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Advice From Bereaved Parents: On Forming Partnerships for Injury Prevention

Deborah C. Girasek, PhD, MPH

We set out to learn whether, and how, parents of children who were fatally injured want to collaborate with injury prevention professionals. In this exploratory study, interviews were conducted with parents who had been identified through medical examiner files. Only a small minority of those we contacted chose to participate. The six mothers and five fathers who did felt that survivors should be offered such opportunities. They suggested waiting, however, at least a year before approaching parents. Our interviewees endorsed medical examiner's offices, health care providers, and police as legitimate avenues for identifying potential partners. They suggested that contact should first be made by mail. Professionals were encouraged to be sensitive, responsive, and realistic regarding the limits of our science. From a practical perspective, safety experts' contacts and political savvy appealed to respondents. Parents also expressed the need for coaching, and gentle understanding of the pain they live with every day.

Keywords: injury prevention; bereaved parents; advocacy; survivors

I don't think that any parent who has been through this would ever wish this kind of pain on their worst enemy. And I mean that literally. If somebody came and knifed me, I wouldn't want him to lose his child. It is just the most horrific experience. . . . So to reach out to other parents and say, "Here is a small way you can prevent that," any parent would want to do that.

—A bereaved mother

► BACKGROUND

There are many reasons why professionals promoting injury control might want to collaborate with families who have suffered the loss of a child. One primary reason is to advance prevention policies that have received empirical support. Many of the field's most

effective countermeasures have come in the form of legislation (e.g., primary seat belt laws, minimum drinking age laws) and/or regulation (e.g., requiring manufacturers to build more crashworthy cars, adopting building codes that mandate smoke detectors). Savvy safety advocates have acknowledged that efforts spearheaded by injury survivors can be very powerful (Bergman, 1992; Brown, 1993). The Mothers Against Drunk Driving (MADD) movement may be the most well-known example of this phenomenon; however, campaigns against gun violence, unsafe cribs, drawstrings on children's clothing (i.e., a strangulation hazard), car trunk entrapment, pool drownings, and brain injury have all been launched by survivor-advocates. Survivors can humanize a policy issue, bringing injury statistics home to those in positions to make change. Indeed, a recently published framework for public health advocacy lists victims among process participants (Christoffel, 2000). That framework's author pointed out that such contributors can "bear witness, lobby, testify and vote."

Safety advocates may find it particularly advantageous to align with injury survivors to draw media attention to their cause. The media have been called "the primary force setting the agenda for politicians" (Brown, 1993). Professionals hoping to get their message out through such channels learn quickly that they must communicate "dramatically through visuals" (Klepper, 1984), providing journalists with the human interest element they seek (Meyer, 1990). Family members of an injury victim may also represent a local angle for media coverage. They may enhance an advocacy organization's ability to take advantage of breaking news, or to get a story aired on the anniversary of an event. For all of these reasons, public health profession-

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als seeking media access have been advised to show “the face of the victim” in telling their story (Pertschuk, 1990; Wallack, Dorfman, Jernigan, & Themba, 1993).

There is also scientific evidence that suggests that risk perceptions must sometimes be increased if we hope to promote safer behavior (Arkin, 1989; Janz & Becker, 1984; Weinstein, 1988, 1992). The health belief model and the precaution adoption process incorporate a personal susceptibility construct; that is, they posit that people are unlikely to take action against a threat unless they feel it can happen to them. Campaigns that feature survivors may enhance viewers’ sense of identification, and hence their feelings of vulnerability. The public information director of a children’s bicycle helmet campaign has reported that local newspaper articles that told the so-called proverbial victim story were her most successful means of reaching parents (Rogers, 1988). The scientific literature supports the notion that risk perception is increased when identifiable versus statistical victims are associated with hazards (Covello, McCallum, & Pavlova, 1989).

It is important to note that taking part in prevention work may also be therapeutic for injury survivors. Because of space limitations, however, that issue along with reasons bereaved parents might want to avoid advocacy work have been addressed elsewhere (Girasek, 2003).

I believe this is the first study to ask parents who have lost children to injury how they would like to collaborate with professionals to prevent future injuries. Because of this work’s exploratory nature, qualitative methods were deemed most appropriate. Qualitative methods enable professionals to understand topics from the respondent’s perspective. They typically use purposive rather than random sampling, which means that participants are selected based on their ability to inform the investigator (Goering & Streiner, 1996). Because understanding someone else’s experience requires in-depth communication, qualitative methods usually involve smaller sample sizes than do quantitative studies. This approach is in keeping with calls that have been made for more qualitative study of injury prevention (H. Roberts, 1997).

