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Pebble on my wing

Qualitative research that explores the grief experience of bereaved mothers after the death of a child has revealed continuing bonds and the possibility of post-traumatic growth

by Gail Ashton

And can it be, in a world so full and busy, the loss of one weak creature makes a void in any heart, so wide and deep that nothing but the width and depth of vast eternity can fill it up? Charles Dickens'

The death of a child is one of the most difficult losses and one that can have complicated, intense and long-lasting effects upon the bereaved parent. Grief after the death of a child is a lifelong process that can often spur significant changes in worldview, perspective on life and personal values, alongside personal growth and a changed view and altered level of understanding and valuing of people.

My journey, which led eventually to the research for my MA dissertation, began 11 years ago when my youngest son Sam died suddenly and traumatically, at the age of five, whilst we were on holiday in France. I was an art teacher, but three years later decided to change direction and train as a counsellor. I worked in primary care for two years and then decided to integrate my clinical experience and educational experience and work in Higher Education as a counsellor.

I began studying for my MA four years ago and decided



that I wanted to explore the experiences of other bereaved mothers for my research dissertation. I decided to use creative qualitative methodology and be visible as a bereaved parent within the research and also open with the bereaved mothers about Sam's death. The research also had to go through the rigorous process of COREC (Central Office for Research Ethics Committees), as the participants were parent volunteers in a hospital bereavement service.

My study explored the grief experience of bereaved mothers after the death of their child and considered how or whether their worldview was changed, how they rebuilt 'self' while adapting to a new and changed life. It also explored the importance of the value of remaining connected to and continuing the bond with their child. As intended, I remained visible within the research, integrating my own personal and professional experience alongside the stories of the research participants.

I formulated a group of questions that informed a semi-structured interview, and was particularly interested in some of the current grief theory emerging related to continuing bonds2 and posttraumatic growth^{3,4,5}. For many bereaved parents, their view of the world and assumptions about safety, security, predictability and trust are understandably challenged and changed. The death of a child contradicts the perceived natural order of life, violating and shattering the

ILLUSTRATION BY GAIL ASHTON

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parents' assumptive world. With this, comes a sense of unjustness and unfairness, which can challenge the basis of all previously held beliefs and assumptions about self, life and the world. Many bereaved parents describe how the death of their child opens up the possible vulnerability and fragility of others they love. However, such a challenge can also create an existential crisis, a search for the meaning of what it is to be human^{6,7} and a search to make sense of the death and to find some important existential benefit or life lesson8.

My own research found that the bereaved mothers I interviewed had experienced significant changes in self and attitudes, such as a new enthusiasm for living, pride in self, contentment, strength, confidence and a new sense of enrichment, joy and pleasure, alongside the continuing pain of loss and an ongoing relationship with the child. The notion of the benefits for the bereaved of continuing the relationship with the person who has died is relatively new, and emerged strongly within this research as vital to healthy grieving.

For the bereaved, there was a juxtaposition of the increased feelings of vulnerability of self and others, alongside an increased sense of their capacity and strength to survive, and of the ongoing pain and sadness of the loss and absence of their child, whilst also experiencing a newfound joy and passion for relationships, life and living. I found that these experiences mirrored my own experiences and those of bereaved parents I had met and known since the death of my own child.

The assumption that trauma always results in disorder should not be replaced with expectations that growth is inevitable either9, nor the unhelpful and rather hopeful idea that 'good comes out of bad' or that 'every cloud has a silver lining'. Life does carry on, even though many bereaved parents wish it to stop. However, it is necessary to find a way of continuing that still holds the pain of losing the child and the knowledge that they lived and died, alongside a realisation that life is short, precious and to be lived.

What was incredibly moving, inspiring and uplifting about the findings of this research, was the way the bereaved mothers articulated their love for their children, their ongoing grief, and also the hopeful changes in their lives since the trauma of their losses.

I will include some of the narrative extracts from the bereaved mothers' interviews to illustrate, in their words, some of the themes that emerged within the research. For the purpose of the study, each mother chose a pseudonym: Angela, Elizabeth, Helen, Janet and Kate. I have represented the child who died with 'C' and partners with 'P'.

Grief

Contemporary culture does not easily accept the idea of irreparable loss. Dennis Klass¹⁰

Grief affects people in many ways, and the mothers spoke of the emptiness, loneliness and isolation they felt and the intensity of the depth of suffering they experienced. Some talked about the experience of pain in both an emotional and physical way, and how that, in turn, affected their day-

to-day lives and ability to function.

