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Participant Reactions to Survey Research in the General Population After Terrorist Attacks

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There remains concern that survey research after a disaster can precipitate or exacerbate distress among study participants. The authors surveyed 5,774 persons in three random-digit-dial telephone surveys of the general population of New York City conducted 1–2 months, 4–5 months, and 6–9 months after the terrorist attack on September 11, 2001. Overall, 746 (12.9%) people who finished the surveys said that the survey questions were upsetting but only 57 (1.0% overall) were still upset at the end of the interview, and 19 (0.3%) wanted assistance from a counselor. Ten persons who did not finish the survey also received counselor assistance. Persons with mental health symptoms were more likely to find the survey questions emotionally upsetting as were participants who lacked salutary resources, including health insurance and a regular health care provider. Although relatively few of those interviewed found the survey assessment disturbing, the presence of a small number of respondents who wanted mental health assistance suggests the need for a mental health backup system for research conducted soon after exposure to large-scale traumatic events.

Most studies have found that participation in research after traumatic event exposure is well tolerated and that a substantial number of persons report positive effects of participation that compensate for any modest level of upset or distress experienced during research participation (Newman & Kaloupek, 2004). Few studies, however, have investigated the impact of research participation following exposure to large-scale traumatic events; we are aware of no studies that have assessed participation in research conducted in the short-term aftermath of disasters. Exposure to large-scale traumatic events such as disasters results in substantial psychological morbidity (Galea et al., 2002; Norris et al., 2002). Participants in disaster-related research may also be struggling with medical, economic, or social difficulties secondary to the event compounding the distress associated with trauma exposure (Newman, Walker, & Gefland, 1999). This suggests that it may be particularly important to investigate the potentially adverse effects of research participation in studies about the impact of large-scale traumatic events. In this article we document participant reactions to participation in research carried out in the aftermath

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of the September 11, 2001 terrorist attacks on New York City.

Method

Sample

We conducted three random-digit-dial (RDD) household surveys to recruit respondents. The first survey was conducted October 15–November 16, 2001, the second survey was conducted January 15–February 21, 2002, and the third survey was conducted March 25–June 25, 2002. For all surveys, 96% of all persons who started the surveys answered all questions. All surveys were approximately 35 minutes long. The Institutional Review Board at the New York Academy of Medicine approved the study and all study participants provided verbal consent at the time of the interview. Further details on research methods and sample selection are provided elsewhere (Galea et al., 2003).

Measures

In all surveys, we asked about demographic characteristics (age, race–ethnicity, gender, education, yearly household income, and marital status) and assessed if respondents had access to a health insurance and a regular health care provider. We asked respondents if they had any mental health problems in the 12 months prior to September 11, 2001. Respondents' exposure to the September 11th terrorist attacks was evaluated by collecting information on a number of potential exposures and we created a composite variable that summarized whether respondents were directly affected by the event.

We identified cases of probable PTSD using a modified version of the National Women's Study (NWS) PTSD module (Kilpatrick et al., 1998), based on the *Diagnostic and Statistical Manual of Mental Disorders, Third Edition Revised* (*DSM-III-R*; American Psychiatric Association, 1987). This PTSD scale is designed for administration by trained, nonclinical interviewers and has been used in a number of large-scale mental health surveys (Acierno et al., 2000; Boscarino, et al., 2004a; Galea, Boscarino, Resnick, & Vlahov, 2003; Galea et al., 2003). We used a modified, validated version of the Structured Clinical Interview for *DSM-III-R*—Non-Patient Version (SCID; Spitzer, Williams, & Gibbon, 1987) major depressive episode module to identify cases of probable depression after September 11. In addition to being used in previous surveys focusing on the effects of the September 11 attacks, this scale has also been used in other population surveys (Boscarino et al., 2004a; Galea et al., 2002).

Counseling Backup System

At the end of the interview, we assessed participant reactions to the survey. We asked participants if they found any of the survey questions emotionally upsetting; if participants answered "yes," we asked if they were still feeling emotionally upset or if they were "okay now." Participants who were still upset were asked if they would like a counselor to give them a call. At that time we also collected the participant's name, address, and telephone number and provided assurance that this information was being collected only for the purposes of counselor follow-up and would not be associated with study responses in any way. Participants who wished to be contacted by a counselor were given the option of either having a mental health professional contact them immediately to provide assistance or of being contacted the following business morning. A licensed psychiatrist who was a member of the research team carried a pager throughout the course of the study; the psychiatrist was paged by the interviewers if any respondents needed immediate assistance. Respondents who asked for assistance the next day were asked what time they would prefer to be contacted. Licensed PhD-level clinical psychologists, also part of the research team, contacted the participant at the requested time. Mental health professionals contacting the respondents used their clinical judgment in arranging follow-up or further contact with respondents as needed and the disposition of those cases were not recorded by the study. All counseling was offered by members of our team free of charge to participants.

Statistical Analyses

Sampling weights were developed and applied to correct for potential selection bias relating to the number of household telephones, persons in the household, and over-sampling. For all three surveys and the aggregate sample we calculated the percentage of total respondents who found any of the survey questions emotionally upsetting, the percentage of persons who found questions emotionally upsetting who were still feeling emotionally upset at the end of the interview, and the percentage of persons who were still feeling emotionally upset at the end of the interview and requested assistance from a counselor. Using data from Survey 3, we used two-tailed chi-squared statistics to test for associations between key covariates and the likelihood of finding survey questions emotionally upsetting.

