Peer reviewed article

Loss of a preterm infant: psychological aspects in parents

A qualitative study

Annette Glaser[a], *Hans Ulrich Bucher*[b], *Hanspeter Moergeli*[a], *Jean-Claude Fauchère*[b], *Stefan Buechi*[a]

[a] Psychiatric Department, University Hospital Zurich, Switzerland
[b] Clinic of Neonatology, University Hospital Zurich, Switzerland

Summary

Questions under study: The unexpected death of a preterm infant is an extremely painful situation for parents. Despite a number of quantitative studies, little is known about parents' inner experience. The aim of this study was to gather more in-depth information about what preoccupies parents in this situation of suffering, thus leading to a deeper understanding of their dealing with the stressful event and enabling more adequate support to be provided by professionals.

Principles, Methods: 10 mothers and 9 fathers, who had lost their extremely premature infant born between 24 and 26 weeks of gestation were invited for a semi-structured interview and retrospectively asked about their emotional, cognitive, physical and social experience at three different points in time (time of hospitalisation, 6 months and 3.5–6.5 years after the loss). The interviews were analysed by method of qualitative context analysis.

Results: The loss of a preterm infant is an extremely intense experience for parents resulting in a rollercoaster of emotions and perceptions as well as relevant effects on the social network. The strain of this situation notwithstanding, parents also experience positive aspects, eg, feelings of closeness to their infant, comforting thoughts or help from their social network. Although still mourning the loss of their baby, most parents have overcome the tragic event.

Conclusions: Most parents seem to have the psychological strength to overcome the traumatic experience of losing their premature infant and are able to face life normally again. Professionals can play an important role in supporting them. Some parents require additional help to overcome the loss.

Key words: extreme prematurity; sudden loss; resilience; death; qualitative study; professional support

Introduction

Losing one's own child is probably the most painful situation a human being can experience. Whilst the death of an older child forces parents to let go of a relationship characterised by a high level of emotional investment with a well established bond, the loss of a preterm infant means losing a potential relationship full of hope and expectations for the future [1]. After weeks and months of waiting, hopes are shattered, often within a few hours or days. Something, that has not even started, is interrupted unexpectedly and the order of life is violated in a brutal way [2].

Studies done in the past show that losing a prematurely born baby, due to stillbirth or sudden infant death syndrome (SIDS) usually generates a tremendous amount of psychological distress in parents, eg, depression, anxiety and despair, especially during the first months after the loss [3–5]. Despite the severity of the symptoms during this initial period, most parents seem to recover from the traumatic event and do not develop chronic mental health problems over time [2, 3, 6]. Only Hunfeld [4] found that after the diagnosis of a lethal foetal anomaly, mothers still showed a clinically significant degree of general psychological distress 4 years later. Likewise, mothers usually show significantly stronger and longer lasting signs of psychological distress such as anxiety and depression after the loss of an infant, compared to fathers. However, when also taking heavy alcohol consumption as a possible sign of psychological distress into account, reactions of mothers and fathers turn out to be equal in the long term [7].

All studies show that stillbirth, prenatal or

No financial support declared.

perinatal loss of a baby has a profound impact on a further pregnancy for both mothers and fathers. Symptoms of anxiety, depression and posttraumatic stress disorder are elevated, quality of life is reduced and the mother-child adaptation tends to be more difficult in this situation [8–12].

Despite increased investigation in this field in recent years, little is known about parents' inner experience when losing a preterm baby. Most studies investigating the impact of the loss of a premature infant, have examined objective clinical symptoms and the effect of the event on a future pregnancy. However, hardly anything is known about parents' personal, inner preoccupation in this extraordinary situation and in the months following the traumatic event. Which feelings and thoughts are triggered by the loss and how do parents experience their social environment during this time? Is there an impact of the event on a physical level in terms of psychosomatic reactions? Moreover, in which way do emotion, cognition, physical reaction and social interaction change over the time after the loss? Knowing more about these aspects may help to understand the process of the parents' coping mechanisms and may facilitate the development of more appropriate support provided by professionals in the time of hospitalisation as well as during the subsequent months. In order to gather accurate in-depth information of this stressful experience we used semi-structured interviews as a method of qualitative research, which would illuminate parents' inner experience in a differentiated way.

Patients and methods

Design

This study is part of a larger retrospective project conducted at the University Hospital of Zurich in collaboration with the clinic of Neonatology and the Psychiatric department. The protocol of the study was approved by the Ethics Committee of the Canton of Zurich (SPUK). The project focused on determining quantitative and qualitative aspects in parents of infants born extremely prematurely at the Tertiary Perinatal Centre [13, 14]. For the quantitative part, 54 parents who had lost their prematurely born infant and 38 parents whose preterm infant had survived filled in an anonymous, self-administered questionnaire examining different topics, such as anxiety, depression, social support, resilience and post-traumatic growth. The qualitative part of the study is presented in this article. All parents gave their informed consent to take part in both parts of the study.

