

Report of New Research on Pregnancy Loss

by Judith Lasker, Susan Borg,
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When Judy moved to Lehigh University in the fall of 1981, not long after the book was first published, she was fortunate to meet Lori Toedter, a clinical psychologist with extensive survey research experience, who had also recently experienced a miscarriage. It seemed like an ideal team to try to carry out a more systematic investigation into pregnancy loss. The research and experience we wrote about in the first edition of *When Pregnancy Fails* formed the basis for this project. They gave us many valuable insights, but there were many questions for which we wanted more precise answers. Who seems to cope best with loss and why? Which people have the most difficulty, and what can be done to help them? How different is the emotional impact of a miscarriage from that of a stillbirth? Do bereaved parents appreciate the interventions that are being recommended for medical staff to implement? How many people's lives and relationships are significantly changed by the loss?

THE STUDY

A proposal to investigate these questions was submitted to the National Institute of Child Health and Human Development, one of the National Institutes of Health. We were funded for three years and then received additional funding for two more years in order to complete the study.

Many of the physicians and hospital clinic staffs in the area

where we live—the Lehigh Valley, which includes Allentown, Bethlehem, and Easton, Pennsylvania, and the surrounding rural areas—cooperated in the study by referring people to be interviewed. We wanted to be sure that the sample represented all social classes in the region, and therefore we included four hospital obstetrical clinics and a city health bureau as well as eighteen private OB/GYN practices.

At each referral source, one or two people, usually nurses, asked every woman who came in for her checkup in the four to six weeks after a loss if she would be willing to participate in the study. All together, 74.6% of those who were asked were actually interviewed. We compared the social characteristics of people who agreed to those who refused. There were no significant differences between the two, suggesting that the people we interviewed are very much like other women in this region who have suffered losses.

We interviewed a total of 138 women who had experienced losses. This number includes 63 women who had miscarriages, 18 who had ectopic pregnancies, 39 who had stillbirths, and 18 who had losses of newborns. Our study includes approximately 31% of all people who had stillbirths or newborn deaths in the two counties we included during the two years we were collecting referrals.

The women in the study ranged in age from 15 to 42, the average being 28.5 years. The great majority (82.6%) were married. They came from a wide range of social classes and occupations, including students, professionals, housewives, single mothers on welfare, secretaries, and factory workers. Two-thirds came from Western European ethnic origins, and less than six percent were Black or Hispanic, reflecting the makeup of the region. Almost all of those interviewed, in filling out a rating form after the interview, indicated that the experience had been a positive one for them.

The interviewers asked each woman if her partner would be willing to participate in the study. Fifty-six men participated in the interview, or 40.6% of the partners of all women who had a steady partner.

The interview was long, lasting at least three hours and in

some cases much longer. We asked for a description of the circumstances surrounding the loss and the responses of friends, family, and professionals following the loss. We gave people forms to complete which assessed the quality of their relationships with their partners and their social support from others. They also rated their religious involvement, their mental health in general, and their children's responses to the loss. A grief scale reflected emotions specific to the loss. People were also asked about other stresses in their lives, about previous losses, and about their hopes and expectations for the future.

A comparison group of pregnant women and their partners was selected from the same clinics and practices. Two hundred fifteen women and 102 men participated in this part of the study. They were asked all of the same questions except those pertaining to pregnancy loss. The pregnant women were very similar in age, race, marital status, social class, and length of pregnancy to the women who had losses. We did these interviews in order to give us a picture of what people would have been like before the loss, to see how the tragedy changed them. The comparison group also served as a check of the loss group's remembrance of how they felt and how much support they received during the pregnancy. Since the answers of both groups were similar, we have confidence in the validity of the loss group's recall, so that changes due to their loss can be accurately assessed.

The purpose of the study was to follow people over time, to measure both short-term and long-term effects of the loss. Therefore, everyone who participated in the first loss interview was contacted approximately one year later and asked if they would be willing to be interviewed again. This interview was somewhat shorter because it did not include the detailed description of the loss again. One hundred eleven women (80.4%) and thirty-seven men (60.3%) agreed to be interviewed a second time. Some of the original group had moved away or could not be reached; others did not have the time or were not willing to discuss the loss again.

A third wave of interviews is now complete, with people being contacted approximately one year after the second inter-

view, or between twenty-six and thirty months after the loss. In addition, the men and women in the comparison group are being contacted for a second interview, which is timed to fall twenty-six to thirty months following their due date.

In this report, we will summarize what we have found so far from the first round, and highlight a few findings available from the second round.

