

Abstract

This article describes a human rights investigation designed to identify bodies exhumed from mass graves in Srebrenica, Bosnia-Herzegovina and the psychological impact of participation on family members, most of whom believed the disappeared could still be alive. A community education intervention, conducted in both group and individual settings, was effective in helping families make an informed decision about participation. For informed participants, the psychological benefits outweighed any deleterious effects. The article concludes that fully disclosing the truth to potential participants, providing culturally and temporally sensitive psychosocial preparation, and securing informed consent are basic ethical and human rights principles that must be upheld at all times. Further studies are necessary to measure the impact of human rights activities of this nature on the survivor participants and implementers alike.

Cet article décrit une enquête sur les droits de la personne ayant pour but d'identifier les corps exhumés des charniers de Srebrenica en Bosnie-Herzégovine et l'impact psychologique créé par la participation sur les membres de la famille, la plupart d'entre eux espérant toujours que le disparu soit encore vivant. Une intervention par le biais d'une éducation communautaire, conduite à la fois dans des situations de groupe et individuelles, a été efficace pour aider les familles à prendre une décision informée quant à la participation. Pour les participants bien informés, les avantages psychologiques l'ont emporté sur tous les effets nuisibles. L'article conclut que la divulgation complète de la vérité aux participants éventuels, l'apport d'une préparation psychosociale sensible sur le plan culturel et temporel et l'obtention d'un consentement éclairé sont des principes de base du point de vue éthique et des droits de la personne qui doivent être respectés en permanence. Des études complémentaires sont nécessaires pour mesurer l'impact des activités relatives aux droits de la personne de cette nature sur les participants survivants et exécutants.

En este artículo se describe una investigación sobre derechos humanos orientada a identificar cadáveres exhumados de tumbas en masa en Srebrenica, Bosnia-Herzegovina y el impacto psicológico de la participación por parte de miembros de las familias afectadas, la mayoría de los cuales creían que los desaparecidos podían aún estar vivos. Un programa de educación individual y en grupo, fue efectivo para ayudar a las familias a tomar decisiones con conocimiento de causa sobre su participación. Para los participantes que gozaban de ese conocimiento, los beneficios psicológicos pesaron más que cualquier otro efecto. El artículo concluye que el revelar completamente la verdad a los potenciales participantes, preparándolos psicológicamente sobre las diferencias culturales y situacionales, y el contar con un consentimiento informado son principios éticos elementales y de derechos humanos que deben ser siempre tenidos en cuenta. Se requiere de más estudios para medir el impacto de este tipo de actividades sobre los derechos humanos tanto de los participantes supervivientes como de las personas que las implementan.

DISCLOSING THE TRUTH: Informed Participation in the Antemortem Database Project for Survivors of Srebrenica

Mary Ellen Keough, Sara Kahn, and Andrej Andrejevic

In June 1996, Physicians for Human Rights (PHR), under contract with the International Criminal Tribunal for the Former Yugoslavia (ICTY), sponsored a team of international forensic scientists to unearth the remains from the mass executions committed during the fall of the former UN "safe area" of Srebrenica in July 1995. The initial purpose had been to conduct postmortem examinations to determine the cause and manner of death, for use in the prosecution of indicted war criminals. It became apparent, however, that the information could also help families from Srebrenica learn the ultimate fate of relatives who had disappeared in the fall of Srebrenica, bringing an end to uncertainty. The need for closure, to exercise the rituals of grieving and burial with dignity, is fundamental to all cultures and societies.¹ Supporting this belief is the United Nations General Assembly's adoption of the Declaration on the Protection of All Persons from Enforced Disappearance.² Article 18(1) of the Declaration states that investigations of a case of "disappearance" should be able to be conducted for as long as the fate of the victim remains unknown.³ The Declaration also guarantees the victim's family the rights to complain to a competent and independent state authority

Mary Ellen Keough, MPH, was the director of the Bosnia Antemortem Database of Physicians for Human Rights. Sara Kahn, MSW, MPH, was the psychosocial coordinator for the Bosnia Antemortem Database and is now the director of the Cross-Cultural Counseling Center. Andrej Andrejevic is the data manager and programmer for the Bosnia Antemortem Database. Please address correspondence to the authors care of Physicians for Human Rights, 100 Boylston Street, Suite 702, Boston, MA 02116 USA.