Sample

For the qualitative study, the 54 parents who had lost their infant where asked to participate in an interview after taking part in the quantitative part of the study. The interviews had already been announced with the mailing of the questionnaires. 2 of the 54 parents were not interviewed because of not being fluent in spoken German. 36 mothers and fathers answered affirmatively to the request (rate of return 69%). For reasons of capacity, only 25 individuals were invited for the interview. They where chosen according to the following criteria: balance of gender, balance between number of parents where both partners were interviewed and parents where only one partner was interviewed, readiness to give the interview at the hospital (steady conditions for the data collection) and promptness of answering to the request. All of the parents were interviewed individually. One person failed to attend the interview. Out of the 24 interviews conducted, 5 were removed from the analysis because of important incidents heavily confounding the results: one parent had lost another child afterwards, in two cases the pregnancy situation was especially complicated and in two cases relationship problems were more dominant than the loss of the infant. The sample of this study finally consisted of 10 mothers and 9 fathers, aged between 20 and 45 years at the time of the loss. There were 12 parents, whose partner was also interviewed and 7 parents, whose partner did not give an interview. All of the interview partners were married. 15 pregnancies had been spontaneous, the other 4 had been induced by hormones or were in vitro fertilisations. 13 of the interviewed parents had lost a single infant, 5 of them twins, one mother had lost triplets. In all cases the infant was born between 24 and 26 completed weeks of gestation. In 16 cases the infant had survived only for a few hours, in one case for 3 and in two cases for 7 days. The time elapsed since the loss of the infant ranged between 3.5–6.5 years with a median of 4 years. 11 of the interviewed parents had one or more children born after the loss, in 2 cases they did not wish another child and in 3 cases, the mothers were pregnant again at the time of the interview. For 3 parents the wish for another child was still unfulfilled. These parameters are comparable with the group of parents who did not want to give an interview (n = 18) or whose interviews could not be included into the analysis (n = 5).

Data collection

Using semi-structured interviews, the 19 parents were retrospectively asked about their emotional, cognitive, physical and social experience at three different points in time: time of hospitalisation (T1), 6 months after the loss of the infant (T2) and at the present moment (T3), eg, 3.5–6.5 years after the loss. All the interviews were conducted by the author, working as a clinical psychologist with an education in psychotherapy at the Psychiatric department. They lasted between 1–2 hours with an average duration of 90 minutes. All interviews were tape-recorded.

Data analysis

All the interviews were transcribed literally and analysed with the computer software Atlas-ti, according to the method of inductive qualitative context analysis described by Mayring [15, 16]. The responses obtained were defined to different subcategories and arranged into the four response-categories (emotions, cognitions, physical aspects and social network). Relevance of each subcategory was determined by its number of responses. This way a system of the subcategories could be established for each of the four response-categories (Tab. 2a-c). In order to test the reliability of the defined system of categories the responses were independently grouped by two "raters". The proportion of overall inter-rater agreement for the four response-categories was 94% while the proportion of specific inter-rater agreement for each of these categories

Table 1

Description of the 19 interviewed parents (group 1) and the 23 parents who refused to give an interview (group 2, N =18) or whose interview was not included in the analysis (group 3, N = 5).

Variable	values group 1	values group 2 and 3
Number of parents	19	23
Age of the parents at loss of the infant		
Range	20–45 yrs.	26–64 yrs.
Median	31 yrs	32 yrs.
Gender		
Female	10	11
Male	9	12
Pair – single parents		
Parents whose partner was also interviewed	12	–
Parents whose partner was not interviewed	7	–
Civil status		
Married or in stable relationship	19	23
Separated or divorced		0
Deceased infant		
Parents with a single child	13	18
Parents with twins	5	4
Parent with a triplet	1	1
Time since loss		
Range	3.5–6.5 yrs.	2–6 yrs.
Median	4 yrs.	4 yrs.
Pregnancy		not known
Regular pregnancy	15	
Pregnancy induced by hormone therapy or in vitro pregnancy	4	
Subsequent pregnancy		not known
Wish for another child fulfilled	11	
No further wish for another child	2	
Pregnant again during interview	3	
Wish for another child not fulfilled	3	

ranged from 75 to 100% indicating high accordance between the raters [17].

In order to examine the changes of the relevance of the four response-categories across time, the number of responses in the four response-categories was quantitatively analysed by descriptive statistics. To get an impression about the proportion of burdensome and positive emotions and cognitions and their shifting over time, the subcategories of these two response-categories were furthermore grouped into the two ranges burdensome (–) and positive (+). Subcategories not adequately belonging to this dichotomy (eg, "searching for distraction") were not taken into consideration for the calculation of the mentioned proportion.

Results

Qualitative analysis

Parents' experience during hospitalisation (time point 1)

Emotions

During hospitalisation including birth and death of their child, parents were primarily preoccupied with burdensome feelings. They felt extreme sorrow, mental pain and feelings of separation and were overwhelmed with helplessness. Furthermore, their worries and hope for the survival of the baby were putting them under great tension. Most fathers were extremely worried about the health of their wives. 7 out of 10 mothers felt strained when confronted at the maternity ward with mothers who were pregnant or had a newborn baby. However, apart from all the sad feelings parents also experienced positive emotions in this situation, eg, great joy about the infant and feelings of intense closeness to it. 12 out of 19 parents had a strong wish to actively cope with the difficult situation by sending the birth announcement or the obituary to family members and friends, by preparing the funeral or buying an appropriate dress for the deceased child. The proportion of burdensome and positive emotions during time at hospital came to 84%: 16%.