RESULTS

Grief

Social scientists are still a long way from agreeing on the best way to measure grief; there is some question about whether it can be measured at all. Most people who try to assess levels of grief use indicators of depression or mental and physical symptom checklists. Others use a psychiatric interview and rely on their clinical judgment to decide who is having the most difficulty in coping with bereavement. Based on our review of the literature and our own understanding of grief after pregnancy loss, we constructed a scale of 104 items. This was based on some questions used by other researchers and on twenty-one aspects of grief which we felt to be most important, e.g., shock, sadness, anger, guilt, jealousy. Participants were asked to rate each item on a five-point scale ranging from strongly agree to strongly disagree. After analyzing the results of this scale, we narrowed it down to thirty-three questions that, based on the way people answered them, fell into three distinct categories. We call these *active grief*, *difficulty coping*, and *despair*.

Active grief includes sadness, crying, and missing the baby. This is what some people might call "normal" grief. *Difficulty coping* describes the situation of people who perceive themselves as being more withdrawn from others and as having difficulty functioning in their daily lives. *Despair* is how we describe the feelings of those people who identified most with such statements as "The best part of me died with the baby" and "I feel worthless since he/she died." The people who rated themselves high in *difficulty coping* and *despair* seemed to be the ones having the hardest time and needing the most attention. There

were other people who were very sad about their loss and ranked high on *active grief*, but they indicated from their responses that they were able to function and were not filled with a sense of hopelessness. We expect to find in the second round that these people have coped well with their losses.

It is perhaps not surprising that women had higher average scores than the men. This was particularly striking for "active grief." Yet there was no difference between them on "despair," and there were some men whose scores on "despair" were significantly higher than their wives' scores. It may be that women and men have different styles of responding to loss.

Why did some people report much more intense grief than others? For the grief scale as a whole, women who suffered losses later in pregnancy tended to report more intense responses. Also, the more troubled their relationship was with their partner, the more grief they experienced. The women who described their overall physical health and their emotional state as poor or who felt unsupported by their friends also had the highest levels of grief.

There is a striking difference in the pattern of results for those who had miscarriages and ectopic pregnancies compared to those who suffered stillbirths or infant losses. For the first group, perception of support from friends was the most important determinant of the intensity of grief. Concerns about fertility and about the likelihood of a successful future pregnancy also played a role in the grief of women who had early losses. In addition, the quality of the partner relationship was important. In contrast, the grief of women who had losses in the latter part of the pregnancy was based largely on their assessment of their overall state of physical health, as well as on relationship quality, mental health, and the length of the pregnancy.

Older women and those of higher social class generally had lower grief scores. It may be that they had more resources for coping with their situation. Also, the older women were more likely to already have children, and this seems to have helped some of them cope with the loss.

We were surprised that a history of previous loss was not associated with grief, and for those with stillbirths and newborn

deaths, concerns about fertility or future pregnancies were also not related to grief. This may be because at six or eight weeks after a loss, the event by itself is more important than its possible meaning for the future or in relationship to the past.

In addition to the grief scale, we asked people how often they were overwhelmed by grief. They could check "never," "rarely," "sometimes," or "frequently." Their answers for the first two rounds are given in Table One:

TABLE ONE
"SOMETIMES" OR "FREQUENTLY" OVERWHELMED BY GRIEF

	MISCARRIAGE AND ECTOPIC PREGNANCY		STILLBIRTH AND EARLY INFANT DEATH	
	Women	Men	Women	Men
6-8 weeks after loss	61.7%	33.3%	82.5%	57.7%
14-18 months after loss	34.7	5.6	61.5	29.4

It is striking that in every category, scores are higher for women than for men. On average, men and women with later losses rate their emotions as more intense than do those with early losses. Every group experienced a decline in score between the first interview and the second, but a large number of people were still very much affected by the feelings of bereavement up to a year and a half after the loss. It should be noted that since not everyone who was interviewed in the first round also participated in the second round, comparisons between the two are based on slightly different groups of people.

Help

We asked people what helped them cope with their feelings of grief. Table Two presents the most common responses.

Some interesting contrasts appear in this table. The presence of other children is more consoling to women who have early losses than it is to their partners, while the opposite is true for later losses—the men are more likely to mention their children

TABLE TWO
WHAT HAS HELPED YOU COPE WITH THE LOSS?

