

# The silent grief

## Grandparents of children who died of cancer



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**A PIONEERING SUPPORT GROUP** for bereaved grandparents was set up in the cancer palliative care unit of Safra Children's Hospital and the group work was recorded and analysed. Here we describe the findings of this research, looking at how grandparents deal with bereavement in the context of the three generations of a bereaved family. During the group discussions significant topics were raised and a window was opened onto an important area that has been only been touched on by previous studies.

**R**esearch into families that have suffered the death of a child has given us a great deal of information about responses, processes and ways in which parents, siblings, orphans and spouses manage this bereavement. However, there are few published accounts dealing with the grief of the grandparents or of psychological work with them. Personal grief and coping strategies of bereaved grandmothers are described by Reed (2000) and Gerner (1990). The scope and special aspects of grandparents' grief on the personal level have been delineated by Ponzetti (1992), Fry (1997), Dent and Stewart (2004) and

Rothman (1999). Nadau (2004) mentions grandparents very briefly in her excellent study of dynamics and communication of a family in grief. Roskin (1984) reports an increased death rate among Israeli grandparents of soldiers killed in war. However, in general, when discussing bereavement, grandparents are not usually considered part of the bereaved family.

The physical involvement of grandparents in a grandchild's illness heightens emotional and intimate ties, both with the sick child and with the family as a whole. When the illness is long and difficult the practical tasks grandparents are asked to perform, as well as their special position in the complex family dynamic that develops at this time, make this a unique experience for them. So we were surprised that we were unable to find in the literature any detailed report of a support group for grandparents who have suffer this particular loss.

### Methodology

#### The group structure

Grandparents of children who died in Safra Children's Hospital in the past two years, and who were known to the staff, were invited to join a grandparents' bereavement group to help them deal with their grief. Of the 15 couples invited, six joined the group. Seven couples said they would like to have come but could not because of poor health or the death of a spouse. Two

couples said they did not feel the need to join such a group.

The group was heterogeneous: the age of participants ranged from early 50s to late 70s. Some participants were still employed and others were fully retired. Two couples still had children living with them whereas the children of the others had left home. Despite differences in age, background and education, the cohesion of the group was established quickly, and attendance was almost complete. A senior clinical psychologist and a head nurse, both trained in this work, led the group.

#### The sessions

There were 12 sessions of two hours each during a nine-month period. Group meetings included problem solving, as well as emotion-focused support.

**Problem-solving support** focuses on providing information and tools to help participants understand what is happening in the grief process, to develop abilities to cope with problems by discovering significance in events, and to encourage an alternative way of seeing reality and coping in the behavioural sphere.

**Emotion-focused support** gives participants an opportunity to share emotions, provides empathetic listening, and deals with loneliness and isolation, sorrow, pain or anger by allowing each group member to share their stories repeatedly and to experience acceptance from the group.

#### ABSTRACT

*Emotional support for families bereaved of a child is generally directed at parents and siblings, rather than grandparents. A literature review revealed that grandparents' grief has barely been studied or reported. To examine the special characteristics, needs and bereavement coping strategies of this group, a qualitative case study was conducted of grandparents of children who had died of cancer. The grandparents met as a group for nine months and during this time data was collected by observation and recording. Themes raised in discussion that were unique to them dealt with such issues as the legitimacy of their grief, the pained relationship with their children and the specific meaning of this loss in old age.*

The group work's orientation was dynamic. During the early sessions the therapists were more active, inviting the participants to share their stories, to talk about their grandchildren and their grief. Later the format became one of a free discussion by the participants. The therapists' interventions were mainly along the following lines:

- making sure everyone had space and got a chance to speak.
- maintaining a balance between emotional expression and support on the one hand, and giving and asking for advice on the other.
- suggesting possible alternative coping strategies, ways of looking at the world and finding new meanings

## RESULTS

### Content raised during meetings

During the meetings different topics were raised, set aside and then raised again. Five main themes emerged, presented here with quotations by the participants.

#### Acknowledging the grief of grandparents

The REAL mourning is that of our children [the parents]. Who are we? *just* grandparents.

I wanted a copy of the video (of the deceased grandchild) and my daughter-in-law asked me, what for?

The participants felt strongly that there is no 'place' for grandparents' mourning. They themselves wondered if their pain was legitimate compared with the pain of their children. The bereavement group became very important because it was a place where their grief was heard and recognised.

There is nowhere else that I can speak of my grief over the death of my grandson.

I can speak to you [another grandfather in the group]. I can't speak about this to anyone *else* - a grandfather is different.

#### Dealing with the illness and its aftermath

Events, memories and feelings connected with the grandchild's illness were very powerful topics, frequently introduced in the meetings. The need to talk about this, hear the experiences of others and find similarities was profound. Helplessness in the face of the disease, lack of knowledge and the uncertainties came up repeatedly.

We sought advice throughout the world; we spoke with every doctor; the cancer can be so violent.

Strong feelings of guilt were expressed. There was anger about the disease and the physicians, alongside gratefulness to the staff.