Cognitions

In terms of thoughts, 12 out of 19 parents said that during hospitalisation they were strongly preoccupied with ethical aspects of the situation: They did not want the infant to suffer, they wished to respect the baby's 'will' or they were relieved about not having to decide about the withdrawal of medical support. In this situation 12 out of 19 parents started to ask themselves why this had happened to them. Over one third wondered if they had 'failed' by causing the preterm birth of the infant themselves, eg, by having worked too hard or not having gone to the hospital soon enough. During time at hospital the ratio of burdensome and positive cognitions was 61%: 39%.

Physical aspects

Psychosomatic reactions were rare in this situation, only 8 responses could be classified as 'physical aspects'. These responses included experiences of pain caused by psychological distress, or vegetative reactions like increased sweating or a raised heart rate.

Social network

In the field of social interaction, support from the professional team as well as from family members and friends was essential. 51% of the answers incorporated this aspect. However, parents also experienced disappointment from their social surrounding, either due to inappropriate remarks, or as a result of insufficient understanding or inappropriate medical treatment. The presence of the partner and feelings of closeness and being supportive with each another were mentioned by 15 of 19 parents. 10 parents quoted having had an urge for withdrawal and being alone.

Parents' experience 6 months after the loss (time point 2)

Emotions

During the few first months after the loss of the child, emotions were less intense compared to the time of hospitalisation. The number of responses related to emotions dropped from 254 to 129. Sorrow and pain were still dominant feelings in this period, as mentioned by 11 out of 19 parents. Novel emotions in this period were preoccupation with questions regarding a potential further pregnancy and anxiety towards it. This was experienced by 10 out of 19 parents. 31% of the parents said that they had gained some distance from the straining feelings regarding the lost child, but 37% reported that they still felt emotionally unstable and became easily sad and depressed. Furthermore, meeting parents who had a living child was still a source of considerable strain for 6 out of 19 parents and they mentioned strong feelings of jealousy, anger or sadness when seeing living children. The proportion of burdensome and positive emotions during the first few months after the death amounted to 58%: 42%.

Cognitions

In this period the first cognitive processing started. 14 out of 19 parents mentioned thoughts of a re-assessment of their situation: comforting thoughts like knowing that the child was now in a safe place or was watching the family like an angel, gained importance. As part of the reappraisal process, parents reported being glad at not having a disabled child. Moreover the integration of medical knowledge also supported the re-evaluation of the experience. The question of 'why' was still ruminating in one third of the parents, as well as the thought of having failed in some way. Troublesome and positive cognitions added up to a ratio of 48%: 52% in this period.

Physical aspects

Psychosomatic reactions were rare in this period, only four responses were obtained and they all mentioned a disturbance of the vegetative nerve system, eg, increased sweating.

Social network

Support by family members and friends, as well as closeness to the partner was the most frequent response during this period (39%). 10 out of 19 parents reported that the relationship to the partner was not only supportive but was also burdened by an increase of conflicts. Heightened tension was often caused by their different coping mechanisms and the speed at which they overcame the loss. While mothers were often still intensely mourning their child during these months, fathers had taken up their daily life more quickly by returning to work. Equally, while mothers still had a strong urge to talk about their child, the fathers' wish to share their feelings and thoughts with other people was less pronounced. As for the first evaluation (time point 1) 10 of 19 parents mentioned disappointing experiences in their social surroundings. They reported to be hurt by inappropriate remarks or the withdrawal of friends. 9 parents described the need for silence and time to themselves and a strong wish for withdrawal.

Parents' experience 3.5–6.5 years after the loss (time point 3)

Emotions

Even three to six years after the loss of their infant, 13 out of 19 parents felt sorrow when thinking of their prematurely born infant. However, the quality of the sadness had changed and was now of a more peaceful and quiet nature. At the same time, 15 parents reported having gained an inner distance from their feelings regarding the loss of the child. 15 out of 19 felt that their child was now a part of themselves in the sense of an emotional integration. They described how their deceased infant had become somehow a part of the family and was integrated in their life. 3.5–6.5 years after the loss, the ratio of burdensome and positive emotions was 37%: 63%.

Table 2

Number of responses and number of parents for each subcategory in regard to the four response-categories (emotions, cognitions, physical aspects, social network) at time point 1–3 (T1 = time at hospital, T2 = 6 months after the loss, T3 = 3.5–6.5 years after the loss) for the 19 interviewed parents. In the interests of a better overview only the most frequent responses are mentioned. Total number of responses in brackets.

