

Normalization of Parental Bereavement and Vicarious Grieving-Living

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Abstract

The purpose of this article is to broaden the perspective on parental bereavement as a life-long and traumatic experience. The normalization of grief in general and of parental bereavement in particular will be discussed through a presentation of the debate in the professional community and of personal experience as a legitimate source of knowledge. Vicarious Grieving-Living will be offered as a concept relevant to parental bereavement as compared to that of Vicarious Grief. Assumptions toward an expanded model of parental bereavement will be presented.

Introduction

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I have many "titles," one of them is that of a bereaved mother. On January 3rd 1990, Gili, my beloved 11 year-old daughter died after she was fatally injured by a drunk driver. It has been years since her traumatizing death, but time changed from its pre-loss meaning as an "incremental" to a "dichotomous" measurement of life events. My life was changed instantly to 'before' and 'after' Gili's death. Since that moment of her injury until today, and probably for the rest of my life, I embarked

unwillingly, on a journey of exploration and discovery; of deep sadness and peaks of wonderment – a journey of re-learning, adaptation and re-adjustment to a life without Gili. Did I lose my mind on that journey? Did I develop a disorder or a mental illness? Is my profound grief considered "complicated? What is "normal" grief? Who decides what is "normal" for me? Who did I become? What kind of relationships with Others evolved or disappeared during the years that have passed? What can I expect for the rest of my life? These were only a few of the questions that haunted me on my journey. In this life-long process of discovery, I eventually re-defined my professional identity: Having been a psychologist who also studied loss and grief before Gili's death, I now devoted my career exclusively to the study of loss and grief - thanatology

Normalization of Grief

Meaningful relationships are central to our sense of well being (Mikulincer, Orbach & Lavnieli, 1998). Relationships that end with the death of one partner, do not end, but transform. Thus grief following the death of a loved one is not resolved or completed but is transformed as well (Shear, 2012). Even when grief is acute, should it be classified as a mental disorder? Can life without the loved one continue as normal; as if nothing has happened? Can the re-building of a life after the death of a central and meaningful person, be expected to be simple, not complicated and profound?

In the 19th century, grief was viewed a condition of the human spirit or the soul although at times it was perceived as the cause of insanity (Prior, 2000). However, in the 20th century, the perception of grief has changed. The notion of pathological grief was first discussed by Freud (1917) in *Mourning and Melancholia*. In that publication he distinguished between normal and pathological responses to a death. Klein (1940) stated that all grief is pathological as it mimics a manic-

depressive disorder. Lindemann (1944) was the first to explore grief, empirically, and establish a symptomatology of grief. Grief reactions, from that time on, were related to (as) physical and mental symptoms that can be located in the biochemistry of the body, in the history of the grieving person and his developmental stage – it could be assessed and measured. The rise of psychotropic medications enabled the medicalization of grief through treatment with antidepressants although there is no evidence even after years of experience that treating recently bereaved people with psychotropic medication is beneficial. However, there is evidence that medicalization can be flawed, even dangerous, since grief should not be suppressed nor should attempts be made to eliminate it (Editorial, *The Lancet*, 2012).

However, the medicalization and normalization of grief was anchored within a theory of developmental stages, where behavior was seen as an unfolding process of human potential moving toward an ultimate stage of homeostasis, stability or integration (Prior, 2000). Such was Bowlby's (1960) Attachment model, Kübler-Ross's (1970) Five Stages of Grief model, or Parkes (1978) Phases of Grief model. It is only with the work of Durkheim (1968) the sociologist, that the attempts to normalize grief in terms of psychological assumptions took a new turn. Durkheim claimed that the intensity of grief is the product of social processes and not some inner unfolding of potential toward a stage of stability or integration (Prior, 2000).

Toward the end of the 20th century the use of the concept of 'pathological grief' has faded out and a new concept, that of 'complicated grief', evolved. During the last decade, with growing discussion on the essence of complicated grief, there is much debate in the professional community about the usefulness of grief counseling. There seems to be some agreement that grief counseling might be helpful for those diagnosed with "complicated grief" while those who exhibit "normal grief" behaviors,

do not require therapy or counseling. The debate continues over a clear definition of both concepts: that of "complicated grief" and of "normal" grief (Bonanno, 1999; Currier, Neimeyer & Berman, 2008; Martin & Doka, 2000; Rando, 1993).