	MISCARRIAGE AND ECTOPIC PREGNANCY		STILLBIRTH AND EARLY INFANT DEATH	
	Women	Men	Women	Men
Support of spouse	23.5%	16.6%	26.4%	11.5%
Thinking a pregnancy is still possible	13.5	20.0	3.6	3.8
Presence of other children	16.0	6.6	10.6	15.5
Contact by others who have had a loss	9.8	16.6	15.8	7.7
Supportive friends	9.8	3.3	21.1	7.6
Supportive family	4.9	13.4	21.1	11.4
Keeping busy	7.4	0.0	1.8	15.3
Spiritual beliefs	8.6	6.6	12.4	7.7

than other sources of help. Thinking that another pregnancy is possible helps both men and women with early losses more than it helps men and women who had stillbirths and newborn deaths. And while women in both groups cite the support of their spouses as most important, the men more often list other responses. Apparently women look more to their spouse and friends to help them cope with the loss. Men look to other children (those already living or those who may be born in the future) and to activities to distract them.

Friends, relatives, and professionals all play an important part in helping bereaved parents to recover. We asked people about the kinds of help they received from others following the loss. When we asked who was most helpful to them, the majority said it was their spouse or partner. Table Three shows the results.

It is obvious that the spouse (or partner) is a crucial person in the time following a loss. This is particularly true for the women, as indicated earlier. Family members (parents, in-laws, and sisters in particular) are next in importance. Interestingly, family members also rated high in some people's responses to the question of who was least helpful.

In addition to asking the open-ended questions about who

TABLE THREE
WHO HAS BEEN MOST HELPFUL TO YOU IN DEALING WITH THE LOSS?

	MISCARRIAGE AND ECTOPIC PREGNANCY		STILLBIRTH AND EARLY INFANT DEATH	
	Women	Men	Women	Men
Spouse	62.8%	55.2%	64.7%	46.2%
Family members	18.0	17.2	23.6	30.8
Friends	15.4	6.9	11.8	15.4
Doctor	1.3	10.3	0.0	0.0
No one	2.6	10.3	0.0	7.7

was most and least helpful, we also listed a number of categories of people and asked how helpful each of them was in dealing with the loss. Spouse (or partner) received the highest rating, with relatives, funeral directors, and friends and co-workers next in order. Then came physicians, other bereaved parents, nurses, neighbors, clergy, and last in order, church members.

Professionals play a very important role in the experience of loss. Fortunately, most parents were very satisfied (63.9%) or satisfied (25.3%) with the care they received. When asked if there was anything they wished had been done differently for them, the comments revolved mostly around the desire for more rapid and attentive care, more sensitivity, and a preference not to be in the labor and delivery or maternity area following the loss. Comments such as these were made by just over half the people.

We also gave each person a list of what we called "hospital and ritual experiences" which they might have experienced, a list which was somewhat different for each type of loss. These experiences are generally the ones which have been recommended in this book and incorporated into hospital programs for helping people at the time of the loss. We wanted to know whether people had had these experiences and whether they considered them to be essential for people suffering losses such as theirs. Tables Four and Five show what percentage of each group checked that the experience was essential.

TABLE FOUR
HOSPITAL AND RITUAL EXPERIENCES CONSIDERED ESSENTIAL (Miscarriage and Ectopic Pregnancy)

	MISCARRIAGE		ECTOPIC PREGNANCY	
	Women (63)	Men (23)	Women (18)	Men (7)
Cause of loss explained	85.7%	91.3%	100.0%	85.7%
Grief process explained	82.5	54.5	94.4	28.6
Have lab tests done	63.5	71.4	64.7	60.0
Option of hospital floor	41.7	52.4	64.7	85.7
Contact by chaplain	23.8	28.6	55.6	28.6
Contact by support group	37.1	45.0	55.6	14.3
Contact by social worker	17.7	30.0	33.3	14.3
Know what happened to remains	38.7	18.2	50.0	14.3
See remains of pregnancy	27.4	22.7	16.7	14.3
Baptism	16.7	10.0	6.3	28.6
Other ritual	10.0	10.0	6.7	14.3
Placed on maternity floor	16.4	5.0	11.1	14.3

There were a number of items on the list which were rated as essential by many people who had not actually experienced them. For women who had had stillbirths and newborn deaths, the experiences they would have wanted were: the option of which hospital floor to be placed on; having the grief process explained; contact by chaplain, social worker, or support group; touching and/or holding the baby after death; touching and/or holding the baby while still alive; being alone with the baby after death; being alone with the baby while still alive; and having written materials on loss provided. Large gaps between what had happened and what was desired were also reported by women with early losses on such experiences as having the option of which hospital floor to be placed on, knowing what happened to the remains, explanation of the grief process and the cause of the loss, and contact by a support group. The major areas then in which many bereaved parents do not get what they want are: the opportunity to be with and hold the baby, information about grief and the loss, and contact by supportive