Response categories	**Subcategories at time point 1 (hospitalisation)**	**No of responses**	**No of parents**
Emotions	Sorrow/Pain	23 (–)	16
	Wish to contribute actively	22	12
	Feelings of farewell	18 (–)	16
	Helplessness	13 (–)	10
	Worries about the infant	12 (–)	12
	Hope for the survival of the infant	12	10
	Closeness to the infant	11 (+)	11
	Joy about the child	10 (+)	10
	Feelings of being overwhelmed	10 (–)	10
	Worries about partner	8 (–)	8
	Disappointment	8 (–)	7
	Confrontation by mothers with living children	7 (–)	7
	Anger about physicians	7 (–)	6
	Dissociation	6 (–)	5
	Desire for distraction	6	5
	Total	**174 (254)**	
	Proportion of burdensome(-) to positive(+) emotions	84%: 16%	
Cognitions	Ethical aspects	13 (+)	12
	Question of ‘why’	12 (–)	12
	Thoughts of own failure	8 (–)	7
	Total	**33 (46)**	
	Proportion of burdensome(-) to positive(+) cognitions	61%: 39%	
Physical aspects	Pain	4	4
	Autonomic reactions	4	3
	Total	**8 (12)**	
Social network	Support by professionals	59	16
	Support by family/friends	29	18
	Disappointment in professionals	27	15
	Closeness to partner	17	15
	Disappointment in family/friends	12	8
	Withdrawal	10	10
	Total	**154 (172)**	
Response categories	**Subcategories at time point2 (6 months after the loss)**	**No of responses**	**No of parents**
Emotions	Sorrow/Pain	16 (–)	11
	Anxiety towards new pregnancy	10 (–)	10
	Wish for new pregnancy	8 (+)	8
	Wish for distraction	8	8
	Emotional instability	7 (–)	7
	Distance to emotions	6 (+)	6
	Confrontation by mothers with living children	6 (–)	6
	Closeness to the infant	6 (+)	6
	Total	**52 (129)**	
	Proportion of burdensome(-) to positive(+) emotions	58%: 42%	
Cognitions	Reappraisal	14 (+)	10
	Thoughts of own failure	7 (–)	7
	Question of ‘why’	6 (–)	6
	Total	**27 (38)**	
	Proportion of burdensome(-) to positive(+) cognitions	48%: 52%	
Physical aspects	Autonomic reactions	4	3
	Total	**4 (4)**	

Table 2
(continued)

Response categories	Subcategories at time point 2 (6 months after the loss)	No of responses	No of parents
Social field	Support by family/friends	28	17
	Closeness to partner	17	17
	Conflicts in the relationship	11	10
	Support by professional	10	5
	Disappointment by family/friends	10	9
	Withdrawal	9	9
	Total	**85 (115)**	
Response categories	**Subcategories at time point 3 (3.5–6.5 years after the loss)**	**No of responses**	**No of parents**
Emotions	Sorrow/Pain	20 (–)	13
	Emotional integration of child	15 (+)	15
	Distance to emotions	13 (+)	13
	Closeness to the infant	6 (+)	6
	Total	**54 (83)**	
	Proportion of burdensome(-) to positive(+) emotions	37%: 63%	
Cognitions	Reappraisal	20 (+)	12
	Thoughts of comfort	13 (+)	10
	Doubts	7 (–)	5
	Thoughts of own failure	6 (–)	6
	Imaginations about the child	6	6
	Question of 'why'	5 (–)	5
	Total	**57 (63)**	
	Proportion of burdensome(-) to positive(+) cognitions	36%: 64%	
Physical aspects	Pain	2	2
	Total	2 (5)	
Social network	Importance of the next born child	9	9
	Including the siblings	6	6
	Total	**15 (28)**	

Cognitions

In this category, the most dominant response (32%) was related to comforting thoughts and thoughts of re-assessment. The parents imagined their child being in a safe place and hoped for a reunion with it after death. Furthermore they realised that they cherished the child that was born at a later point in time and that it may not have been born if their premature infant had survived. 5 out of 19 parents still had doubts about the appropriateness of medical treatment and wondered if the doctors had made mistakes, especially during pregnancy. 6 parents imagined how their child would be if it had survived. The question of why all this had happened and if they had failed themselves still persisted in about one third of the parents' thoughts. The ratio of troublesome and positive cognitions at this point in time amounted to 36%: 64%.

Social network

At the time of the interview, 32% of the responses concentrated on the importance of the next born child or children. These children were now in the centre of the parents' life, while the lost infant had, at least to a certain degree, moved to the background. 31% of the parents considered it important to tell their children about the loss of their premature sibling, to show them photographs and to go to the graveyard with them.

Quantitative analysis

In order to support the preceding results the number of responses within the four response-categories at the three different points in time were also evaluated by descriptive statistics. (fig.1). The high number of responses in the category of emotions in all three evaluation time points indicates clearly, that the loss of a premature infant was primarily an emotional experience for parents (T1: $md_E = 13$, T2: $md_E = 6.3$, T3: $md_E = 3.8$). During the time in hospital and the first few months afterwards, the social category, alongside with the emotional category, was also very important for parents (T1: $md_{SN} = 8.6$, T2: $md_{SN} = 5.8$). Compared to these two categories, cognitive thought processes were less dominant at all three points in time (T1,T3: $md_C = 2.4$, T2: $md_C = 1.9$). However, compared to the decreasing number of answers regarding emotions and the social network, cognitions gained in relative importance after a couple of years. Physical reactions in terms of psychosomatic