Copyright © 2000 by the President and Fellows of Harvard College.

and to be informed of the findings of an investigation.⁴ PHR fully supports these rights, but it also recognizes the potential risk that realization of these rights poses to families' mental and physical well-being. Attempting to mentally prepare families for participation in the process of investigating the missing is critical and just.

Following the exhumation of the mass graves in and around Srebrenica, PHR developed a project to help identify the recovered bodies. It was determined that in order to produce identifications, data would need to be collected from families about their missing relatives for later comparison with data collected from the exhumed bodies.

Complexities soon emerged, however, revealing the multiple challenges of implementing a policy of full disclosure—i.e., that the interviews would help to identify the *dead*—with a vulnerable community who steadfastly maintained hope that their missing were still *alive*. This article describes an evaluation of participants that was designed to examine the potential retraumatization resulting from participation in interviews in which full disclosure of purpose was given and informed consent secured. To the knowledge of the authors, no previous studies have addressed this issue.

Background

Established in 1993 as the first-ever UN safe area, by 1995 the town of Srebrenica had swelled from 9000 to nearly 60,000 persons, most of whom were Muslims who had been ethnically-cleansed from their own towns in other regions of Bosnia by Serb forces. Despite the presence of Dutch UN peacekeepers, Serb tanks invaded the town on July 6, 1995. During the next few days, amid cries for NATO air strikes by officials witnessing the mounting crisis, Serb forces rounded up approximately 3000 men and boys of military age, most of whom were civilians, and placed them on buses for deportation to sites where they were to be questioned for alleged involvement in war crimes. Approximately 5000 other men and boys attempted escape on the only road out of Srebrenica, a journey that would be dubbed by one survivor as “The Marathon of Death.”⁵ Thousands of others reportedly sought refuge in the forests surrounding the town.

Women, children, and the elderly were shepherded by Serb forces onto separate buses that dropped them in Tisca, nine kilometers short of the Muslim-held safe city of Kladanj, where they were eventually transported to the relative safety of Tuzla. Here, they waited for husbands, brothers, sons, and fathers who never returned. The International Committee of the Red Cross (ICRC) lists approximately 7350 persons missing from the fall of Srebrenica in July 1995, accounting for almost 38% of the war's missing.⁶

In August 1995, aerial imagery of the parcel of land surrounding Srebrenica revealed evidence of graves.⁷ Concurrently, a handful of survivors told of mass executions of the men and boys at various locales. The ICTY mobilized teams of forensic experts, including teams sponsored by PHR, to find and exhume the graves. In July 1996, with four sites identified, the initial exhumations were begun.

The Antemortem Database Project (AMDB)

From the beginning of the exhumations, two confounding factors were strikingly apparent. First, most of the recovered bodies were male, similar in age, stature, and other identifying characteristics. Second, only a small percentage of those recovered had been found with identification documents, and, even when present, documents alone could not be considered conclusive proof of identity. The forensic anthropology professionals agreed that another level of investigation was needed. Antemortem data—detailed descriptions of clothing, physical characteristics, medical history, and personal effects of missing persons before their disappearance—would be matched with postmortem data collected from autopsies of the remains to support the identification. In order to facilitate this process, PHR began the development of an antemortem database—a computerized database comprised of information collected both from families of the missing and from postmortem examinations of the remains. The computer would be used to link these two pools of data, thereby narrowing the field of potential matches between particular remains and particular families. From these initial computer matches, more complete investigations would be conducted, including the

use of DNA analysis in some instances. In order to increase the chances of eventual identifications, it was hoped that all Srebrenica survivors would be located and interviewed for the database. No comparable project of this scope had ever before been attempted.

Phase One

From the beginning, PHR published information in Bosnian and English describing its goal of assisting in identifying bodies. During the project's initial phase, from July 1996 through June 1997, PHR managed the computerized database and the postmortem examinations. The Ludwig Boltzmann Institute directed and implemented the family interview component. The assumption during this first phase was that most families believed their missing relatives were still alive, and that they should, accordingly, be shielded from the truth: that the information collected in the antemortem interviews would be used to identify the dead. It was also feared that disclosing the truth could adversely effect participation. Therefore, no participants were told of the purpose of the interview, and none were asked to give informed consent.