TABLE FIVE
HOSPITAL AND RITUAL EXPERIENCES CONSIDERED ESSENTIAL
(Stillbirth and Newborn Death)

	STILLBIRTH		NEWBORN DEATH	
	Women (39)	Men (17)	Women (18)	Men (9)
Cause of death explained	79.5%	64.7%	88.9%	100.0%
Grief process explained	84.6	56.3	83.3	55.6
See baby while still alive	—	—	94.4	100.0
Touch and/or hold baby while still alive	—	—	94.4	88.9
See baby after death	74.4	64.7	83.3	77.8
Touch and/or hold baby after death	73.5	76.9	83.3	66.7
Provided written materials on loss	76.5	50.0	88.9	66.7
Be alone with baby while still alive	—	—	83.3	66.7
Be alone with baby after death	58.8	76.9	77.8	66.7
Have picture taken	60.6	46.2	83.3	77.8
Picture given to parents	56.3	58.3	83.3	66.7
Baby named by parents	58.8	76.9	83.3	88.9
Baby's name on death certificate	50.0	40.0	81.3	62.5
Keepsakes given to parents	42.4	50.0	83.3	55.6
Funeral service held	55.9	53.8	66.7	55.6
Mother attended funeral	62.5	77.8	81.3	55.6
Burial arranged by parents	56.7	53.8	76.5	55.6
Baptism	54.1	37.5	66.7	66.7
Have autopsy performed	56.8	56.3	43.8	44.4
Memorial service	42.4	53.8	47.1	22.2
Have option of hospital floor	47.4	41.2	66.7	44.4
Contact by chaplain	45.9	33.3	61.1	66.7
Contact by support group	48.6	33.3	61.1	55.6
Contact by social worker	27.8	26.7	61.1	55.6
Placed on maternity floor	21.1	43.8	35.3	55.6

personnel. The one item experienced that was thought undesirable but which often occurred was placement on the maternity floor.

Many parents received counseling from their physicians, nurses, and other hospital personnel following the loss. When asked

what they found most helpful about the counseling, they focused on the sympathetic responses, reassurance about future pregnancies, being told that the parent was not responsible for the loss, assurance that grieving is normal, and the provision of concrete information about the cause of the loss. Insensitivity and lack of information were the most frequent complaints about the responses of professionals.

Changes

We also asked people about the ways in which the loss had changed them and their relationships with others. Table Six gives the answers regarding change in relationship to one's spouse or partner.

What is most notable about this table is that there is little change over time, with similar percentages in each category at both the first and the second interview. The only exception is women who had stillbirths and newborn deaths, some of whom apparently experienced a deterioration in their relationships during the time between the two interviews. For the most part, however, people said the experience had brought them closer

TABLE SIX
HOW HAS THE LOSS AFFECTED YOUR RELATIONSHIP WITH YOUR SPOUSE OR PARTNER?

	MISCARRIAGE AND ECTOPIC PREGNANCY		STILLBIRTH AND EARLY INFANT DEATH	
	Women	Men	Women	Men
Positive Change				
6-8 weeks after loss	56.6%	49.8%	80.8%	66.8%
14-18 months after loss	58.3	47.3	61.5	69.2
Negative Change				
6-8 weeks after loss	15.1	13.6	8.5	19.2
14-18 months after loss	13.9	10.5	28.2	7.7
No Change				
6-8 weeks after loss	28.3	36.4	10.6	14.3
14-18 months after loss	27.8	42.2	10.3	23.1

together and made them more appreciative of each other. Those who referred to negative changes mentioned that they were having more arguments and more difficulty talking to each other. Four of the women (3.6%) had separated from their partners.

Relationships with other people were not affected as much as was the relationship to spouse or partner. Most people said that their other relationships had not changed, and this was even more true for the second interview than for the first. Although some people did indicate a deterioration of their relationships with others, more of those who thought there had been a change said they felt closer to friends and relatives and more appreciative of them because of the loss. Twenty-six percent of the women who experienced stillbirths and newborn deaths reported this positive change at the time of both interviews.

We also asked people how the loss changed their attitude to religion. Again, the majority responded that there was no change. People who experienced losses later in pregnancy reported more change, both positive and negative, in their attitude toward religion than did those who had early losses. In both groups, early and late, the men spoke of more positive changes at the time of the first interview (e.g., beliefs strengthened, closer to the church) than did the women, who were more likely to say that they had lost faith and were angry with God. By the second interview, the opposite pattern appeared, with the men's accounts of greater faith dropping, and the women's increasing. Some people mentioned that they were initially angry with God but that this did not last, and it may be that some of the women in particular turned back to faith and to their church over time.