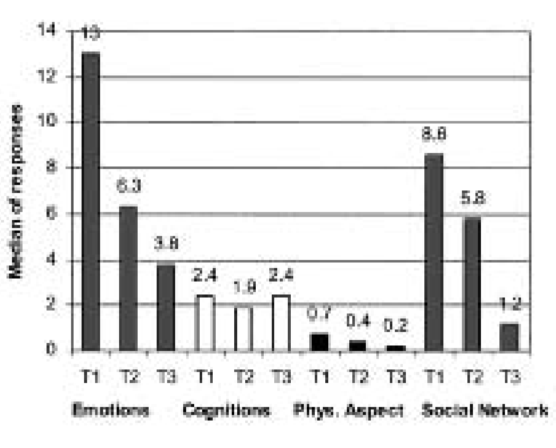

Figure 1

Median of responses per person for the four response-categories (emotions, cognitions, physical aspect, social network) at time point 1–3 (T1 = hospitalisation, T2 = 6 months after the loss, T3 = 3.5–6.5 years after the loss).

reactions were of minor importance at all three time points (T1, T2, T3: $md_{PA} < 1$).

Looking at each of the four response-categories separately, it becomes evident that over time, parents' emotional, cognitive and social experience underwent considerable change. This dynamic process is expressed by notable differences in the number of responses, in their median and along the time axis. While at the time of hospitalisation the number of responses in the emotion and social field categories were very high, their numbers decreased considerably after half a year and again after some years. Interestingly, responses in the cognition category demonstrated an opposite effect: The median of the responses remained with values between 1.9 and 2.4 relatively stable between the three points in time T1–T3.

Discussion

Parents' coping

The results of this study indicate that there is a big difference between the emotional, cognitive and social experiences that parents dealt with in the acute phase after losing their child and during the months and years following the traumatic event. This reveals a dynamic process in parents of coping with the situation and in overcoming the loss of their child. Interestingly and unexpectedly the aspect of psychosomatic reactions is negligible at all investigated points in time.

Changes over time in the nature of the responses, from burdensome to more positive, indicates that the majority of parents have overcome the loss of their preterm infant 3.5–6.5 years later. During hospitalisation, parents are predominantly preoccupied with troublesome feelings and thoughts of sorrow and pain, helplessness, worries and questions of their own failure; these negative aspects decrease as time passes. Months and years after the loss, they report more positive emotions and cognitions, eg, the wish for a further pregnancy, thoughts of comfort and reappraisal and the emotional integration of the lost child. Furthermore, the decrease of responses in the emotion category and the stable number of responses in the cognition category would indicate emotional distancing from the incident as time passes. These results support the data found in the literature. 1996, Boyle demonstrated, that mothers who had lost their baby due to stillbirth, neonatal death or SIDS, suffered from significantly higher psychological distress for at least 30 months than mothers whose infant had survived. However, they did not develop serious mental health problems in response to the loss [2]. A similar result was found by Janssen who reported an increase in depression, anxiety and somatisation 6 months post-trauma in women who had lost their infant early during pregnancy, compared with mothers with a living infant [3]. One year after the bereavement, the differences in mental health disappeared between the two groups. In an elaborative longitudinal quantitative-qualitative study Dyergrov found that parents, whose infant had died of SIDS, were not psychologically at risk 12–15 years after the event. The parents who were psychologically functioning well had an inner representation of the deceased child, eg, memories and associations. Such inner representations of the lost baby seem to be a natural consequence of grief and a sign of successful processing of the bereavement [6]. Summarising the data found in literature, it can be said that the death of an infant due to preterm delivery, SIDS or stillbirth is an overwhelming event for parents. Remarkable effects on the psychological well-being are found, such as elevated levels of depression and anxiety during the first period after the death, with mothers in general being more affected than fathers. In the longer term, most parents overcome the bereavement without lasting symptoms of psychological disturbance [2, 3, 5–7, 9].

Parents' inner experience

Our data not only support the results of previous research, but also give a new and more differentiated insight into parents' inner experience and their way of coping after the loss of an infant.

Emotionally, the time of birth and death of a preterm infant is extremely intense with mainly troublesome but also positive moments. Half a year later, apart from pre-existing feelings of sorrow and pain, emotions regarding a new pregnancy gain importance. Some years after the death of the preterm baby, sadness remains, but is less overwhelming and more controllable. Parents have gained a distance from these feelings and have integrated their lost infant into their inner self.

At a cognitive level, for all three time periods, parents are preoccupied with the question of why this should happen to them and whether they have failed in one way or another. During hospitalisation however, thoughts regarding ethical aspects predominate, a cognitive re-assessment of the experience and comforting thoughts gain importance as time passes by. A few years later, parents also imagine how the child would have been and behave as if it were still alive. Some parents still have doubts about the quality of the medical treatment they received.

With regard to social aspects, support by professionals, family members and friends as well as the emotional closeness of the partner is very important during hospitalisation and the following months. Many parents also report moments of disappointment in their social surroundings. Quite a few of parents sense an urge to withdraw and be alone. During the first months after the loss, conflicts emerge owing to different ways of coping and quite often put a strain on the partnership. On a daily basis, the lost infant is of less importance, whilst subsequent children are the focal point of family life. Many parents wish to tell their children about the older sibling they never had.

