strategies in disaster research – convenience, purposive, clinical, random, and census sampling. Convenience sampling enrolls participants for study if they meet inclusion criteria without regard to how representative they are of the population of interest. These samples are relatively easy to access, conserving time and resources. Researchers use purposive sampling to select participants with specific characteristics or because they are 'information-rich cases' for in-depth study from which to explore specific issues (Patton, 2002, p 243). Clinical sampling accesses individuals receiving services. Random sampling involves individuals who are representative of a population under investigation. Census sampling attempts to assess all individuals in a given population. We modify Norris' categorization some to emphasize the distinction between the population being studied and the sampling strategy being used. In that regard, we note that clinical and purposive populations can be assessed through convenience, random, or census sampling and clinical populations can also be assessed through purposive sampling.

Access to representative samples is often difficult especially with disaster populations. Thus, many child disaster studies use samples that are not representative, relying on convenience and purposive sampling, sometimes without clarifying the extent to which the samples reflect the population under question. Relatively few child studies have used control samples. Notable exceptions are studies of disasters that affected somewhat isolated groups of children such as

children in the World Trade Center at the time of the 1993 bombing (Koplewicz et al., 2002) or children traumatized while away on a school outing (Bolton et al., 2000; Yule et al., 2000). In these studies researchers were able to identify and study suitable controls like the disaster samples except for exposure.

Access to participants and recruitment

Researchers seeking to assess directly-affected children, who constitute a high-risk group, may have a particularly difficult time accessing participants. The recruitment process can be challenging. For example, Yule et al. (2000) sought to enroll a census sample of children personally involved in a shipping disaster during their youth. Participants were identified through various means including schools, a national health register, newspaper articles, voter registration, and peers. Also seeking a census sample, Earls et al. (1988) contacted all households in two small housing subdivisions located near St Louis to obtain a sample of children and parents one year after evacuation from their homes during a severe flood. Breton et al. (1993) drew children randomly from a list of families which had received financial support for lodging during evacuation and selected a control group randomly from families residing in a nearby area which were on financial assistance rolls. Green et al. (1991) used psychiatric records created as part of disaster litigation to study children exposed to the Buffalo Creek disaster. Census sampling is limited by the response rate and by the samples themselves. Even random samples taken from registers designed for other purposes are representative only of those on the register.

Classrooms have emerged as a popular venue for conducting research because schools provide access to large numbers of children in convenient locations where children naturally congregate. Public schools tend to be located in neighborhoods and may be representative of children in the vicinity; research has not addressed the extent to which children in private and religious schools or those schooled at home may differ from general school samples. Researchers may have difficulty obtaining cooperation from schools because of the many consuming primary demands placed on schools, school personnel's general protectiveness of children, differences in opinion about the appropriateness of locating disaster programs in schools, concern about perpetuating distress and postponing recovery in

children, shortage of resources, the lack of school-based clinicians with specialized expertise, and the general bureaucratic complexities of the education system. In some instances, schools recognize the importance of identifying at-risk children in need of services. For example, working in collaboration with a school district in South Carolina, Shannon et al. (1994) sought to enroll a census sample after Hurricane Hugo. They succeeded in administering questionnaires to the majority of the children attending most of the county's schools. Hoven et al. (2005) drew a representative sample of children in the New York City school district to study reactions to the September 11, 2001, attacks and stratified the sample by location of the school at ground zero, in high-risk areas, and in all other areas. Many studies have used large purposive or convenience samples that may not have represented the children in the schools or community.

Other studies focused on children residing in disaster-affected communities or across the nation have used telephone sampling to obtain information about children from their parents (see e.g. Fairbrother et al., 2003; Schlenger et al., 2002; Schuster et al., 2001; Stein et al., 2004; Stuber et al., 2002; Stuber et al., 2005) or to obtain access to children themselves (Pfefferbaum et al., 2006). Gil-Rivas et al. (2004) used a national household sample participating in a web-enabled research panel to study adolescents and their parents approximately two weeks, and again one year, after the September 11 attacks. Telephone and web-based approaches are not representative of families without telephones or internet access or families that do not respond to this kind of contact. In addition, these approaches typically yield samples of children without direct personal exposure to a disaster and thus cannot be used to investigate post-traumatic stress disorder (PTSD) with its requisite exposure.

Study design and methodology

The timing and the type and number of assessments, instruments, and informants are critical to the design of disaster protocols.