METHOD

When this research and its materials were first designed, they were presented to a focus group of seven parents who had lost children to injury to ensure that our proposed procedures were appropriate and sensi-

tive. We asked the group to review our plan for identifying families, our recruitment letter, and interview questions. Participants discussed how bereaved parents would likely answer our questions and whether study involvement posed potential risks to them. Group members had no concerns about what we planned to do. They did suggest that we only approach parents if their child’s injury-producing event had some conceivable link to a potential prevention campaign. Prior to making contact with actual study participants, our protocol was also approved by the Institutional Review Boards (IRB) of my university and the health department of the state in which our data were collected.

Potential study participants were identified through the chief medical examiner’s office of one state on the Atlantic coast of the United States. A review was made of all deaths ruled accidental among persons younger than age 18 years in 1995 and 1997. Cases were eliminated if names and addresses for a parent or guardian were not listed in the medical examiner’s file, if insufficient details were available to suggest a preventive strategy, if the child or parent lived in another state, if the child was a fetus at the time of death, or if she or he had died more than 1 year after the injury-producing event.

Recruitment letters were sent to 97 eligible households in January of 2000. Approximately one third of those letters were returned because of expired addresses, leaving 68 households in our potential sample. Three months after the first mailing, a reminder letter was sent to parents who had not responded. No further (i.e., telephone) contact was permitted because of IRB concerns.

Recruitment letters were signed by the state’s chief medical examiner. They alerted parents that he had been contacted by a researcher who wanted to learn “what survivors think about getting involved in injury prevention efforts.” They were told that they would not be asked to take part in a prevention program, just to give their opinions about them. Parents were also informed that the goal of the study was for prevention efforts to be “effective, yet sensitive and respectful to all whose lives they touch.”

Potential participants were told that the researcher was willing to come to their neighborhood. In eight instances, parents chose to be interviewed in their homes. Two chose their places of work, and one participant wanted to come to the principal investigator’s (PI’s) university. All interviews were conducted in private, by the PI (a middle-aged White woman). The six volunteers who were married to other participants (i.e., three parent couples) were interviewed separately. They had no opportunity to discuss their responses with each other in advance. Informed consent was obtained prior to data collection. Interviews were audiotaped and lasted 1 to 2 hours. The discussion was guided by a set of questions that explored the participant’s experience with injury prevention campaigns, their views on a range of such activities, and their advice for professionals who hoped to collaborate with

survivor-parents. When the interview was finished, participants completed a brief demographic questionnaire and were paid U.S. \$25.

Interview tapes were transcribed, and explored using NVivo⁸ software for qualitative data analysis. The PI read through all transcripts and coded passages that were responsive to specific research questions (i.e., What advice would you give to an injury control professional who wanted to collaborate with surviving parents?). Nvivo⁸ facilitated navigation through this narrative because it allows for search and retrieval by code or keyword. Major themes that emerged from this process are outlined in the Results section.

To explore how the parents who did not respond to our request for volunteers might have differed from study participants, we calculated relative risks (RRs) and 95% confidence intervals (CIs) for the prevalence of known characteristics within both groups.

► RESULTS

In this section, we describe our interviewees and present a summary of the advice they asked us to pass on to injury control professionals hoping to collaborate with parent-advocates.

Sample

Six mothers and five fathers completed interviews for the current study, representing approximately 12% of the households assumed to have received our invitation. Participants and nonresponders did not differ with regard to whether their child's record contained mentions of risk behaviors (e.g., lack of restraint use, speeding), the time since their child's death (i.e., 3 vs. 5 years), their children's ages, nor their children's genders. Parents of deceased boys were approximately 5 times more likely agree to study participation than were parents of deceased girls; however, the 95% CI for this relative risk included 1 (RR = 4.7, 95% CI = 0.6 to 34.5).