Interestingly, the process parents describe and go through emotionally, cognitively and in their social network resembles the four levels of natural mourning process described by E. Kübler-Ross and V. Kast who describe feelings of denial; sadness, anger, guilt; depression and, finally acceptance with finding a new basis to one's life [18, 19].

Tips for professionals

This knowledge of parents' inner experience can give professionals valuable hints as to what parents need after losing a premature infant during the acute period and the months afterwards.

Time in hospital

While in hospital parents are in a state of high emotional alertness and preoccupied solely with themselves. In this period, they are dependent on the support of professionals mainly on an emotional level. They require professionals to be available and present, to experience the situation with them and to offer ritual activities. In contrast to the common notion that the experience of such trauma is solely burdensome, parents also experience positive feelings like joy over the baby and closeness to it. These emotions can be reflected and boosted by professionals in order to counterbalance the many straining emotions. At the same time it is important to give the parents the opportunity to actively participate in the processing of the loss, for example preparing the funeral and creating a birth announcement for family members and friends. To contribute actively is often an urgent need for parents. Likewise they need space and time to themselves and the opportunity for withdrawal. It is important to be aware that parents are very sensitive to inappropriate or careless words and actions, and are easily disappointed and hurt by their surroundings. The confrontation of parents with living babies is very stressful in this situation and should be avoided if possible.

First months after the loss

After a few months, many parents wish to have another pregnancy. At the same time, as is also found in other studies, they are very anxious about this. [4, 10, 12]. Doctors, nurses and other professionals dealing with parents who become pregnant after the loss of a premature infant should be aware of these fears and give the parents appropriate support, by being especially attentive to the sensitivity of the situation and enabling them to express their anxieties. Since in this period, parents are more preoccupied with the cognitive processing of the loss, they are also more open now for medical explanations and psychological or pastoral support. This support can help their processing of the event. Professionals should be aware that the relationship between partners is often burdened by conflicts due to different ways of dealing with the loss. They should explain that such feelings of alienation belong to the natural process and should not cause too much concern. Parents can equally be encouraged to express their wish for withdrawal during this time. Feelings of sorrow and pain are still very prominent and should be accepted as part of a natural grieving process.

3.5–6.5 years after the loss

Even several years after the loss and despite the emotional integration of the child many parents still feel sorrow and pain when thinking of their lost baby. This should be acknowledged by professionals who deal with such parents. Since parents, who have given birth to another child after the loss, emphasise the importance of this child in their life, special attention should be given those parents whose wish for a next child is still unfulfilled. They may need special support to progress to a more profound grieving process.

Further reflections

The results of this study are in line with the data found in the literature, which argue that parents usually do not suffer from long-lasting psychological distress after the losing of a premature infant. However, the question arises, why the parents in our study adapted psychologically so astonishingly well? The following reflections may serve as an explanation:

- In 16 of the 19 interviewed parents the wish for another child was fulfilled, they were expecting a child again or they had no further wish for another child. Those whose subsequent pregnancy led to the birth of a healthy child all reported being extremely happy and somehow felt recompensed for what had happened to them.
- Most parents mentioned the importance of professional help during the hospitalisation,

eg, being cared for by the professionals working at the neonatal intensive care unit and the obstetric clinic. The feeling of being well supported in these critical moments, for example by being provided with clear medical information, being offered rituals when the infant died, or receiving emotional support certainly helped the parents in the process of overcoming the bereavement. At the neonatal intensive care unit, parents are provided – if they wish – with pastoral and psychological support during the hospitalisation of the child. When they leave the hospital they are given addresses of self-help groups and an organisation that offers psychological support. Furthermore they are invited for a medical interview about three months after the death of the child. In many cases the nurses contact the parents by telephone after they have left the hospital in order to learn about their psychological condition and their need for professional help.

- End of life decision: The neonatologists are in contact with the parents from the beginning of the hospitalisation, ie, before the birth of the child. This way parents are prepared for the possibility that the child may not survive already at an early stage. Furthermore the clinic disposes an elaborate ethical concept for end of life decisions [20]. The decision to abandon intensive medical care is made by a group of professionals from the treatment team. The parents' wishes are always considered in their reflections. Retrospectively asked, 78% of the parents whose infant had been hospitalised in the clinic of Neonatology agreed with the end of life decision that had been made [21]. In the sample of our study the situation of end of life decision occurred only in three cases, with the other 16 interview-partners the infant had survived only a few hours after birth.
- The small amount of psychosomatic reactions and the high number of emotions reported by the parents indicates that the sample consists of psychologically healthy participants who were able to go through this experience quite consciously without converting straining emotions into more unconscious psychosomatic reactions. Equipped with this psychic resilience the majority of the parents of the sample seemed to be able to handle this painful situation without being heavily traumatised.
- All parents interviewed were in a stable relationship and experienced mutual support during the time of hospitalisation as well as during the following months. Nearly all of them emphasised that they felt very close to their partner in the first days and weeks after the loss.