The intensity of grief which many bereaved parents experience is often labelled as 'abnormal' or 'atypical', due to mythical but commonly held assumptions and norms related to grief theory or models. This is unhelpful to grieving parents, who might then judge themselves for failing to conform or deal with their grief better, and this can create a sense of inadequacy and failure, which further compounds their grief.

I, from that point on went into a slow decline.
...and when I was at home, I wanted to go out, and when I was out I wanted to be at home. (Kate)

No matter what people tell you, you have always got that big hole. (Janet)

Grief can impact on physiology too:

I can remember...the
physical pain and the
mental pain...I am
convinced it went into my
body. I couldn't even explain
how I felt. I just felt I was in
a vice. (Angela)

Most had a strong need to manage their own grief first, before they could let others back into their lives. During the period of withdrawal, what emerged was the need to either find a lost self or develop a new self, and some spoke of the need to consider their own death through suicidal



Fig 1. Woman with a dead child 1903
'Drawing is the only thing that makes my life bearable.' Kathe Kollwitz

The mothers spoke of emptiness:

It was like being in an empty room. This was all part and parcel of grief...whatever grieving process means? (Angela)

The void was immense and I felt very redundant. (Elizabeth)

ideation, as an option before choosing to live.

Oh, I didn't want to be here. It was too hard, because at the beginning I wanted to kill myself. (Janet)

I didn't like standing alone, but maybe I needed that time. (Angela) I built walls...I just turned into myself. (Elizabeth)

I put myself in a hole. And I didn't like the hole, but I felt OK in there, and I got to like it. (Helen)

The mothers reflected on how they experienced and needed to express their anger, and how difficult it was to communicate it, but also how necessary anger is to preserve survival:

He says he doesn't know where I got the strength. I just wrecked the whole place. (Angela)

It was like I had so much anger that I couldn't express it. (Janet)

They say that anger is not good, but in some forms anger is better than the place where I was in wanting to die and wanting to be with him. (Kate)

Relationships

Grief separated and isolated the mothers from others, and they experienced a loss of joy, and feelings of their lives being pointless. This resulted in withdrawal from relationships with immediate family, friends, colleagues and neighbours. Four of the mothers spoke of the initial pressures on their relationships with their partners and then how they became close again. The impact on sexual relationships was talked about. For some, it was difficult to have intimacy alongside the feelings of loss, whilst for one mother the intimacy was necessary to cope. One described the need for another child and how that brought an intimacy and bond between her and her husband. For another mother, the relationship with her partner ended as a result of her child's death.

It was difficult to talk even to my husband. Trying to protect each other all the time. (Angela)

I didn't want P to feel how I felt. I couldn't cope with him having to deal with it. (Helen)

And I also missed the closeness I had with my husband...because how could you do something that gave you so much enjoyment when there is so much sadness in your life. (Kate)

I didn't want the phone to ring, I didn't want to see anyone, I couldn't face anybody. (Angela)

I didn't need anyone, I didn't want anyone. I couldn't be bothered with people. (Helen)

I didn't want my friends around, I didn't want my family, I didn't want anybody. (Janet)

I didn't want to look at my daughters, I couldn't handle their hurt. (Helen)

And these two children were determined that they would protect me. And I wasn't even aware that they were around. (Kate)

What helped?

There is no one way to survive the death of a child, no proven method of processing grief that ensures the best possible accommodation of this traumatic loss.

Kay Talkot⁶

Kay Talbot⁶

Re-engaging in life after the death of a child can take many years. The mothers reflected on what helped and what didn't and the changes they had needed to make in their lives and to self to adjust. Whilst for some there was a strong need to make sense of what had happened to their child,

through the pursuit of answers and finding meaning, there was also engagement in new interests and activities, which helped them to become involved in life again and resulted in significant lifestyle changes and re-ordering of what was now important and supportive to their sense of self.

I just knew that I needed to be with somebody else who felt like me. Our biggest help was talking to the other bereaved parents, getting involved. (Janet)

Re-engaging in life...
picking up the pieces of the
life I had, and building on
my self-worth. Getting back
in touch with others and
getting in touch with myself.
(Angela)

Yes, I had to change my lifestyle...I had to come away from people who I thought had no conception of life at all. (Kate)

At the time it was the garden...I bought azaleas, because C liked azaleas. I played golf and I played tennis...and the other part of my life is the children, and I have a social life, so that's the good part about it. (Elizabeth)

I decided that I wanted to pack in my job...and that I needed to find something which would give me an inner peace. (Kate)

Three of the mothers reflected upon the benefits of walking and how this enabled a space for the self to feel a sense of freedom to reflect and be.