Srebrenica families had been relocated to the cities of Tuzla, Sarajevo, and surrounding villages. Bosnian interviewers secured lists of names of resettled Srebrenica families from officials and traveled to many of these small villages. Because the families had no telephones, interviewers arrived unannounced, explained the project briefly, and requested that a family member take approximately 90 minutes to describe intimate details of their missing relative(s). During this phase, approximately 3100 Srebrenica families participated in the interviews, which had been designed to address the unique circumstances of the Srebrenica disappearances.

No formal evaluation of the reaction of the participating families to the interviews was conducted during this initial phase. Feedback from a survey on the effectiveness of written information about the project, however, indicated that only 10% of the 64 persons surveyed believed the inter-

views would be used to help identify bodies from mass graves.⁸ Others believed the information would be used to locate missing persons who were still alive.

Phase Two: Project Reassessment

In the summer of 1997, PHR accepted sole responsibility for both the data collection and computer management of the database. A reassessment of the project was undertaken, and family interviews were temporarily suspended.

In a focus group, Bosnian interviewers admitted that they had been afraid to fully explain the purpose of the data collection for fear of destroying the only hope that sustained Srebrenica survivors, most of whom were living in the bleakest of circumstances. Even uttering the words “identification of bodies,” the interviewers worried, could ruin the fragile foundation upon which families relied for their psychological survival. The interviewers—all of whom had been affected by the recent war—wished to protect the families, and *themselves*, from confronting a terrible reality. As one interviewer put it, “we did not wish to be the ‘messengers of doom.’”⁹

The reasons for these concerns sprung from a complex social tapestry. Most families interviewed revealed a belief that their missing relatives were being detained in a Serb labor camp, or were living in the forest, and would someday return. These beliefs persisted despite a lack of any substantial evidence to suggest that any of the missing were alive. Even Bosnian government officials had publicly stated that most of the missing were probably deceased.¹⁰ This persistent belief phenomenon can be explained through several factors: (1) the majority of survivors had not actually witnessed the execution of their family members; (2) there were a scant number (approximately 1000) of recovered bodies compared with the thousands of missing persons; and (3) the Srebrenica community lacked trust in their government and the international community as a result of the failure to intervene in 1995 to maintain Srebrenica as a safe area.

These families’ beliefs were fueled further by false reports in a local newspaper, which spouted headlines such as “1500 Muslim Men and Boys Discovered in Serb Labor

Camp.” In addition, a story circulated in almost every village about a bedraggled, stray survivor from World War II who returned to his family 10 or even 20 years after the war had ended. Opportunists swept through villages with promises to retrieve missing persons for a fee. Destitute families scraped together the bounty, only to be devastated when the erstwhile savior never returned.

In addition, the ICRC delivered death notifications to some families based on information in tracing requests for missing persons, but were unable to produce bodies to confirm the death and permit burial rites.¹¹ These death notifications incited increased distrust of the international community. On many occasions, PHR interviewers were present in a village when the ICRC’s white vehicle approached; they watched while family members became agitated or fell ill in dreadful anticipation of the news that a son, husband, brother, or father was presumed dead.

PHR also utilized white vehicles for transporting staff, and families often associated these vehicles with news of death. PHR interviewers often spent the first several moments of interaction with family members differentiating their task from that of the ICRC and responding to extreme anxiety—and sometimes anger—among the family and neighbors.

A New Methodology

Based on the project reassessment, PHR established two broad goals: (1) to employ the concept of informed participation by conveying the true purpose of the interviews and inviting families to make a choice whether or not to participate, and (2) to help mitigate any negative consequences of informed participation.

Community Intervention and Interviewer Preparation

To attain its new goals, PHR staff initiated a community outreach and education campaign aimed at Srebrenica survivors. Bosnian interviewers were coached to step out of their narrow role of “survey-takers” and actively lead the process. First, PHR staff held meetings with community leaders, Muslim clergy, and Bosnian mental health profes-

sionals working with the families of Srebrenica to discuss the exhumations and the antemortem database project and to solicit their concerns and advice. Bosnian community leaders and professionals urged the use of the broadcast media to begin to penetrate the collective denial of the families in the least intrusive manner, followed by multimedia presentations to small groups on the purpose of the interviews and the processes involved in identifications.