Maybe we didn't do enough...maybe we did too much.

I was angry about the treatment, but I believe the doctors did everything they could.

Despair and impotence in the face of the pain and suffering of the child, and the impossibility of calming his fears, were raised again and again:

I lied to him. I can't forgive myself for lying to him. I promised him that everything would be all right.

#### The pain of the parting and the memories

Initially participants were hesitant about sharing their thoughts and found it difficult to express themselves. As the meetings continued, it was difficult to staunch the verbal flow of pain, yearning and memories. Group members debated, advised each other, and reported developments between meetings on practical problems: where to place the grandchild's pictures in their home, parents' wishes about the grandchild's possessions, what to do with the toys, clothing and when to visit the grave.

The group swung from pain, emptiness and loss, to joyful memories of happy moments with the grandchild, and back.

#### The bereaved family: the grandparents' point of view

The dynamics of the bereaved extended family, and the special role of grandparents within this, were discussed at length: the different ways in which family members mourned, the difficulty of bridging these differences, and the desperate need to do so. The emotional relationship to surviving grandchildren could also be a problem.

I am afraid to *love*... [sibling of the deceased grandchild]. I am not attached to him the way I was to... [deceased grandchild].

The grandparents struggled to find their place in the multigenerational bereaved family. Where adult children still lived at home, they could find themselves in an impossible position. For example, one grandmother found

herself caught between her depressed husband, whose life was on hold while he grieved for his grandchild, their 16-year-old son who acted as if death had not visited the family at all, and their daughter, mother of the dead child, whose marriage was crumbling. The bereaved parents often caused much anger and hurt feeling by putting a distance between the generations.

The [adult] children don't come for holidays.

They are moving to a new apartment far away.

They won't talk with us about the pain.

#### A parent's voice

We decided to invite a bereaved parent to one of the sessions and a mother from a parents' support group agreed to come. This joint meeting was unusually honest and open, and highly emotional. The mother shared her understanding of the interaction between the grandparents and parents.

When we [parents] want to distance ourselves from you [grandparents] it's not that we have anything against you; this is our way of dealing with our pain. I understand that this is perceived as hurtful to you, but this is not our intent.

We have a hard time with your pain; we can barely manage our own pain and that of our other children. We decided to do what is best for us and put you out of the picture...

It's like you are stealing our grief. You came before us to the grave and you lit the first memorial candle. [this is the role of the primary grievers]

The grandparents responded, describing their distress about the emotional and, sometimes, geographical distance between the generations.

I suffer doubly for my daughter and my grandson. I have a great vacuum in my heart. When my daughter smiles, I am happy. When she is down, my world falls apart.

In the beginning the illness brought us together. Now we have stopped talking about it and it's frightening. It's impossible to talk about it with my daughter. There is too much [emotional] distance.

I used to be the head of the family [before the death]. I am no longer the head. Now I just get in the way.

I am growing old; I didn't want her [daughter] to move far away. I may need her help but they are moving to another city.

**Returning to everyday life**

I was at a meeting in my senior citizens' club. It was nice and I laughed, when suddenly I said to myself 'How can you laugh? Your grandchild is dead!' And I got up and left.

The grandparents talked about giving themselves permission to laugh, to enjoy life. They gave each other advice and encouragement about attending family celebrations after an absence, returning to hobbies, going again on previously-loved outings. They advised each other on how to deal with the sudden burst of tears that can well up in a public place, the shocking pain of recognition of, for example, a favourite toy shop.

Perhaps it is harder for retired people like us. When people are not busy, it is harder.

They wondered if they should plan extended family meetings when these caused so much pain for all concerned, but hoped that in time their isolation from their own children would pass.

I have begun to understand my daughter. I thought that I am the mother and she must come to me for help, but she distanced herself from me. Now I understand that she needed her space as I needed mine.

I understand their [the parents'] pain. They are trying to cope and we sometimes interfere. I am less angry and hurt by this now.

In the safety of the group they were able to allow themselves to smile, to share some of the good things that happened to them since their last meeting, even sometimes to argue about politics.

**Ending**

Subjects that arose during the meetings will continue to occupy the participants long after the group is over. The fluctuation between pain and yearning and the good memories will continue.

Time heals, I believe this saying. But it [the pain] stays with you all your life. You continue living, but this wound slowly eats at your heart.

The group parted sadly but with a sense of achievement, of openness to others who had shared their fate, and with the comfort that their grief had been spoken and heard. This, they felt, was crucial to the journey ahead.

**Discussion**

The expression 'bereaved grandparent' is not common. In our opinion, the cultural expectation is that bereavement is experienced almost exclusively by the nuclear family – siblings, widows, widowers, orphans – and grandparents are not included in this small circle of formal grievers. Their loss is silent and has no cultural framework. Ponzetti & Johnson (1991) called them 'the forgotten grievers'.

Most grandparents are no longer young and will have already dealt with loss in the past, of a parent, spouse, sibling or good friend. Comparing those losses with the death of a grandchild, the group concluded that losing a grandchild is by far the most difficult blow. Some of them are already retired, and have less to occupy their time; some have limited social support networks. In many cases they no longer have the energy to support others while they struggle to hold their own heads above water.

