

represent approximately 20,000 devastated parents. Whereas experiencing the death of any loved one is painful, parental bereavement is recognized as exceptionally severe (Davis, Wortman, Lehman, & Silver, 2000; Rando, 1986a; Rosof, 1994; Videka-Sherman & Lieberman, 1985) and resistant to resolution (Hazzard, Weston, & Gutterres, 1992; Lehman, Wortman, & Williams, 1987). There is also considerable evidence that relatives of people who die suddenly are at risk for experiencing more problematic grief (Davis et al., 2000; Hazzard et al., 1992; Rando, 1996).

Despite the overwhelming anguish that bereaved parents experience, some find it within themselves to champion campaigns aimed at preventing future deaths. National initiatives aimed at preventing drunk driving, drowning, crib deaths, strangulations due to drawstrings, and firearm deaths have all been spearheaded by grieving parents. Professional safety advocates have acknowledged that surviving family members make powerful allies in carrying out such work (Bergman, 1992; Brown, 1993; McLoughlin & Fennell, 2000).

Background

There is evidence to suggest that engaging in advocacy work is therapeutic for survivors. Creating something positive from tragedy and re-orienting one's sense of purpose are forms of making meaning: a process that accompanies grief for the majority of people who are bereaved by trauma (Neimeyer, 2000). Videka-Sherman (1982) found that bereaved parents who were altruistic reported decreased depression and increased personal growth over time. Recounting a traumatic story has also been shown to aid recovery (Lord, 1996; Mercer, Lord, & Frogge, 1998). The fragile nature of parents who have suffered the ultimate loss however, suggests that there may also be risks inherent in "employing" survivors for the purposes of advocacy.

This investigation represents an attempt to identify barriers and benefits that bereaved parents associate with advocacy. No reports on their perspective have been published. The exploratory nature of this work drove its methods.

Method

Prior to undertaking this research, our protocol was reviewed for sensitivity by a focus group of parents who had lost children to injury. It was

also approved by the Institutional Review Boards of the principal investigator's university and the department of health in the state in which data were collected.

Potential participants were identified through a state medical examiner's office. In January of 2000, we sent 68 recruitment letters to parents of children whose accidental deaths occurred in 1995 and 1997. All letters were signed by the state's chief medical examiner and alerted parents that his office had been contacted by a researcher who wanted to "learn what survivors think about getting involved in injury prevention efforts." Interested survivors were instructed to contact the principal investigator (the author) directly.

I conducted all interviews, in private. Informed consent was obtained prior to data collection. Interviews were tape-recorded and lasted 1–2 hours. The discussion was guided by a set of questions that explored the participants' exposure to injury prevention campaigns, whether they had ever been asked to contribute to such a campaign, and whether they would agree, if asked, to engage in escalating levels of preventive work (i.e., providing a photo of their deceased child, providing a videotape, telling their story in a local community setting, giving a media interview, testifying before a legislative body). Finally, parents were asked for reasons that someone in their situation might or might not decide to take part in such activities. When the interview was completed, participants completed a brief demographic questionnaire and were paid \$25.

Interview audiotapes were transcribed and explored using NVivo[©] software. I developed a coding scheme of reasons for and against preventive involvement. It was structured under headings that corresponded with topics covered in the Interviewer's Guide (e.g., "What are some reasons that parents might want to take part in prevention work?"). Response categories were derived directly from the data. As a check on the reliability of this coding scheme, a second reviewer was used to re-code narrative from three interviewees. For each of these transcripts, inter-rater agreement exceeded 90%.

Results

Sample

Approximately 12% of the families who were invited to participate in this study completed interviews. The six mothers and five fathers with

whom we spoke ranged in age from 36 to 55. A majority of interviewees were Caucasian, and reported household incomes that exceeded \$60,000 per year. These parents represented eight children who, at the time of their deaths, ranged in age from 1 to 17 ($M = 11.6$, $SD = 6.5$). Four of the children had been killed in motor vehicle crashes, one was asphyxiated, one drowned, one had died in a farming accident, and one in a train collision.

Engaging in Prevention Work

When asked whether they had ever been approached to participate in prevention work, all interviewees said they had not. Yet virtually every parent went on to describe engaging in activities that could be characterized as injury control education or advocacy (e.g., testifying before the state legislature). When asked whether they would be willing to take part in escalating levels of advocacy activities, most of our interviewees responded affirmatively. Many qualified their answers, however, by saying that they could not have engaged in such work during their earliest stage of bereavement. Acute grief is one of multiple barriers to participation that were raised by the parents we spoke to (see Table 1).

Nonetheless, all of our respondents felt that survivor/parents should be given the opportunity to contribute to safety promotion campaigns. Their views on the benefits that might be associated with such work are summarized in Table 2, with explanatory quotations.

Discussion

Although the parents who took part in this study were generous and articulate, we were struck by the small proportion of invited survivors who chose to participate. Although qualitative research's in-depth approach most typically involves small sample sizes and non-random selection, readers may be wondering whether the parents we spoke to are particularly atypical.