Table 1. Respondents Who Reported Distress After Participating in Research in the First Year After the September 11 Attacks

	6–8 weeks[a]		4–5 months[a]		6–9 months[a]		Totals[b]		
	N	%	*N*	%	*N*	%	*N*	%	% of total sample
Survey questions were emotionally upsetting									
Total	1,008		2,011		2,755		5,774		
Yes	149	15	268	13	329	12	746	13	
No	847	84	1,732	86	2,414	88	4,993	86	
Still feeling emotionally upset at the end of the interview									
Total	149		268		329		746		
Yes	16	11	19	7	22	7	57	8	1.0
No	132	89	246	92	306	93	684	92	
Wants assistance from a counselor									
Total	16		19		22		57		
Yes	6	38	8	42	5	23	19	33	0.3
No	10	62	11	58	17	77	38	67	

[a]Respondents from surveys conducted 6–8 weeks, 4–5 months, and 6–9 months after September 11, 2001. [b]Additional respondents requesting assistance not represented in the data: 6–8 weeks: 1; 4–5 months: 4; 6–9 months: 5.

Results

Overall, we analyzed results from 1,008 adults in Survey 1, 2,011 adults in Survey 2, and 2,755 adults in Survey 3. As shown in Table 1, the prevalence of persons who found any of the survey questions emotionally upsetting was 15% for Survey 1, 13% for Survey 2, and 12% for Survey 3. Among those who said that they were upset by the survey questions, the prevalence of still feeling emotionally upset at the end of the interview was 11% for Survey 1, 7% for Survey 2, and 7% for Survey 3. Among persons who were still feeling emotionally upset at the end of the interview, assistance from a counselor was requested by 38% for Survey 1, 42% for Survey 2, and 23% for Survey 3. For the aggregate sample ($N = 5{,}774$), 746 respondents (13%) said that they found the survey questions emotionally upsetting, 57 respondents (1% overall) were still upset at the end of the interview, and 19 respondents (0.3% overall) wanted assistance from a counselor. Ten persons who were emotionally upset early in the interview did not complete the surveys, and received counselor assistance.

Among 2,755 respondents in Survey 3, the current prevalence of probable PTSD related to the September 11 attacks was 1.6% and the prevalence of probable PTSD since and related to the September 11 attacks was 7.9%. The current prevalence of probable depression was 4.1% and the prevalence of probable depression since the September 11 attacks was 11.1%. Nine point six percent (9.6%) of Survey 3 respondents reported a previous mental health problem in the past 12 months. Factors associated ($p < .05$) with a greater likelihood of finding any of the survey questions emotionally upsetting included (a) being aged 45–64, (b) female gender, (c) not being married, (d) not having health insurance or a regular health care provider, (e) being directly affected by the September 11 attacks, (f) having current probable PTSD or probable PTSD since the attacks, (g) having current probable depression or probable depression since the attacks, and (h) reporting previous mental health problems in the past 12 months (data not shown).

Discussion

Overall, we found that the level of emotional distress after three assessments conducted within a year of the September 11 terrorist attacks was relatively modest. The proportion of the aggregate sample (13%) reporting that the surveys were upsetting was well within the range of distress related to research described by participants in studies of the psychological consequences of exposure to interpersonal violence (Henderson & Jorm, 1990; Jorm et al., 1994; Newman et al., 1999; Walker, Newman, Koss, & Bernstein, 1997).

In accord with other research (Griffin, Resnick, Waldrop, & Mechanic, 2003), we found that feelings of emotional distress experienced during our survey were short-lived and rarely persisted beyond the assessment itself; only 8% of persons who indicated that they found survey questions emotionally upsetting (1% of the aggregate sample) reported that they still felt emotionally upset at the end of the interview. We also found that the prevalence of finding questions emotionally upsetting decreased slightly as more time elapsed since September 11, from 15% at 1–2 months to 12% at 6–9 months after

September 11. Other studies have suggested that assessments conducted more recently after a traumatic event may produce greater levels of distress among participants (Boscarino et al., 2004b) and our results provide preliminary evidence for this notion.

Persons who were more directly affected by the September 11 attacks were more likely to find survey questions emotionally upsetting. These findings substantiate those from prior studies that indicate that persons with greater traumatic event exposure or injury severity are more likely to experience distress during research participation (Newman et al., 1999). Almost 45% of our respondents with current probable PTSD found survey questions emotionally upsetting compared to only 12% of those without current probable PTSD. Similarly, for depression, we found that 27% of respondents with current probable depression found questions emotionally upsetting compared to only 11% of those without current probable depression. Consistent with previous work we also found that women may be more likely to report distress during research participation (Ruzek & Zatzick, 2000).

There were limitations to this assessment. First, it is plausible that persons who were most psychologically affected by the disaster did not participate in the surveys reported here, and that those persons might be more significantly affected by research in the postdisaster context. However, given that such persons would be less likely to participate in disaster research in general, we suggest that our findings are generalizable to most postdisaster general population research. Second, it is possible that respondents who were most emotionally upset by survey questions were more likely to terminate interviews prematurely, thereby preventing them from answering questions concerning their reactions to the assessment and from being included in these analyses. However, 96% of all persons who started the three surveys completed them, and as such this limitation probably did not substantially influence observed levels of emotional distress. Third, we note that our assessment made use of a self-report measure to assess participant distress. It is possible that our measure was not sensitive enough to detect participant distress or that participants may have underreported distress.

With caveats considered, our findings suggest that participation in a general population survey assessing the mental health effects of the September 11 terrorist attacks was well tolerated by the majority of respondents. The presence of a small number of respondents who requested mental health assistance, however, suggests that a mental health backup system is needed for research conducted soon after a large-scale traumatic event.

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