In response to these suggestions, educational materials describing the identification process were developed, including a video, a slide presentation, and a variety of written brochures with pictures (since many of the families could not read), such as a special brochure to help parents talk about the interviews with their children. Community representatives provided feedback on content and optimal implementation strategies.

Concurrently, staff received additional training in standardized interviewing techniques, patterns of psychological trauma, and basic trauma intervention and counseling skills to assist them in managing predictably emotional interactions with families. In order to enhance their understanding of how antemortem information could contribute to the identification of bodies, and thus to be able to explain the procedure to families more clearly, interviewers observed postmortem examinations and comparisons with antemortem information. Interviewers also participated in training sessions wherein their own reactions to the war, and their concerns about telling the whole truth to families, could be aired and addressed. In the end, interviewers agreed that families had the right to be fully informed.

Next, local television and radio stations broadcast panel discussions and an educational video to help explain the purpose of the antemortem database and to encourage participation. On one such broadcast, a Muslim imam, or cleric, and a Bosnian psychiatrist discussed the spiritual and psychological impact of living with uncertainty about a loved one's fate, and the importance of identifying recovered bodies for moral and spiritual reasons. To keep expectations realistic, the announcements acknowledged that participation in the project would not bring answers to all families.

The number of recovered bodies was growing, but still small. In the end, only the presence of a body could generate leads or clues for an identification.

Following the media campaign, PHR interview staff piloted an approach using small-group meetings and multi-media presentations designed to fully inform families about the purpose of the AMDB project, prepare families for the types of questions to expect and the possible emotional ramifications of the interview, and create an opportunity for family members to decline participation, if they so chose. To assess the impact of participation, some families received a follow-up evaluation visit within two to three weeks. The possibility of this second visit was discussed with families at the time of the initial survey.

Pilot Intervention

The town of Rosulje was selected for piloting this community strategy, since it was representative of other communities where survivors lived, and the town's representatives were willing to help.

The first meeting in Rosulje included both formal and informal community leaders and the local imam. PHR interview staff and the Psychosocial Coordinator explained the project and its purpose, utilizing drawings and the educational video. A question-and-answer period followed. PHR staff asked the attendees for their help in scheduling several small group presentations for family members. Later in the week, PHR staff discussed the identification process and family interviews on local radio.

Over the next five weeks, PHR staff conducted nine small group presentations. Families were invited to schedule interviews for later in the week; only a few were absent from their homes when the interviewer returned at the appointed time. Of the 52 families participating in AMDB interviews, 13 received follow-up evaluation visits.

The apparent success of the Rosulje model led this approach to be used in other communities of similar demographics, and it became the standard intervention throughout the remainder of the data collection period. The content of the approach to families remained the same, whether

delivered by interviewers using videos or by oral presentations in group or individual meetings in the communities.

Evaluation Survey and Methodology

Of primary concern in implementing the revised AMDB strategy was the risk of retraumatizing participating families by discussing their missing loved ones in intimate detail, with no promise of a definitive outcome. With the evaluation tool, PHR staff sought to measure both negative and positive impacts of participation in the AMDB interview—for example, did participants experience any physical, emotional, or behavioral changes or disruptions in their daily activities that may have been caused by the stress of responding to the AMDB survey items? Did participants experience the interview as helpful, were they satisfied with the process, and would they recommend participation to others? In addition, PHR staff sought to assess the usefulness of the community education campaign in helping both to prepare participants for the interview and to mitigate the potentially retraumatizing aspects of participation.

Many participants were oriented to the project through both community presentations and individual interactions with the interviewers during home visits. The follow-up questionnaire was designed to help determine through self-reporting: (1) if the AMDB community education effort had imparted information to the participants to increase their understanding of the purpose of the project, and specifically how the data were going to be used; (2) families' motivation for participating in a process which held no promises of finding missing relatives; (3) the immediate impact of participation in the AMDB collection process; and (4) the quality and effectiveness of the interviews.