Grandparents who are relatively young, perhaps in their 50s, may still be working and some are at the height of their careers. Grief can affect their functioning at work or at home but, unlike the situation for bereaved parents, no allowance is made for this.

In the family, too, the place of the mourning grandparent is not clear. Meetings of the extended family for events, or holidays, or in the normal course of life, can be very difficult and the pain can be especially pronounced at these times. Differences in mourning styles can affect relationships and closeness among family members,

causing emotional or physical distance and distress. In one family, the parents refused to stay for the Sabbath dinner because the grandparents wanted to leave an empty chair for the dead grandchild. Nadeau (2004) writes about the importance for coping of families making sense of a death. In our group the grandparents yearned to be part of the grieving family but did not believe that they were.

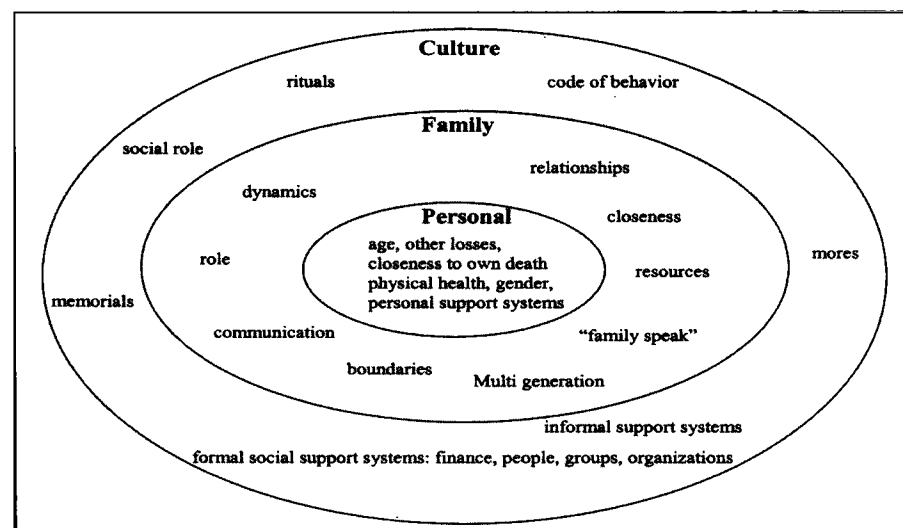
The isolation of the bereaved grandparent can be a very heavy burden. The alienation that can arise between the two parents in a bereaved couple is well documented, but this also occurs with grandparents. Just as parents cannot carry the additional weight of their own parents' grief and become more distant from them, the grandparents find it difficult to cope with the grief of their children, so they become silent. They may not be able to find a way to support each other or speak of their grandchild or of their own pain. At the same time they are experiencing separation, isolation and inability to fulfill their role as parents and help their children (the bereaved parents).

The group members had experienced a very significant intimacy with their families during their grandchild's illness, but this was then followed by alienation after the death. The fight for life drew them together; the grief over death tore them apart.

In orders to better understand the world of bereaved grandparents we suggest a model of three concentric circles (see diagram below):

**The social - cultural circle** contains the norms, mores, rituals, social functions, social roles and duties related to the

**Diagram** The world of bereaved grandparents



behavior and conduct of the grieving person. It delineates accepted ways of expressing grief, formal and informal resources and support systems

**The family circle** contains roles, functions, processes of the grieving family, with the family as the focus. It also contains support mechanisms in the family, dynamics, communications, relationships, boundaries, distance and closeness, and ways of healing.

**The personal-individual circle** contains the age and maturity of the grieving individual (child, adolescent or old person), gender, personal style of coping, health, personal resources. It also relates to other losses and events in a person's history that affect the grieving.

Analysing the data using this model illuminates the difficult situation in which grieving grandparents find themselves. On the **cultural circle** it is not clear what their place is, or even if they have one: their grief is 'silent'. For example, in Jewish culture the grieving family should sit *Shivah*, a ritual which has a rich set of expected behaviours for family, friends and acquaintances. It includes family members staying at home for seven days and nights. In Israel, working griever get a week's paid leave, by law, not deducted from their holiday entitlement. This does not apply to grieving grandparents; it seems that they are expected to continue working as if their grandchildren had not died.

On the **family circle** our data suggests that the grandparents' role is not clear and often the *grieving family* boundaries do not include them within the communications and dynamics surrounding the grief. Relationships and family discourse are coloured by this ambiguity and the healing process is affected.

Finally, the **personal circle** raises questions still to be investigated as to what being a grieving grandparent signifies and entails. The characteristics of an old person grieving for the death of their spouse are much more widely investigated at all levels. This model suggests that we should integrate our knowledge of the grandparents' grief, their family role and the related cultural aspects. ●

*Adapted with permission of Taylor and Francis from an article, 'A voice unheard: grandparents; grief over children who died of cancer', first published in Mortality 2007; 12(1): 66-78.*

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