Seven of our 11 interviewees were between the age 46 and 55 years, while the remainder were age 36 and 45 years. Nine of our participants were White, one was Hispanic, and one was African American. Six of the parents we spoke to had college degrees or had received higher education. Three had some college, one a high school diploma, and one had not finished high school. Five respondents had household incomes that met or exceeded U.S. \$90,000 a year. Four of the remaining volunteers had incomes spread evenly between \$35,000 and \$90,000 per annum. One participant earned between \$5,000 and \$10,000 per year, and one reported a household income of less than \$5,000 per year. The parents we spoke to represented seven sons and one daughter who, at the time of their deaths, ranged in age from 1 to 17 years (0 = 11.5). Four of the children had been killed in motor vehicle crashes, one was asphyxiated, one drowned, one died in a farming accident, and one died in a train collision. Six of the deaths had

Key Points

The parents we spoke to suggested that professionals

- wait at least a year postdeath before approaching survivors about advocacy work
- identify parents through medical examiners, health care providers, or law enforcement officials, rather than the media
- initiate contact with families via letter or a veteran survivor-parent, not by telephone
- put parents at ease, taking time to earn their trust and honor their child's memory
- justify the preventive strategy you want parents to promote, without exaggerating its effectiveness
- make multiple methods of participation available to parents, so that they can contribute on a level that feels comfortable to them
- expand parents' understanding of how policy is made and facilitate their access to the people who make it
- provide opportunities for parents to rehearse public remarks in advance, and to practice maintaining control of interview situations
- remember that parents who have lost children to injury have themselves been gravely injured. Strive to take actions and offer services that address their unmet needs

occurred 5 years previous to the interview, and five had taken place 3 years before.

Approaching Parents

All of the parents we spoke to felt that it was appropriate and desirable for professional advocates to approach survivors about contributing to prevention work. Because of acute grief that would make participation impossible early on, however, interviewees advised that potential partners not be approached within the 1st year of their child's death.

I would say easily a year. Because it takes a year to get through all of the firsts. I mean they may look like they are doing fine after 6 months, and then bam they will get hit by the kid's birthday.

The actual time it takes families to feel ready was reported to vary greatly. After it had passed, however, the common view was that professionals

shouldn't leave them alone and shouldn't be a pain in the butt about it. But something needs to be done to bridge that gap, that says, "It is here and it is available. If you want to do it, let us know."

When asked about advisable means of approach, most respondents felt that working through a medical examiner's office was appropriate. That office was viewed as legitimate, as was identifying families

through hospitals or the police. Many parents said that they would not like to be contacted directly by the media. Being contacted by letter appealed to all respondents. It did not put them on the spot and gave them time to consider the request carefully. Phone requests were characterized as “a little bit intrusive, sort of like a shock.”

A couple of participants recommended that first contact should be made by a veteran survivor-parent. One specifically mentioned The Compassionate Friends (a national self-help organization for families who are grieving the death of a child) as a means of identifying potential partners for this work.

Setting the Tone

It was clear that professionals hoping to work with bereaved parents would need to invest time gaining the family’s trust and demonstrating that they were safe people to get close to.

People can see through [professionals who go into it with an attitude that it’s just a job]. A professional has to have some degree of caring, and they have to be able to show openly that, “I’m doing this because I want to help, not just because it’s a livelihood,” or “I’m doing some kind of study for MIT,” or whatever. The parent has to know that this person wants to do as much good as the parents themselves want.

Parents held their child’s memory in reverence. Many participants, for example, wanted the interviewer to see their child’s photo or read poems written by classmates in his or her honor. One mother described an encounter in which legislators were disrespectful as “the only time I ever felt that it didn’t matter that Stephen was dead.” Her husband, discussing another incident recounted,

There were a couple of senators eating potato chips, like they were just passing the day away. I couldn’t believe it when you are speaking about a son who has died and everything and they are sitting there talking and eating chips.

Another mother explained,

For me to share my experience with someone is very difficult. It is almost like you are walking on sacred ground. And I don’t let too many people in. So just walk very, very softly.

Interviewees advised taking steps to put families at ease, such as meeting in the parent’s environment. Professionals were also cautioned to listen carefully for cues as to readiness for participation.

You have to listen to them, and you have to be receptive to that. You have to know when to pull and know when to push, and that is a tough job.

I think you would need to first ask them, “Are you strong enough?” You know. “Your nose maybe be rubbed into what happened. They may think you faulted somewhere. Can you take it?” Put right up front what this road can entail. “This could happen. And when we are finished, this is what we could achieve.”

When discussing how to avoid putting parents on the defensive, a couple of participants suggested talking about prevention with regard to the future, as opposed to “going back to that day.” And some parents suggested we use moderation in extolling the state of our science.