By the end of February 1999, 6150 families with missing relatives from Srebrenica had been interviewed. A total of 98 families (1.5%) received follow-up evaluations, 13 of which were from Rosulje, the remainder from other demographically similar communities. Eighty of those (81.6%) had attended a community educational presentation. Eighteen of the 98 (18.4%) who had received a follow-up evaluation had not attended a community presentation.

Implementation of the follow-up evaluation survey, a secondary task to the main priority of antemortem data collection, presented particular challenges. It was decided that adherence to strict, scientific sampling and methods of data collection could not be accomplished in this setting. The evaluation sample was chosen based on availability of the families in their communities and the interviewers' time needed to seek out families for follow-up visits that took a minimum of an hour. Many families lived in rural areas without telephones, necessitating drop-in visits. Therefore, with the exception of the pilot community, Rosulje, where 25% of the AMDB families were revisited, no sample target population was identified for the survey. Support for the revisits had been secured from participants at the time of the initial interview, when they were informed that the interviewers would return to some families for follow-up visits. Time and resource constraints prevented extensive revisiting, necessitating that the sample size be kept small.

In addition, PHR interviewers were concerned that the follow-up visit not be perceived by family members as burdensome or painful. Staff became attached to the families they interviewed, and they wanted to communicate a sincere interest in their well being. They feared that arriving with another survey would serve to alienate the families. Consequently, PHR interviewers did not display the survey during the revisit, but instead used a one-page prompt sheet to weave memorized questions into a more relaxed conversational setting. All of the data were self-reported. Interviewers recorded the information on the survey immediately upon returning to their vehicles. This method resulted in some missing data, but fostered a more open discussion.

Although this approach represents a non-standardized method of data collection, it served to provide the project with information to be incorporated into future planning and helped to determine the emotional cost to families participating. Because of the small numbers (1.5% sample), the data in most instances are presented in the aggregate; differences between cases and controls are too small to measure for statistical significance.

Results

Effectiveness of Information Campaign and Understanding of the AMDB

Of the 98 respondents, 90 (91.8%) were female, of which 25.5% were mothers of the missing and 55% were wives. The remaining respondents were sisters, daughters, brothers, sons, and fathers. The age of respondents ranged from 20 to 74 years.

Participants were asked what their understanding was of how the information from the AMDB was going to be used. Sixty-four percent of those who had attended a presentation and 50% of those who had received only individual orientations responded correctly. Many still believed that the data would be used to find live missing persons, a category selected by 32.05% of the attendees and 27.78% of the non-attendees. This finding may indicate psychological denial, or perhaps simply the profoundly human experience that, without proof of death, families hold onto the hope that a missing relative is still, somehow, alive.

Community presentations proved to be more effective than radio and television programming in reaching the population. A total of 84.2% of those evaluated reported no exposure to the AMDB project from either radio or TV.

When participants were asked if they had heard about the project from someone else, however, 41.25% of those who had attended presentations and 61.1% of those not attending reported yes. This may support the value of word-of-mouth and informal community networks for those who have no other access to information.

We asked the families if the community presentation had helped to prepare them for the antemortem interview. Of the 80 attendees, 92.5% replied "yes," 6.25% replied "no," and one individual replied "didn't know."

Reasons for Choosing to Participate

The three reasons for participating in the interview cited most often by both those who had attended a community presentation and those who had not were: (1) the need to know the destiny of a missing person, (2) to help find a missing person, and (3) to help to identify all bodies.

Another less-frequently stated reason was that the antemortem data collection process gave participants a chance to tell their story.

Impact of Participation on Family Members

Assessment of the psychological, emotional, and functional impact of participation in the antemortem interviews showed some similar reactions between those who had attended a community presentation and those who had not.

Self-reported data showed an increase in specific symptoms as read from a list by the interviewer. The results are shown in Figure 1. The three most reported effects from the combined groups were presence of headaches (18.6%), increased fatigue (17.5%), and feeling more sad than usual (7.2%). It is important to note that while there were several symptoms reported among the 98 respondents, 30 respondents (30.6%) reported no symptoms.