We also asked people how they felt the loss had changed them, and as Table Seven shows, most of the responses suggested a positive change. Although the bereaved parents were distressed by their experiences, most of them looked at what they had gained from the tragedy.

TABLE SEVEN
CHANGES IN ONESELF AS A RESULT OF THE LOSS*

	MISCARRIAGE AND ECTOPIC PREGNANCY		STILLBIRTH AND EARLY INFANT DEATH	
	Women	Men	Women	Men
More appreciative of life, of family, of spouse	39.3%	43.3%	49.2%	61.3%
More understanding of losses and sympathetic to others	17.2	13.2	30.1	23.0
More aware of fragility and insecurity of life	14.9	13.2	17.8	15.4
Stronger, experienced personal growth	17.2	3.3	7.2	11.5
More in touch with feelings	8.6	6.6	3.6	3.8
More depressed, irritable	15.9	0.0	14.2	18.6
More cautious about pregnancy	8.6	6.6	7.1	3.8

*Since the question was open-ended and it was possible to give more than one answer, the percentages may add up to more than 100%.

The last question we asked in the interview was what advice the parents would give to others experiencing similar losses. The advice took on a very positive tone, one of sympathy, encouragement, and understanding.

The bereaved people we interviewed clearly recognized the value of seeking support from others. Talking with friends about feelings can help parents enormously in coping with their grief. This coincides with our finding that women who were highest on the dimensions of despair and difficulty coping were those who felt least supported by friends.

A striking result in this study is that although many people felt that contact by a chaplain would be helpful, very few said that their religious faith was important in dealing with grief. Being more religious did not make grief any less intense; clergy and church members were not considered very helpful; and spiritual beliefs were rarely mentioned as important tools for coping.

TABLE EIGHT

WHAT WOULD BE YOUR ADVICE TO SOMEONE EXPERIENCING A LOSS SUCH AS YOURS?*

	MISCARRIAGE AND ECTOPIC PREGNANCY		STILLBIRTH AND EARLY INFANT DEATH	
	Women	Men	Women	Men
Rely on and talk to others	59.1%	46.6%	79.1%	72.8%
Be positive, put it in perspective, go on with your life, hang in there, you'll survive	32.0	56.5	32.0	53.5
Accept grieving, know your needs, it will get better, everyone grieves in own way, you're not alone	19.8	23.3	24.8	19.1
Don't blame yourself	23.5	20.1	10.7	7.6
Try again	23.4	10.0	5.4	11.5
Rely on faith	9.8	6.6	8.9	7.6
Get good medical care, understanding doctor	4.8	0.0	5.3	0.0

*Since the question was open-ended and it was possible to give more than one answer, the percentages may add up to more than 100%.

When we returned for the second interview, fourteen to eighteen months after the loss, just over half the women were pregnant or had already given birth. Another ten percent had had a subsequent loss, one woman had adopted a child, and most of the others were planning to or trying to become pregnant. By the third interview (twenty-six to thirty months after the loss) many more women had given birth successfully, some more than once.

Friends and relatives do help, and so does time. We have seen by the second interview, and even more so by the third, that people were much less likely to feel overwhelmed by their loss. The memories are there, but the intensity and frequency of feelings have diminished. Some are finding it difficult to go on, but most people are looking ahead to new babies, career changes, and continuing the ongoing pattern of their lives.

APPENDIX A

Support Groups for Families After Miscarriage, Ectopic Pregnancy, Stillbirth, and Infant Death

NATIONAL SUPPORT ORGANIZATIONS

SHARE
c/o Sister Jane Marie Lamb
St. Elizabeth's Hospital
211 S. 3rd St.
Belleville, IL 62222
(618) 234-2120

The most complete source of information on local support groups and resources of all kinds

The Compassionate Friends, Inc.
National Headquarters
P. O. Box 3696
Oak Brook, IL 60522
(312) 990-0010

A self-help organization of bereaved parents helping each other; local chapters exist throughout the world

National Sudden Infant Death Syndrome Foundation
8200 Professional Place, Suite 104
Landover, MD 20785
(301) 459-3388

Information and referral for parents regarding crib death

LOCAL SUPPORT GROUPS

Alabama

SHARE
Family Resource Center
2914 Linden Avenue
Birmingham, AL 35209
(205) 879-1717
Marty Eason
(205) 967-3706

AMI Brookwood Hospital
c/o Elaine Hickman, Chaplain
2010 Brookwood Medical Center Drive
Birmingham, AL 35209