I was free and uninhibited about anything...I just felt at peace. I was free from the vice. I was me. I connect with my joy when I am walking. (Angela) I love walking in the wind...and kicking all the leaves in the autumn...I am aware now of the world. (Helen)

I did a lot of walking...when I went out my shoulders were up to my ears, and when I came home I was in a more relaxed state. (Kate)

Some used the creative process of writing and poetry to express and communicate their feelings, and the research explored their narratives. One mother expressed her grief through flower arranging and two of the mothers expressed their grief through gardening.

Beliefs: world, future and existential

The death of a child presents the kind of suffering and challenge to self that creates an existential crisis – a search for the meaning of human existence.

Kay Talbot⁶

The death of a child can create an existential crisis; a search to make sense of the death and to find and explore existential realities, benefit or life meaning^{7,11}.

Some of the bereaved mothers explored their view of death and the meaning of life and death. Individuals who face trauma may be more likely to become sensitively aware and cognitively engaged with fundamental existential questions about death and therefore also with the meaning and purpose of life.

It caused me not only to reflect on the life and death of C, but also on my own life and death. (Angela)

I am aware of the world now. (Helen)

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This is life coming out of death. I am the mistletoe, the new life. (Angela)

Continuing the bond

The end of grief is not severing the bond with a dead child, but integrating the child into the parent's life in a different way than when the child was alive.

Dennis Klass²

Continuing the relationship and bond with the child who had died was important for all of the participants, challenging the traditional thanatological approach that promotes the 'breaking of bonds' as a major task for the bereaved¹².

Theory is emerging that encourages the maintenance of continued bonds with the deceased and integrating the memory of the deceased into the survivor's ongoing life. In the past, continuing the relationship would have been regarded as pathological or abnormal. However, it can not only enable the parent to keep the memory of the child alive and to integrate the child's story into their continuing life, but also play a positive part in parental grief. All of the mothers interviewed had good engagement with life and relationships and still included their child in their lives, through conversation, memories, special objects, rituals and new interests and all still used the child's name in everyday conversations.

We don't stop talking about her. (Elizabeth)

He is there with me on holiday. (Kate)

He continues on, the love... and I have this freedom to know that he lived, to know that he died, and to know that he is still part of our family. (Angela) It's part of our way of life, it is used. Hundreds of people have slept in there but it is still C's room. (Helen)

Keeping his memory alive is very important to me. (Janet)

Yes, and I bring him a present back, sometimes wind chimes for the cemetery...Because the others get a gift, he gets a gift. (Kate)

Growth and grief

My life is far richer, more fulfilled, I believe it has given me a level of understanding, and a level of sensitivity that I didn't have prior. (Janet)

Literature, philosophy and art have, for many centuries, explored the idea that there can be personal growth or gain through suffering. Heightened existential awareness has been explored, and the concept that, when confronting illness, suffering and death, such a confrontation may lead to pronounced positive psychological changes¹³.

The experience of the death of a child may spur parents to experience their lives in sharp new ways, which bring to them new levels of meaning. For others, loss wounds the ability to negotiate and live life adequately.

A turning point in the bereavement process occurs when the parent identifies a reason, passion or focus in their new life. Some bereaved parents can completely transform their way of thinking and being, and this can result in the reordering of life's priorities, enabling a greater appreciation for each day and relationships.

New models of grief and trauma are highlighting the increased appreciation of the possibility of life-enhancing spirituality and post-traumatic growth that often follows in the wake of adversity³. However, the assumption that trauma always results in disorder should not be replaced with expectations that growth is inevitable either. Every cloud does not have a silver lining, but sometimes people can emerge from the dark, bleak place and see hope and life again.

When someone dies, we stop seeing and touching them with our bodies, and our conversations with the person no longer include her or his objective otherness. But the person is still a part of us, and our conversations with the person continue.

Dennis Klass¹⁰

I think I have learned and I have realised that you can grow, you can move on.
(Elizabeth)

There was a time when I felt like a butterfly with a pebble on its wing and I was kept down there. I felt the butterfly within me but I had a pebble on my wing, but now I can fly. (Angela)

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