There were two related questions regarding the immediate and short-term impact of the AMDB interview on the participant's functioning. The first asked whether the participants proceeded with their normal daily activities on the day of the interview or did something unusual. Seventy-

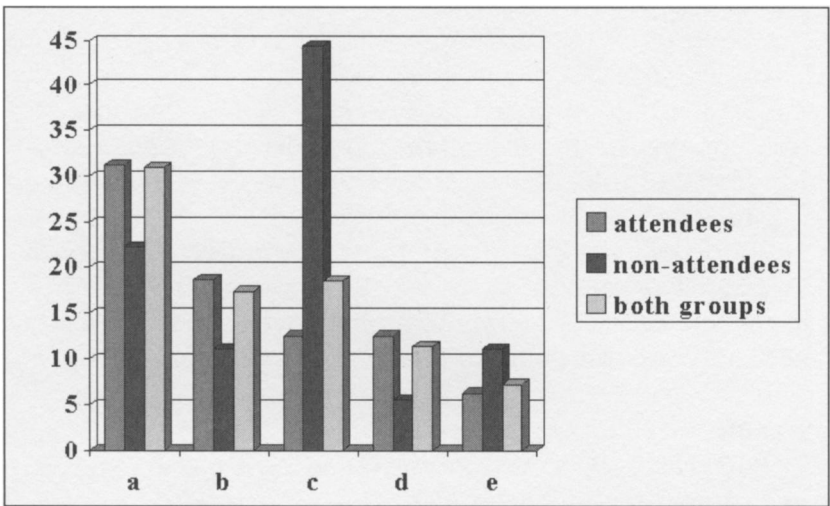


Figure 1. Responses to the following question: "Have you noticed, either on the day of the interview or since then, any of the following: a = no change, b = more fatigue than usual, c = more headaches than usual, d = crying more than before, e = feeling more sad than before?"

eight of the 80 who had attended presentations responded. Of these, 94.9% responded that they continued with their usual daily activities. Among the non-attendees, 68.8% did so, giving a combined figure of 90.4% for all participants.

The second question asked whether or not the participants had noticed any changes in their daily activity during the weeks following the interview. Among the attendees, 97.4% of those responding noticed no changes between the time of the original interview and the follow-up evaluation interview. Among the non-attendees, 88.2% reported no change, giving a combined figure of 96.8% for all participants.

Open-ended questions in this area, however, generated descriptive comments that substantiated the responses to the symptoms question. When asked how they had been since the initial AMDB interviews, some participants responded as follows:

- “Always when I speak about my missing person, about everything that happened, I don’t feel very well; I am sad, I cry.”
- “Strange. It is so difficult [to take,] the fact that one day this information will be used for identification of my father.”
- “I feel like before; my husband is every day in my mind. After [the] interview, [for] two–three days, I lost my appetite; after a few days I had normal appetite.”
- “I feel good. I feel better because I told PHR my story.”
- “Several nights I couldn’t sleep and I had bad dreams.”
- “I am worried. It’s so difficult when every night I watch and listen [for] information about mass graves. I began to lose hope that my husband is alive.”
- “I feel afraid. I feel bad, as before, I am still in hope that my sons are alive, and one of the three of them will return.”
- “The same day and after I felt bad. Now I feel better because I have to live for my children.”

Perception of Participation as Helpful

The perceived impact of the interview process on an individual was assessed in two other ways. Interviewers

asked if talking about the missing person throughout the AMDB collection process had been helpful to the family. Of the 91.8% responding from both groups, 77.8% said yes, 17.8% said no, and 4.4% said they did not know. Comments such as "I feel better when I know that someone is trying to find my missing sons" were recorded. Conversely, one who responded no commented: "My pain is the same."

Participants were asked if they had regrets about having participated. Only one of the 97 respondents replied "yes," and one replied "don't know." Similarly, 98.9% of those responding reported that they would recommend participation to a friend or neighbor.

Interviewer Effectiveness and Support of the AMDB Project

Regarding interviewer knowledge and preparedness, 100% of the 88 who responded from both groups said yes when asked if the interviewer had been able to answer all of the families' questions. Similarly, 98.9% said the interviewer was able to clearly explain the purpose of the project.