The good outcome for the parents of this study may be biased by *two important limits of the study*:

Retrospective nature of the study

3.5 to 6.5 years after the loss of their preterm infant, parents may have different recollections of their experiences than at the time they occurred.

As known from theories of cognitive and social psychology, the process of perceiving and memorising information can be biased by a variety of different mechanisms. Known as the effect of 'priming', already existing knowledge may influence the memory of a new experience. Likewise, expectations of a possible outcome will have an influence on the memory of an event when recalled later on [22]. Furthermore, experiences made *after* a certain event can interfere and bias the memory of it. Moreover emotions can also influence how well people remember things: more emotional experiences are more easily remembered, and events unpleasant to an individual are more likely to be forgotten, ie, repressed [23]. Therefore the experiences the parents report may not reflect their feelings and cognitions at the time at hospital and six months later but may be remembered and narrated in a distorted way.

Likewise it can be argued that the parents who have overcome the loss of their child and are psychologically well again may recall the tragic event and the time afterwards as less straining than it had actually been. Parents who have not overcome the loss and are in a more depressed state of mind may emphasise the burdensome and straining aspects of their experience more, in their recollection. The psychological mechanism of seeing past things either in a more negative or positive way according to the actual emotional state is well known from theories of clinical Psychology and research about depression [24, 25].

Even though these arguments can not be disproved, an observation made during the interviews may argue against a strong bias in the results found: parents clearly "went back in time" when talking about their experiences of the past, indicated by their emotional reactions like crying or sobbing – feelings that belonged to their experience of the past. This phenomenon is well known from the description of psychotherapeutic processes and is used as a tool to understand and alter the emotional patterns of patients.

Selection of the sample

It is likely that parents who have overcome the loss of their child and gained some distance from the tragic event were more ready to talk about it in an interview, whereas the ones who were still very much occupied with their loss decided not to take part in the study in order not to stir up their feelings. This way the results found in this study could be biased by these parents' better coping than would have been observed when taking all parents into consideration. Again, this argument can not be refuted. The impression though when conducting the interviews was that even parents who were still mourning a lot did not try to avoid the subject but took the possibility of talking with a professional as an opportunity to work through the tragic event again. Moreover, the data from the quantitative study gives hints that the parents who were ready to give an interview do not differ in important parameters like grief, depression, anxiety, resilience and posttraumatic growth from the parents who refused to take part in the interview study.

Conclusions

With support from the social network and professionals provided, most parents seem to have the psychological strength to overcome the tragic experience of losing their premature infant some years afterwards. Despite these positive findings, it is important to be aware that the process of working through such an event is hard, painful, and takes a long time. It can only be achieved with a lot of personal struggle, and support from the partner, family and friends. Professionals can play an important role in the assistance of these parents, by being aware of and by responding to their individual needs at the different stages during the process.

There are a few parents who still suffer a lot from the loss of their infant and have not overcome it several years later. Most of them have not yet had another child. They still suffer from quite a few negative emotions and cognitions like sorrow, depressive feelings and the question of "why". These parents may not be able to overcome the bereavement of their premature infant with their own resources and therefore be in need of additional, for example, psychotherapeutic support.

Correspondence:
Annette Glaser
Clinical Psychologist
Psychiatric Department
University Hospital
Rämistrasse 100
CH-8091 Zurich
E-Mail: annette.glaser@usz.ch