You can reduce the amount of tragedies that would occur in that particular way (but) to say . . . 100% reduction, that’ll never happen. . . . You might get someone to work with you if you say to them, “Well look, we’d like to have fewer of these.”

Being Parent Centered

It seemed important to understand how the family had come to terms with the death and to respect their interpretation of what had transpired. Respondents often had to make sense of events that they experienced as random.

I believe in fate too. You can never go back and say if I did this or I did that. It was an accident. It happened. It just happened. Now he had a girl in the car with him. She had not a scratch on her. Nothing. But my son was killed.

The fatalism that many families had developed in an effort to make peace with what had happened was not associated with an unwillingness to engage in prevention efforts. Parents did, however, say that they would need to understand the rationale behind the preventive strategy we wanted them to endorse.

Respondents were clear that for participation to be centered on the needs of the survivors, professionals would need to be flexible and responsive. One way of doing this would be to offer different levels of involvement, allowing families to participate in whatever way that felt comfortable to them. The mom who got a manufacturer to distribute safety brochures explained: “It is something that you can do that doesn’t put you in the limelight necessarily. . . . It doesn’t make you be a public speaker when you are not.”

One father felt that prevention programs should include information on what to expect after the fatal injuries that will occur, do occur.

We are taught to deal with grief as if it is our parents who die way before us. But that child is not supposed to die before me. He shouldn’t do that. But he did. And then how do you deal with it? Nobody discusses that. Nobody talks about it. Nobody touches it. It is like it is taboo. It is an emotional injury that people don’t know how to deal with. You know I can put a

Band-Aid on a cut, but how do I put a Band-Aid on your brain?

This father suggested that crisis intervention teams be set up around the country to visit families who lose children unexpectedly. He felt they could include police or clergy but should definitely include survivor-parents.

Resources and Opportunities That We Might Offer Parents

Professional advocates were sought as partners for their perceived understanding of the policy process: “It would be very enticing to work with an already established organization who knows how to do some of these things I am floundering in the dark doing.” That speaker called for a Web-based clearinghouse that parents could contact to lobby on injury-related issues throughout the country. It would name legislators who could be counted on to champion injury prevention, provide sample legislative language, and so on.

Because unfortunately there may be another child who dies the same way that Isaac¹ died, and some other mom is going to have to do all of this homework on her own.

It was suggested that professional collaborators might have contacts or allies whom they could leverage on behalf of surviving parents. For example, one mother had gotten a neighbor who was a television reporter to call off aggressive journalists. And her lawyer got his professional organization to support a bill she favored.

Most respondents felt that having opportunities to rehearse their remarks, in advance of public or media testimony, would be useful. They endorsed this method as a stress reducer and confidence builder. They also spoke specifically of needing help with setting limits (about what they would discuss), and to practice segues should the discussion take a turn that made them uncomfortable. Parents needed to feel that they could set the tone and direction of their public remarks.

Interviewees likened the professional’s role vis-à-vis theirs as that of a coach. They admitted that energy and focus were still problematic for them at times. “It would be nice to have someone who isn’t in the throws of this coming in and saying, ‘Here, let’s do this.’ . . . Someone that would work with you to keep you sort of on track.”

Lending Support to Parents

Parents also felt that professionals could help them deal with the frustration, discouragement, and disillusionment that advocacy sometimes engendered.

Nancy [a lobbyist] said, “Now be prepared. It takes 7 years to get a bill through. Don’t be upset if it doesn’t pass.” [Interviewer: “Do you think it helped you to kind of know that ahead?”] “Oh, absolutely. I would

have been crushed. Because [the legislators] were so positive and responsive to me when I testified. And I thought, it is passed. And then I get the word, it didn’t pass.”

A number of parents described the notion of having “back up” as comforting: “You are not just one person trying to change the world.”

Just listening was endorsed by a number of respondents as the appropriate response to take when parents are discussing something painful, or uncomfortable for the professional. Plus, more than one parent cautioned that collaborators should not take parents’ mood swings personally.

Even after 5 years, I have bad days when all I want to do is sit around and cry. And if someone I was working with on some legislation were to call me, I would be very abrupt with them. I would not want to talk to them. I would hang up. . . . I allow myself a day now and then. And if I am working with an accident prevention group, they have to allow me a day now and then too.