Families overwhelmingly supported the antemortem data collection process. In the end, over 80% (6150) of those who reported missing persons from the fall of Srebrenica were located through community outreach efforts and interviewed to obtain antemortem data. Few refusals were reported by interviewers, and follow-up inquiries regarding regrets about participating and willingness to recommend participation to friends confirm strong support. The biggest challenge was not achieving voluntary participation, but rather locating families from Srebrenica, who were scattered throughout Bosnia-Herzegovina.

Beliefs about the Destiny of the Missing Person

When asked what they believed the destiny of their missing relative to be, 55.1% replied "unknown," 14.3% believed the missing person(s) to be alive, and 30.6% believed the person to be dead.

Expectations of the Project

Interviewers asked what the respondents' expectations were of the project now. Themes of truth and destiny came

forth. Closure—an end to the waiting, regardless of the outcome—is desperately sought, as evidenced by the following comments:

- “I want PHR to bring me some information, but with proof.”
- “To bring some result, whatever it is.”
- “I expect to know the destiny of our missing persons and find out the truth.”
- “To identify bodies that are already found.”
- “I hope that this uncertainty will stop.”
- “I hope that this uncertainty will end. If my sons are dead, I want to bury them with dignity, and then I can go [to] their graves, where I can pray for them with my grandchildren.”

Discussion

Giving people the opportunity to speak about their personal grief, to tell their own story, can be perceived as cathartic or may instead be interpreted as opening old wounds for no apparent benefit. The issue of retraumatizing an already severely affected population has remained in the forefront during this lengthy and sometimes futile identification process. As of December 1999, 70 identifications of persons missing from Srebrenica had been made, two of those based on the AMDB.

Despite the numerous reports of immediate and short-term emotional and physical effects of participation, the need to learn the truth, to find missing relatives, and even to fulfill a perceived duty to the missing, appear to be stronger driving forces for families.

When asked why they would recommend participation to someone else, numerous responses contained the refrain of needing to know the truth: “Because everyone is interested to finally find out the truth.” “It’s time for truth.” “To know the destiny of our missing persons and to find out how many people disappeared when Srebrenica fell.”

One of the most poignant statistics from the follow-up survey relates to destiny, a word used during almost every family’s interview. After three years, and even longer in

many cases, over half of the families were not able or willing to state an assumption that their loved one was deceased. Despite PHR's attempt to present objective, factual information that over 1000 bodies had at that time been exhumed and not yet identified, many families still held that the destiny of *their* loved one could not yet be determined. In the absence of physical evidence, there is an overriding hope and faith that the missing are still alive. This phenomenon should be viewed as essentially human. In the absence of a body, accepting that a missing relative is dead is tantamount to committing a psychic murder of a loved one.

The new policy of full disclosure employed by interviewers in all settings, whether at community presentations or in homes where individual families were hearing of the purpose of the AMDB for the first time, was effective in providing accurate information to families. The evaluation shows a notable change in understanding of the purposes and use of the data from the days prior to the implementation of the policy of full disclosure. The education process emphasized that identification of bodies was the purpose, not finding missing persons. A sample of those interviewed in March 1997, before the full disclosure process was implemented, showed only 10% understood that the data were to be used to identify bodies. Following the intervention, that number had increased to 64.1% among those who had attended community presentations and 50% among those who were oriented individually by the PHR interviewers.

In relation to the traumatic effects of the antemortem interview process, interviewers and respondents alike regularly commented that there was no choice but to go on with normal activities. A frequent comment was, "What else can we do?" There are few alternatives for affected families who might wish to take time out. Most must continue with the struggles of day-to-day living as they learn to cope with a changed family structure, frequently without men and with minimal subsistence resources or external support.

This analysis demonstrates the need for ongoing technical training and psychological support for human rights workers who intervene with traumatized communities.

Interviewers reported that they often wished they worked on a project that delivered food or supplies to families, so that they could offer tangible help with tangible benefits. Instead, they asked questions of a deeply intimate and painful nature but could provide nothing definitive in return, at least in the short term.

Although the results of the evaluation survey and observations from the field suggest that families of the missing have their own methods for psychological survival, great care should be taken to assess and prepare for the impact of the interaction on both the worker and the survivor. While it may seem compassionate and humane on the surface, withholding information in an effort to protect survivors undermines both dignity and rights related to self-determination. The formal and informal data described here reveal that providing survivors with truthful information and strong community-based psychosocial preparation—thereby enabling them to decide for themselves what to believe and how to behave—is basic to human rights. No respondent reported that his or her hope had been destroyed by participation. Furthermore, the benefits of participation in an effort to uncover the ultimate truth about the destiny of at least some of the Srebrenica missing cannot be underestimated.