Timing of assessments

Time is a crucial element in understanding disaster reactions and must be considered in research design and in interpreting results (Benight et al., 2006; Norris, 2006). Rapid entry into the field is essential to obtaining indispensable early data about disaster effects and

survivor needs, but early entry may be difficult because of the priority for attention to clinical concerns, safety and security, ethical standards, and logistical barriers. In addition to the need for early data, relatively few child studies have examined long-term disaster effects (Norris, 2006). Studies by Green et al. (1994) and by Udwin et al. (2000) are noteworthy exceptions in this regard as they documented long-term disabling effects of intense personal disaster exposure and compared the findings to data obtained earlier in the post-disaster course.

Type and number of assessments

Many child disaster studies use a single post-event cross-sectional assessment (Norris, 2006). A preferred design includes multiple assessments which help establish a temporal sequence of reactions and recovery and which support conclusions about causality (North and Pfefferbaum, 2002). Studies with multiple assessments can use a panel (the same respondents over time) (see e.g. Koplewicz et al., 2002) or a trend (a new cross-sectional sample with each assessment) (see e.g. Stuber et al., 2005). Trend samples, while able to document population effects, do not yield important information on changes in individual children over time.

Comparison of symptoms pre- and post-disaster helps determine attributable risk (North et al., 2002) but because disasters are typically unpredictable, few studies can use prospective design, although pre-disaster information can be retrieved, albeit imperfectly, retrospectively. Researchers must be careful not to attribute common findings (e.g. sleep disturbance, irritability), present both pre- and post-disaster, to the disaster (North and Pfefferbaum, 2002). Occasional studies have taken advantage of ongoing investigations to obtain prospective data on post-event samples. For example, Asarnow et al. (1999) were conducting a family genetic study of childhood depression at the time of the Northridge earthquake. Thus, they had extensive pre-earthquake data on a sample of children who they assessed again to study effects of the disaster. Similarly, La Greca et al. (1998) compared children's reactions to Hurricane Andrew in light of pre-event anxiety, inattention, and academic skills.

In addition to their cross-sectional random-digit-dial telephone surveys four and six months after the September 11, 2001, attacks, Stuber et al. (2005) also compared their September 11 findings with pre-September 11 data from the National Survey of America's Families

(NSAF) (Judkins et al., 2000). The NSAF, a nationally representative cross-sectional survey of households across the country, had been conducted 11 months before September 11. The Centers for Disease Control and Prevention (CDC) provides funding to various state and local agencies and governments to monitor health-related behaviors in high-school students using the Youth Risk Behavior Survey (Centers for Disease Control and Prevention, 2006). These surveys could provide baseline rates of a host of variables potentially useful in longitudinal research. A problem with prospective pre-disaster research, however, is that it typically does not include the variables of greatest interest for disaster research.

Instruments

A number of instruments – structured diagnostic interviews and rating scales – have been used in child disaster studies (see e.g. Balaban, 2006; Pynoos et al., 2005). Several issues related to instruments used with children are worth noting. Though ideally the choice of instruments should be guided by the research questions and populations being studied, all too often it reflects instead the exigencies of time and resources. The preference for screening instruments and symptom scales that do not assess full diagnostic criteria may inflate rates of diseases such as PTSD (North et al., 2002). Children may lack the cognitive ability to understand terminology associated with the constructs being measured. For example, young children may not comprehend terms and concepts such as numbing. In addition, some constructs may not be valid with respect to young children. For example, our limited knowledge about the development of memory functions in children makes it difficult to contemplate measures to explain and assess amnesia. Post-event normal developmental changes, the context in which assessment occurs, demographic characteristics, and other factors may confound results and lead to erroneous conclusions that observed findings are caused by the disaster experience. Finally, a lack of consistency in the instruments used in disaster studies makes it difficult to compare data across events and to draw conclusions from multiple studies.

Observers and informants

Researchers can obtain information about children by examining children themselves or through collateral sources like parents or teachers. Decisions about who to query should be based on issues integral to the

research questions. Unfortunately, practical difficulties in accessing children typically drive decisions about who should serve as respondents. Disaster studies that have questioned parents about their children have addressed a number of topics. For example, research after the September 11, 2001, terrorist attacks included studies in which parents reported perceptions of their children's reactions and the factors that affected their reactions (Fairbrother et al., 2003; Schlenger et al., 2002; Schuster et al., 2001; Stein et al., 2004), the use of services for children (Stuber et al., 2002), and children's event-related television viewing (Fairbrother et al., 2003). Other studies used adult samples to obtain access to children for direct assessment (Pfefferbaum et al., 2006).