Another debate nowadays is associated with the revision of the fourth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR) and the anticipated fifth edition –DSM-V (Shear, 2012). It regards the proposal to eliminate the bereavement exclusion to major depression. In the draft version of the DSM-V there is no such exclusion, which means that grief reactions such as a sense of loss, deep sadness, crying, sleeplessness, fatigue, and more that continue beyond two months after the death of a loved one, could be diagnosed as depressive disorder, rather than a normal and expected grief reaction. There is no reference to a specific type of loss or characteristic grief that follows. The report by psychiatric researchers (Zisook, 2007; Zisook & Kendler, 2007) argues that the current definition of depression which excludes bereavement – the normal grieving after the death of a loved one – is accurate. They claim that bereavement-related depression is similar or the same as standard (non-bereavement-related) depression. Carey (2012, p.1) cites Zisook et al.. "If the bereavement exclusion is eliminated, they say, there is the potential for considerable false-positive diagnosis and unnecessary treatment of grief-stricken persons" and cautions that anti-depressant drugs have various undesirable side effects. Wakefield and First (2012) and The Scientific Advisory Committee in their Executive Summary Report to the Association for Death Education and Counseling (ADEC) Board of Directors (ADEC, 2010), disagree with Zisook and Kendler's conclusion. Wakefield et al., and ADEC based their argument on testing the methodology used by Zisook and Kendler. All arrived at a similar conclusion: The studies that were reviewed were flawed. ADEC further asserts that "most of the

research has been inadequate because of selective samples, failure to include appropriate comparison groups" (p. 8), and more. Therefore, the Scientific Advisory Committee considers the Zisook and Kendler article (2007) "to be severely limited" (ADEC, 2010, p.4). The Scientific Advisory Committee contacted experienced clinicians working with bereaved people, who are also immersed in the bereavement literature, and are well-known to ADEC. These clinicians were asked for their reactions to the proposal to eliminate the exclusionary criterion. A few of the most pertinent comments were that "bereaved people generally do not match the criteria for Major Depressive Disorder" (p. 5), although some symptoms of bereavement overlap with Major Depressive Disorder, "but primarily differ in cognitive attributions (for instance, persons with Major Depressive Disorder have morbid feelings of worthlessness"), and "exceptions to the bereavement exclusion should occur when it is clear that the client is engaging in self-destructive and dangerous behaviors" (p.5). ADEC further recommends that "thorough assessment is vitally important" and "rigorous investigations into bereavement remain of paramount importance" (ADEC, 2010, p. 5, 9). The Zisook and Kendler studies did not focus on people who were bereaved in the initial two months following the death of the loved one – "a time limit central to the exclusionary criterion" (ADEC, 2010, p.3). It is important to consider the time factor in assessment of Major Depressive Disorder, since currently the DSM-IV-TR the time limit is two months and yet, as research conducted by Bonanno (2009) and Parkes and Prigerson (2009) indicate that the bereavement process is much longer than the two months mentioned, "particularly in the case of parental bereavement" (ADEC, 2010, p. 8).

Parental Bereavement

Parental Bereavement refers to parents who grieve the death of their child regardless of the child's age and type of death. Sudden and traumatic circumstances of death elicit traumatic grief reactions, similar to those of a post-traumatic disorder. However, in bereavement, the grief may become 'complicated' or chronic but nevertheless never develop into a post-traumatic disorder (Malkinson, Rubin & Witztum, 2000). Gender differences in bereavement are found among fathers and mothers (Hunt & Greeff, 2011). However, Martin and Doka (2000) reject the idea of gender differences in bereavement. They identified two coping strategies: intuitive and instrumental. While the first one focuses on emotions, the second focuses on action and problem solving. The intuitive style of coping was traditionally attributed to women and the instrumental to men. Neither is specific to parental grief. Martin and Doka claim that both men and women may exhibit either one style or a combination of both depending on circumstances. The death of a child, whether expected or unexpected, tears the 'fabric' of family life, and is considered a high-grief death (DeSpelder & Strickland, 2009). But, the death of an older child - an adolescent, a young adult or an adult- has the potential of eliciting more complex grief reactions, simply because of the sheer duration of relationship. The longer and more profound the bond created between parent and child, the larger storage of memories and experiences, conflicts, pleasures shared, all hold the potential for complexity (DeSpelder & Strickland, 2009). The untimely death of a child is experienced by most parents as a traumatic event. Thus their grief reactions, extreme and prolonged as they may appear to the outside observer, can be considered at least in the developed parts of the world, as "normal reactions to an abnormal event". (Kagan(Klein), 1998)).