Misinterpretation of this pattern can lead to isolation that is painful to grieving families: “There are people I have known my whole life, and when they see me in the supermarket now they walk the other way. They don’t know what to say.”

Anniversaries of the death, and missing milestones (i.e., graduation of the class their child should have been in) can be very difficult for bereaved families. Professionals may want to acknowledge such times with a card or note: “The day of his accident is always a real tough day. I am grouchy and nasty, and my wife wants to pack the kids up and go someplace else for that day”; “Every Mother’s Day, I would really rather just sleep through it.”

It is important to remember that parents who give every indication of having recovered are harboring a permanent injury.

Maybe that is the thing. To remember and not to ever forget that these are parents that have lost children. Because believe me, they never do. On a minute-by-minute, hour by hour, day-by-day basis, I never once forget that I have lost a son. . . . Back then [before the accident] I always had two boys that I had to keep track of and where they were and what they were doing and their activities. And now, I have, you know, a 16-year-old and a dead son. And I always have that. There is never a time when I can just lie back and be happy and forget that. . . . And you can never forget that I have a dead son. I mean you can be talking to me and . . . you know, I am normal and I am whole and I am healthy. I walk and I talk and we have fun and everything else. And [the people in my life] can forget that I have a dead son, but I never can. And that is something that if you are going to work with parents who have lost children, you are going to have to remember forever and ever.

► DISCUSSION

The current study suggests how potential safety advocates residing within the community of bereaved parents may prefer to work with public health and injury control professionals. Although qualitative research methods are not designed with the goal of generalization, there are indications that what we learned from this sample may be valid for a wider population of survivors. Many of their themes were echoed—almost verbatim—by the bereaved parents (from another state) who took part in our planning focus group. Our sample's views are also supported by published accounts of the grieving parent's experience (Bernstein, 1998; DeVries, Lana, & Falck, 1994; Finkbeiner, 1996; Nixon & Pearn, 1977; Rando, 1986; Rosof, 1994).

Although qualitative methods seek answers to questions such as why, rather than how many (Pope & Mays, 1995), we were struck by the proportion of parents who chose not to take part in the current study. It is not clear that this finding reflects survivor attitudes toward prevention work per se. Researchers trying to recruit bereaved parents for other purposes have also reported low response rates (Lehman & Wortman, 1987; Oliver & Fallat, 1995; Vassar & Grogan, 1995; Videka-Sherman, 1982). It is possible that nonresponders are at an earlier stage of reorganizing their lives in response to their children's deaths. The bereavement literature suggests that survivor grief following the sudden death of a loved one often extends beyond 5 years and that the pain of mourning may actually increase in Years 2 and 3 postdeath (Lord, 1996). Although the comparisons we were able to make between study participants and nonresponders did not reveal significant differences, we could not evaluate the two groups' psychological functioning or attitudes toward injury prevention. It is possible that those survivors who did take part in the current study resemble the parents we would encounter if we asked for volunteers to help us in our work. Their relatively high socioeconomic status is consistent with the profile of parents whom I. Roberts (1995) described as being "prepared for advocacy." Such speculation could only be verified, however, with a larger study.

While we await additional data on injury survivors, professionals can find guidance on how to partner with affected parents in the disability literature (Zirpoli, Wieck, Hancox, & Skarnulis, 1994). Cunconan-Lahr and Brotherson (1996) used methods that were similar to our own in identifying supports and barriers to successful parent advocacy. Relevant resources have also been published on crime victims (National Center for Victims of Crime, 2002; U.S. Department of Justice, 1998). General advice on interacting with bereaved parents is also available (The Compassionate Friends, 2003; Lehman, Ellard, & Wortman, 1986).

Perhaps most encouraging, however, are recent initiatives launched by the Trauma Foundation in San Francisco. They devoted an entire issue of their newsletter to the topic of injury-survivor advocacy

(McLoughlin & Fennell, 2000) and have also dedicated space on their Web site to facilitating collaboration between survivors and professionals (www.tf.org/tf/advocates/advocate1.shtml).

For the most part, however, professionals interested in promoting injury prevention have not engaged in dialogue with surviving family members. Hopefully this work will increase our sensitivity to their needs and enhance our ability to build more effective partnerships. It may also motivate us in our work to remember that fatal injuries leave lifetimes of pain in their wake.

NOTE

1. All of the names used in this article have been changed.

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