Recommendations

PHR fully supports the rights of families to know the fate of their missing relatives. The Draft International Convention on the Protection of All Persons from Enforced Disappearance, although not yet adopted by the United Nations, also guarantees the victim's family the rights to a competent and independent State authority and to be informed of the findings of an investigation, among other rights.¹² It is the responsibility of governments to put into place the mechanisms necessary to establish and enforce those rights, and of nongovernmental organizations and human rights groups to pressure them to do so.

It is also the responsibility of the human rights community, while attempting to foster the rights of families and victims, to anticipate the positive and negative psychologi-

cal impact of a given intervention or investigation upon the affected group—as well as the interviewer or investigator—so that programmatic responses may be designed accordingly. Community involvement in planning and implementation not only lends cultural and psychological sensitivity to both content and design of such projects, but may also be viewed as an ethical and moral mandate.

Information should be both gathered and disclosed in a manner that will minimize the potentially negative impact of the interaction. Unavoidable negative consequences of disclosing painful material should be openly acknowledged and discussed. Therefore, the practice of fully disclosing the truth and enabling survivors to make an informed choice regarding participation in a human rights investigation, can be viewed in and of itself as upholding the survivors' essential human rights.

While the difficulties of measuring the implications of participation are numerous, there is a need for further studies including more scientific assessments that seek to understand the ways in which human rights activities may inadvertently affect a community of survivors and the international and national human rights workers who are involved.

Acknowledgments

The authors wish to acknowledge the following people for their assistance: the families of Srebrenica; the AMDB field interviewer staff; the data entry staff; Edita Dedic for translation; Sejdefa Salkic for historical information; Laurie Vollen, MD, MPH, Director for Physicians for Human Rights Bosnia Projects; Doug Ford, JD, Deputy Director for Physicians for Human Rights Bosnia Projects; Harvey Weinstein, MD; Laurie Seidel, Stanford University Center for Research in Disease Prevention; and the Physicians for Human Rights Boston staff, especially Leonard Rubenstein, Susannah Sirkin, Barbara Ayotte, and Amida Tea, for editing and technical support.

The Antemortem Database Project was funded by the European Union and The International Commission on Missing Persons.

References

1. S. Sirkin, V. Iacopino, M. Grodin, and Y. Danieli, "The Role of Health Professionals in Protecting and Promoting Human Rights: A Paradigm for Professional Responsibility," in: Y. Danieli et al. (eds.), *The Universal Declaration of Human Rights: Fifty Years and Beyond* (Amityville, NY: Baywood, 1998), pp. 357–66.
2. Declaration on the Protection of All Persons from Enforced Disappearance, GA Res. 47/133 (18 December 1992).
3. Declaration on the Protection of All Persons from Enforced Disappearance (see note 2), art. 18(1).
4. Declaration on the Protection of All Persons from Enforced Disappearance (see note 2), art. 1(2), 13(1).
5. D. Rohde, *Endgame: The Betrayal and Fall of Srebrenica* (New York: Farrar, Straus and Giroux, 1997), p. 180.
6. *ICRC Special Report: The Issue of Missing Persons in Bosnia and Herzegovina, Croatia and the Federal Republic of Yugoslavia* (ICRC, 1998), p. 14. The percentage of total missing is found in Rohde (see note 5), p. 350.
7. Rohde (see note 5), p. ix.
8. Physicians for Human Rights Bosnia Projects, Publications and Information Processes Survey, March 1997.
9. Focus group with Bosnian interview staff, Tuzla, Bosnia, July 1997.
10. A. Masovic, President of the Bosnian Commission on Missing Persons, 1997.
11. A. Williamson, "Bearing the News," *Red Cross, Red Crescent* 1997, 1.
12. Draft International Convention on the Protection of All Persons from Forced Disappearance, E/CN.4/Sub.2/1998/25, August 1998, art. 13(1), 13(4), 24(3).