Normalization of Parental Bereavement

Thanatology is still struggling to define, conceptualize and validate the construct of "normal" grief. Rando (1993), in her discussion on complicated grief, asserts that the traditional criteria for pathology are inappropriate when it comes to describing bereaved parents: What is considered abnormal or pathological in other losses is typical after the death of a child in the sense that it is experienced by the majority of bereaved parents (Rando, 1993; Kagan(Klein), 1998)). Rando (1986) and Klass (1988) among others, argue that the traditionally criteria used for classifying abnormal grief reactions, such as life-long attachment to the deceased child, prolonged crying, heightened anxiety, withdrawal, sleep disturbance, deep sadness or grief-related depression, intense thoughts focused on the deceased child, a need to commemorate the child, are themselves some of the symptoms or components of expected, thus normal parental grief reactions (Shanun-Klein, 2009; Klass, 1999). Rando said that "failure to recognize this precipitates further stress for bereaved parents" (Rando, 1986, p.41).(Stroebe, Stroebe) Stroebe & Hansson (1993) warn that we must approach these symptoms with caution when attempting to detect or diagnose abnormality within parental bereavement. Only from the mid 1980's, especially with the work of Rando (1986); Silverman and Worden (1993), Klass, Silverman & Nickman(1996); Attig (1996, 2001); Kagan(Klein), (1998); Talbot (2002), Neimeyer (1994, 2001, 2006) and others, have discussions on parental bereavement considered the idea of the normalization of parental bereavement; conceptualizing it as a unique process, although complicated in some individuals. Hence, the debate on defining criteria for 'complicated grief' is ongoing, and a new diagnostic category, "traumatic grief", has been proposed and is under study for the DSM-V, Axis I (Neimeyer,2000). It is vital to stress that subjecting bereaved parents to diagnosis and assessment of symptoms that are expected and normal although

extreme at times, as a debilitating disorder is harmful (Shanun-Klein, 2011; Talbot, 2002). It makes sense to think that if a parent's behavior was described by herself and by others as "normal" that her behavior is not expected to become "abnormal" following the death of her child. To further elaborate the difficulty in defining parental traumatic bereavement as a form of pathological grief: parental bereavement especially following a sudden or violent death of a child, is described as extreme, intense and prolonged, even as a life-long process of adapting to a new reality. Its undesirable manifestations resemble post-traumatic, anxiety or depressive disorders. From a view point that interprets any excessive psychological or physical manifestations as a deviation from the expected course of development; such expressions are labeled as "pathological." But if we believe that for most parents the death of their child is traumatic, we may presume the possibility of post-traumatic growth as well. If parental bereavement may last a life time with an unexpected variety of manifestations – undesirable and desirable, depending on the grieving individual, culture, background and actually an infinite number of factors – should we label the extreme but possibly temporary expressions of grief as "pathological," "absent," "atypical," "distorted," "truncated," "maladaptive," "prolonged," "intensified," or "complicated" (Shanun-Klein, 2009; Balk, 2007, pp. 44-45), and conclude a maladaptive process? "Complicated grief is much less common. Most people heal naturally even after complicated bereavement" (Shear, 2012, p. 107). There might be a minority of parents, who suffered from a disorder of any sort including symptoms of a severe posttraumatic disorder prior to the death of their child. There might be parents who even "deny" their loss for an unreasonable length of time. (However, what are the criteria for 'reasonable' or a 'grief timetable'?) But, those symptoms might be temporary and not permanent. And, the symptoms might be

misdiagnosed as disorders instead of grief-related. Such premature classifications may be misleading and harmful to grieving parents. "Though painful and disruptive, this response (i.e., acute grief) helps us adjust to a new reality" (Shear, 2012, p. 115).

Two of the most often repeated questions I heard from bereaved parents were: Am I insane? Is what I experience normal? My answer to those questions is: There is a good chance that if were 'sane' by any professional criteria and self-testimony, prior to your child's death that you are 'sane' now although temporarily and periodically distraught. From a lifelong perspective and not from a focused momentary perspective, you are 'sane' considering what you have been experiencing. The death of your child is the 'abnormal' event, not your grief for your child's death. However, functioning following the death of a child cannot be expected to return to a pre-loss level or state, since life has changed drastically before and after, as I have experienced and many other parents describe it (Kagan(Klein), 1998)). And if 'complicated grief' is defined as "—the failure to return to pre-loss levels of performance or states of emotional well-being," (Halamish & Hermoni, 2010, p. 100), then parental bereavement should not be described as a form of 'complicated grief.'