References

1 Rubin SS. Death of the future: an outcome study of bereaved parents in Israel. Omega. 1989;20:323–39.
2 Boyle FM, Vance JC, Najman JM, Theale MJ. The mental health impact of stillbirth, neonatal death od SIDS: prevalence and patterns of distress among mothers. Soc Sci Med. 1996; 43:1273–82.
3 Janssen HJ, Cuisinier MC, Hoodguin KA, de Graauw KP. Controlled prospecitve study on the mental health of women following pregnancy loss. Am J Psychiatry. 1996;153:226–30.
4 Hunfeld JA, Wladimiroff JW, Passchier J. The grief of late pregnancy loss. Patient Education Couseling. 1997;31:57–64.
5 Sansoni J, Giaquinto A. Parent's grief for the loss of a preterm child. Professioni Infermieristiche 2001;54:3–18.
6 Dyergrov A, Dyergrov K. Long-term impact of sudden infant death: a 12–15-year follow-up. Death Studies. 1999;23:635–61.
7 Vance JC, Boyle FM, Najman JM, Thearle MJ. Gender differences in parental psychological distress following perinatal death of sudden infant death syndrome. Br J Psychiatry. 1995;167:806–11.
8 Hunfeld JA, Agterberg G, Wladimiroff JW, Passchier J. Quality of life and anxiety in pregnancies after late pregnancy loss: A case-control study. Prenat Diagn. 1996;16:783–90.
9 Hunfeld JA, Taselaar-Kloos AK, Agterberg G, Wladimiroff JW, Passchier J. Trait anxiety, negative emotions and the mothers adaptation to an infant born subsequent to late pregnancy loss: A case-control study. Prenat Diagn. 1997;17:843–51.
10 Cote-Arsenault D, Bidlack D, Humm A. Women's emotions and concerns during pregnancy following perinatal loss. Am J Maternal Child Nursery. 2001;26:128–34.
11 Armstrong DS. Emotional distress and prenatal attachment in pregnancy after perinatal loss. Journal of Nursing Scholarship. 2002;34:339–44.
12 Cote-Arsenault D. The influence of perinatal loss on anxiety in multigravidas. Journal of Obstetical Gynecolgical Neonatal Nursery. 2003;32:623–9.
13 Jenewein J, Fauchère J-C, Glaser A, Moergeli H, Büchi S. Was belastet Eltern nach dem Tod ihres extrem frühgeborenen Kindes? Eine qualitative Studie. Geburtshilfe und Frauenheilkunde. 2005;66:745–51.
14 Büchi S, Moergeli H, Schnyder U, Jenewein J, Hepp U, Jina E, et al. Bereavement and posttraumatic growth in parents 2–6 years after death of a preborn baby. Psychotherapy and Psychosomatics.
15 Mayring P. Einführung in die qualitative Sozialforschung: Weinheim: Beltz; 2002.
16 Mayring P. Qualitative Inhaltsanalyse. Grundlagen und Techniken.: Weinheim: Beltz.; 2003.
17 Cicchetti DV, Feinstein, A.R. High agreement but low kappa: II. resolving the paradoxes. J Clin Epidemiol. 1990;43:551–8.
18 Kast V. Trauern. Phasen und Chancen des psychischen Prozesses. Stuttgart: Kreuz Verlag; 1982.
19 Kübler-Ross E. On death and dying. New York: Collier; 1969.
20 Baumann-Hölzle R, Maffezzoni M, Bucher HU. A framework for ethical decision making in neonatal intensive care. Acta paediatrica 2005;94:1777–83.
21 Jina E. Eltern nach der Geburt eines extrem Frühgeborenen – eine retrospektive Querschnittsuntersuchung. In: Inaugural-Dissertation der Medizinischen Fakultät der Universität Zürich; 2006.
22 Fiedler K. Die Verarbeitung sozialer Informationen für Urteilsbildung und Entscheidungen. In: Stroebe W, Hewstone M, Stephenson GM, editors. Sozialpsychologie. Berlin: Springer; 1997. p. 143–75.
23 Spada H. Lehrbuch Allgemeine Psychologie. Bern: Huber Verlag; 2006.
24 Davison GD, Neale JM. Klinische Psychologie. Weinheim: Psychologie Verlags Union; 1996.
25 Roth D, Rehm LP. Relationships among self-monitoring processes, memory and depression. Cogn Ther Res. 1980;4: 149–57.

SMW

Established in 1871

Formerly: Schweizerische Medizinische Wochenschrift

Swiss Medical Weekly

Official journal of the Swiss Society of Infectious diseases, the Swiss Society of Internal Medicine and the Swiss Respiratory Society

The many reasons why you should choose SMW to publish your research

What Swiss Medical Weekly has to offer:

- SMW's impact factor has been steadily rising. The 2005 impact factor is 1.226.
- Open access to the publication via the Internet, therefore wide audience and impact
- Rapid listing in Medline
- LinkOut-button from PubMed with link to the full text website http://www.smw.ch (direct link from each SMW record in PubMed)

- No-nonsense submission – you submit a single copy of your manuscript by e-mail attachment
- Peer review based on a broad spectrum of international academic referees
- Assistance of our professional statistician for every article with statistical analyses

- Fast peer review, by e-mail exchange with the referees
- Prompt decisions based on weekly conferences of the Editorial Board
- Prompt notification on the status of your manuscript by e-mail
- Professional English copy editing
- No page charges and attractive colour offprints at no extra cost

Editorial Board
Prof. Jean-Michel Dayer, Geneva
Prof. Peter Gehr, Berne
Prof. André P. Perruchoud, Basel
Prof. Andreas Schaffner, Zurich
(Editor in chief)
Prof. Werner Straub, Berne
Prof. Ludwig von Segesser, Lausanne

International Advisory Committee
Prof. K. E. Juhani Airaksinen, Turku, Finland
Prof. Anthony Bayes de Luna, Barcelona, Spain
Prof. Hubert E. Blum, Freiburg, Germany
Prof. Walter E. Haefeli, Heidelberg, Germany
Prof. Nino Kuenzli, Los Angeles, USA
Prof. René Lutter, Amsterdam,
The Netherlands
Prof. Claude Martin, Marseille, France
Prof. Josef Patsch, Innsbruck, Austria
Prof. Luigi Tavazzi, Pavia, Italy

We evaluate manuscripts of broad clinical interest from all specialities, including experimental medicine and clinical investigation.

We look forward to receiving your paper!

Guidelines for authors:
http://www.smw.ch/set_authors.html

EMH FMH SCHWABE
Editores Medicorum Helveticorum

All manuscripts should be sent in electronic form, to:

EMH Swiss Medical Publishers Ltd.
SMW Editorial Secretariat
Farnsburgerstrasse 8
CH-4132 Muttenz

Manuscripts: submission@smw.ch
Letters to the editor: letters@smw.ch
Editorial Board: red@smw.ch
Internet: http://www.smw.ch