Most investigators attempting to recruit bereaved parents as research participants experience difficulty and often report response rates of less than 50% (Hazzard et al., 1992; Nixon & Pearn, 1977; Oliver & Fallat, 1995; Vassar & Grogan, 1995; Videka-Sherman, 1982). Working with parents of children who had been injured as pedestrians, Ian Roberts

TABLE 1 Barriers to Engaging in Prevention Work Suggested by Bereaved Parents

Category	Example of a supporting quotation
Acute bereavement	<i>"You walk around in a daze for months before you realize where you've been or what you are doing."</i>
Pain re-experienced	<i>"Now I don't go into a lot of detail because when I do it refreshes the pain."</i>
Issues of privacy	<i>"There is a part of Tim that I like to keep just for our family. That is the little boy we knew on a day-to-day basis. I don't know that I want to make that person public."</i>
Desire to maintain composure	<i>"People are afraid of embarrassing themselves in public."</i>
Closed coping style	<i>"I sort of like to dig my own hole and be in pain by myself, thank you very much."</i>
Denial	<i>"They may just be thinking, 'Oh well, my child is just away,' and not dealing with the fact that they are gone forever."</i>
Intimidation	<i>"It has the potential to become a very high profile thing, and rather intense. Speaking to Congress, hotel rooms full of other parents... some folks aren't cut out for that."</i>
Competing commitments	<i>"There wasn't enough of me around. It wasn't until I cleaned up a whole variety of issues in my life that I was able to say, 'Okay, now is a good time.'"</i>
Unresolved litigation	<i>"Our attorney strongly advised us not to do anything until after we had completed this lawsuit."</i>
Fear of reproach	<i>"Once you open up, it sort of invites people. You become a target. And then people start passing judgement, 'You didn't do what you were supposed to do.'"</i>
Conflicting approach to prevention	<i>"I am offended by the holier than thou attitude that most government people seem to have over those of us who live out in the world, that it is their responsibility to legislate to us what needs to be done."</i>
Unaware of avenues	<i>"That is what I kept feeling when Jill died. I wanted to do something to change something to make it better so that no one ever, ever had to feel that again. But I didn't know what to do."</i>
Discouragement	<i>"Why do you have to fight and fight to get somebody to listen to you?"</i>
Negative attitudes towards the media	<i>"My wife is sitting there holding the baby in her arms before they took him away. People are telling me that is what they saw on TV. So scum is what they [i.e., journalists] are in my mind."</i>
Objections of family members	<i>"I talked to [the deceased child's brother] and said, 'Do you have a problem with this? This is going to bring it in your face.'"</i>

(Continued)

TABLE 1 Continued

Category	Example of a supporting quotation
Barrier judged to be illegitimate	
Desire to protect child's reputation	<i>"Maybe they don't want the fact brought out that their kid was drinking when they got into the accident... I mean that could be a reason they don't want to do it, although I think that is a stupid reason."</i>

Note. Any names used in this article have been changed to protect families' confidentiality.

TABLE 2 Reasons for Engaging in Prevention Work Suggested by Bereaved Parents

Category	Example of a supporting quotation
To save other parents from bereavement	<i>"The hardest thing in my life was losing my son. And if it could prevent someone else from going through the same thing, I would probably do most anything."</i>
To save children's lives	<i>"I don't want any more kids getting hurt."</i>
To promote healing	<i>"It helps me to talk about it instead of suffocating."</i>
To give meaning to their tragedy	<i>"[Advocacy work] is worth every minute of it. I mean it just doesn't let your son go down for nothing."</i>
To honor their child	<i>"It would be a type of honoring his memory."</i>
Because they are uniquely qualified	<i>"[Survivor-parents] are the only ones who can make it real, because they have lived the experience. If you're not getting it from them, then you're just getting a fake."</i>
To right a wrong	<i>"I mean my God, I can't believe this. Look how long this has been going on and nobody has come forth to do anything."</i>
To increase awareness of their plight	<i>"I think it is a good thing to get across to people what the parent goes through."</i>
To increase impact of campaign	<i>"I mean it hits home because they can put a face on it."</i>
To meet other bereaved parents	<i>"A lot of programs, it isn't just one person getting up but maybe a couple of people that have shared the same type of ordeal. It's kind of like a support group."</i>
Reasons judged to be illegitimate	
To get attention/publicity	<i>"I think that some people like to be in the limelight."</i>
For financial gain	<i>"Money was never the motivation."</i>

(1995) found that they were less willing to endorse a prevention campaign than were parents of uninjured children. It has been suggested by at least one safety advocate that few families touched by fatal injury will become active in prevention work (McLoughlin & Fennell, 2000). The survivor-parents I spoke with before carrying out this investigation also suggested that only a "very special person" would take on that role. They pointed out that bereaved parents are drawn from the general population, and that few members of the community-at-large become political activists. It may be that the mothers and fathers I spoke to represent that small group, who reside in the community of bereaved parents.

The validity of our findings is supported by how closely our participants' views match those expressed in the focus group convened prior to conducting the interviews, and in published reports of the grieving parent's experience (Bernstein, 1998; DeVries, Lana, & Falck, 1994; Finkbeiner, 1996; Nixon & Pearn, 1977; Pine & Brauer, 1986; Rando, 1986b; Rosof, 1994).

This work was not conducted by a therapist attempting to determine whether participation in prevention campaigns is beneficial or detrimental to bereaved parents. Rather, it is a first attempt to understand what survivors associate with engaging in safety advocacy. Their responses suggest that once acute grief has passed, it may be appropriate to make bereaved parents aware of such opportunities. As one survivor (Ruby, 1996) has suggested:

Don't be overprotective. Survivors need to make decisions that affect their daily lives. Regaining a small sense of control helps them to rebuild their self-identity [*sic*]. At a time when they feel powerless and paralyzed by the destruction of their world, survivors should find something they *can* do...

We hope that the issues raised here help open a dialogue between professionals and the bereaved parents who are looking for that something.

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