Vicarious Grief and Vicarious Grieving-Living

We may aspire to feel 'one' with all of Nature, but separateness and individualism is rooted in our culture. We acknowledge that one can experience Life vicariously, that is living through another. Levinas (2007) defined the Other through a face-to-face encounter in which the other person's proximity and distance are both experienced powerfully. According to Kant (Heideger, 1962), in an encounter we instantly recognize the potential of the other for personal profit or potential harm for us. Expounding on Gurevitch (2011), In the face-to-face encounter, in a moment of

distraction, strangeness may be reflected in the familiar face. But only the acknowledgement of the gap between familiarity and strangeness starts the movement toward nearness, toward the Other. The 'other' might be represented by any medium of virtual reality, literature, or real person: An individual may feel excited, inspired, scared or grieve indirectly through another. Nevertheless, we value direct and original experiences and the individual who lives 'authentically' experiencing Life 'first hand.' We even acknowledge the phenomenon of Vicarious Grief, a concept that was first reported by Robert Kastenbaum (1987). Vicarious Grief or Vicarious Bereavement follows having suffered a vicarious loss. A vicarious loss is one experienced through imaginative or sympathetic participation in the experience of another person. Vicarious grief is genuine grief although it usually involves deaths of others not personally known by the mourner. There are two types of vicarious grief. In Type One, the losses to the vicarious mourner are exclusively vicarious. In Type Two, the losses are vicarious to the vicarious mourner but his personal losses are sustained vicariously because of similarity in type of loss, intense identification etc. (Rando, 1997; Kastenbaum & Kastenbaum, 1989). The concept usually refers to individuals affected indirectly by a disaster that occurred to unknown others. These individuals or entire communities exhibit distress and grief reactions as if they were hit directly. We acknowledge the existence and impact of the indirect-secondary-vicarious experience. But we value the original-direct-primary experience as the type of experience that has the most important or lasting effect: Living or experiencing through the other – living vicariously - is less desired than living/experiencing directly.

This principle can be applied to an encounter of the bereaved with the non-bereaved.

In the framework of bereavement, I propose to differentiate between *Vicarious Grief* and *Vicarious Grieving-Living*. In *Vicarious Grief* the emphasis is on the non-traumatized or the non-bereaved. It describes to the pain, the less desirable aspects of grief or pain experienced by the bystander; the non-bereaved through the Other who is bereft. In *Vicarious Grieving-Living*, the emphasis is on the experience of the bereaved. It refers to life affirming experiences, painful and joyful alike, that the bereaved experiences through the Other who is not bereaved.

In expanding on Kant (Heidegger, 1962) and Gurevitch's (2011) statements: In the real or symbolic-virtual encounter with the Other lays the potential for mutual benefit: Inner growth, as well as detriment and harm. In other words, the tension created particularly in the face-to-face encounter, between closeness and distance; between familiarity and strangeness, is a fertile 'soil' for mutual awareness, understanding, inner and intra-growth and compassion.

We may experience our own pain and the pain of the other through identification and connection with parts of the Other's narrative. This vicarious experience can be processed intentionally or not. Intentional vicarious experiencing the Other's grief for instance, can be expressed internally in Inward Steps – covert motions of self discovery (Kagan (Klein), 1998)) through the inclusion of the Other's 'story' and externally in Outward Steps (Kagan (Klein), 1998)) – overt motions of connectedness to the outside world, via emulation of the Other, i.e., "as if" experiencing the Other's 'story.' Emotional companying and nearness to the Other who is non-bereft can be considered as manifestations of the desire to connect to Life through the Other, to have the "as if" experience of living a life with no crushing grief. The "as if experience" and nearness to the non-bereft has the potential of eliciting pain as well. At times, I have felt pangs of jealousy at the lives of friends or

family whose lives appeared to be 'whole' or 'normal' while mine was chaotic, consumed with bottomless grief. At the same time, their life narrative also represented to me a potential for a life that is not defined only by grief, but rather by freedom to define my Self, and my Grief as a possibility. Listening, witnessing the life of the Other who is not grieving, is similar to the experience of watching a 'happy' movie: We might be swept into the tale and for a brief moment we live the illusion of a different life, perhaps with no pain. We may experience options of a different life through movies, through virtual social networks that provide empathy and support, through an Internet community where the deceased is an avatar allowing the bereaved to re-create a momentary reality that he can control. The re-telling of one's story of loss and grief has a numbing effect, a long term anesthetizing effect that causes the lessening of pain, eventually. We create a fantastic reality in which every "as if" and "like" is possible (Lahad, 2006). That fleeting moment, when we are cradled in each other's 'story,' enables the bereaved to catch her breath for the long journey of grief awaiting her. The awakening from that momentary reality comprises pain but also hope and possibility of a life balanced once again with joy and new meaning.