Parents are generally considered better observers of externalizing reactions while children are better at reporting internalizing reactions. For example, parents of children in the World Trade Center during the 1993 bombing reported a decrease in their children's post-traumatic stress and incident-related fears at nine months, but their children reported no decrease (Koplewicz et al., 2002). It is unclear the extent to which discrepancies between child and parent report reflect parental distress related to the traumatic situation, parental pre-occupation with other issues, and/or parental difficulty acknowledging the suffering of their children. In addition, studies suggest that children may be unusually compliant in the aftermath of a disaster and thus may not fully display their distress (McFarlane et al., 1987; Shaw et al., 1995), perhaps to avoid further burdening their parents (Mollica et al., 1997). An ideal approach would include reports from children directly and from their parents (Breton et al., 1993; Koplewicz et al., 2002). For a truly comprehensive assessment, reports of school personnel or a clinician would add a third dimension to understanding the reactions and needs of children. Shaw et al. (1995) examined child self report and teacher report as well as existing school data in their study of children exposed to Hurricane Andrew. Putnam (1996) raised the prospect of peer-report. Available information about the pre-disaster emotional status and functioning of individual children would provide baseline measures from which to interpret results.

The use of multiple informants and the potential for discrepancies in their reports requires researchers to reconcile discrepant findings and to consider these differences when interpreting results. This should be

guided by the information sought and how objective each informant's perspective is thought to be. In general, children are considered more accurate in describing their own experiences, perceptions, and internal emotions which may be missed even by close adults. Parents provide better descriptions than children of the child's external behavior across various situations. Teachers can identify variations from peers in normalized settings and mental health clinicians can determine what constitutes psychopathologic reactions and condition (Myers and Winters, 2002).

Interpreting results

Several issues are fundamental to interpreting study findings. First, associations do not establish a cause-effect relationship even if a temporal relationship is established. That a family moves after a disaster does not mean the family moved because of the disaster. Thus, the disaster researcher must always entertain the possibility that relationships may go in either direction or may be indirectly related by virtue of a common factor in both. In this regard, for example, a relationship between post-traumatic stress reactions and viewing disaster-related television coverage of an incident could mean that children who had stronger reactions to the disaster were drawn to television coverage, that viewing television coverage caused an increase in post-traumatic stress reactions, or that something else common to both was responsible for the association.

Second, symptoms and reactions alone do not necessarily indicate pathology. A score on a post-traumatic stress reaction scale, no matter how high, does not mean that the child is suffering PTSD. To be diagnosed with PTSD requires meeting all criteria for the disorder, some of which (e.g. the stressor or exposure criterion, the temporal element, the requirement of distress or impaired functioning) are commonly ignored in survey instruments. For example, the avoidance/numbing and hyperarousal criteria require that the reactions begin or increase after the event; thus, mere presence of the reaction does not suffice in determining a diagnosis of PTSD. Thus, applying diagnostic terminology without attention to all criteria can inflate reported rates of diagnoses (North and Pfefferbaum, 2002) and confuse the distinction between normal and pathologic reactions to stress.

Third, just because a finding is statistically significant does not mean that it is clinically significant or large enough to have meaning and be useful (Kraemer

et al., 2003). Clinical significance is based on external standards that consider, for example, how meaningful differences are or whether there are clinical benefits or side effects (Morgan et al., 2007). Thus, finding an association between disaster-related post-traumatic stress reactions and viewing television coverage of a disaster does not mean that viewing television coverage is of sufficient magnitude to suggest that it causes serious distress let alone psychiatric illness.

Conclusions and future directions

The current portfolio of child disaster assessment research is limited by its general focus on adverse and psychopathologic effects, by its failure to distinguish clinically-relevant outcomes, and by the methodology used in studies to date. We know relatively little about resilience, post-traumatic growth, and the course of recovery – all areas of increasing interest in the current generation of child disaster research. Like studies of adults, much of the child research has used a single cross-sectional assessment of non-representative samples (Norris, 2006), it fails to consider pre-disaster contribution to post-disaster problems, and it inappropriately leaps to causal conclusions from results providing mere associations. Despite concern about the accuracy of parental report and concern about children's understanding of certain terms, most child studies have used a single source of information – either the children themselves or their parents. The field would benefit from longitudinal studies using multiple informants to shed light on the long-term effects of disaster trauma and on the influence of development and family and social factors. Instruments that are sensitive to and account for developmental changes will be necessary for this work. As the field matures, greater attention to the sophistication of research methods and design will increase our understanding of children in the context of mass trauma.

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Declaration of Interests

No conflict of interests declared.

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