Toward an alternative Model of Parental Bereavement

Most of the models describing processes of grief are general and not specific in describing the dynamics of parental bereavement. Talbot (2000) studied bereaved mothers of an only child. She concluded that mothers' bereavement does not end with the death of their child; that there is no 'acceptance' of the child's death but instead, adaptation and relearning through the continuation of the emotional bond with their deceased child. In an earlier study of bereaved parents (Kagan (Klein), 1998)) I presented a model describing the dynamics of parental traumatic grief due to the traumatizing circumstances of their child's death. Although the model relates

specifically to a traumatic death and to the process of traumatic bereavement, nevertheless, almost every death of a child, regardless of the death circumstances, can be considered as a traumatizing experience to a parent who was attached to that child.

The expanded model of - The Readjustment Model of Parental Bereavement: Inward and Outward Steps and Vicarious Grieving-Living (Kagan (Klein), 1998; Shanun-Klein, 2011).

Assumptions:

- In this century and in developed societies, the death of a child is considered in most cases as an unexpected event and therefore potentially traumatizing.
- Parental bereavement is a unique process of grief. It is a complex constellation of psycho-physiological, cognitive and behavioral reactions. Some of the extreme and prolonged others are overt or covert.
- Parental bereavement is a non-linear (no defined 'stages' or 'phases' progressing from beginning to an end-of-grief). But rather a multi-dimensional and changing. It is a life-long process of learning, adaptation and re-adjustment to a new reality.
- There are no timetables for parental bereavement, although the grief may vary in intensity during the life span, it is often unpredictable.
- Parental bereavement in spite of its temporary intense, extreme or debilitating manifestations should not be labeled as a disorder, since unlike a 'disorder' this process contains the potential for radical change for a better, more meaningful life than pre-loss.
- The death of one's child, as a traumatic event, can shake one's existence. But even in such immense tragedy, lies the potential for a positive change. The

principles of Positive Psychology (Seligman, 2000) and of Post Traumatic Growth (PTG), a concept coined by Tedeschi, R. G., and Calhoun, L. G., (2006), can be applied. Although, neither of the principles were developed specifically for bereaved parents but rather for trauma survivors or any other meaningful crisis and loss, they refer to a positive psychological change; a profound experience of improvement of life post traumatic loss; a change in the grieving parent that enables him or her to see that there is hope even in life with devastating loss (Shanun-Klein, 2011).

- The pain of grief in its less desirable manifestations is expected. But even the desirable post-traumatic growth can be painful as well: Any change in the parent's life that the deceased child is no longer part of, is painful. Nevertheless, pain needs to be experienced to the fullest and not be distracted from or masked by medication.
- *Deep Sadness* underlies parental grief. Although DS may resemble clinical Depression or a Post Traumatic Stress Disorder, it is a constellation of normal and expected emotions, cognitions, and behaviors with varying intensity.
- Often parents express a wish to die or to join their child. Although such an expression should be taken seriously to rule out the possibility of suicidality, nevertheless it might be a common expression of deep attachment to the child; helpless longings or of the temporary inability to grasp the 'event' in the entirety of life perspective.
- In this lifelong process, a *new self* emerges which has incorporated and internalized some aspects of the deceased child. For example, a grieving parent may become aware that s/he exhibits some behaviors typical to their

deceased child, such as preference of music, change of voice, likes or dislikes of readings, and more.

- A parent's grief is an individual journey. In order to understand this individual's experience, we must consider his relationships with those alive and deceased, his health – physical and mental, his history, values, hopes and aspirations, social, cultural and spiritual worlds, and much more.
- Bereaved parents do not detach themselves emotionally from their deceased children, i.e., there is no 'final goodbye.' Their relationship continues symbolically.
- Often grieving parents resist the concept of 'acceptance' in reference to the death of their child. Perhaps because 'agreement' might be hidden in 'acceptance.' Therefore, the concepts of 'adaptation,' 'adjustment' or 're-adjustment' to a life without the physical presence of the child are more acceptable.
- The bond with the deceased child continues to evolve through a *dual-image* process: The *Real Image* and the *Shadow Image* that the parent has and develops of his or her child: The *Real Image*—is past-oriented. This image of the child existed in reality. It entails the actual image and memories a parent has of his or her child. The *Shadow Image*—is future-oriented. It is characterized by "as if" and "what if" thoughts that the parent develops, such as: "What would my child have looked like today?" This image unfolds in time along with the sense of future that returns.
- Some parents because of fear that their child will be forgotten appoint themselves as the family's 'historian' or the deceased child's biographer. They commemorate, memorialize and continue reminding those around that the life

of a child is valuable; that the parent's life matters. But even in doing so, while focusing for a while on the deceased child, he is still capable of keeping the rest of his world in his 'peripheral vision' and diverting attention when needed.

- *Intentional Forgetfulness* is a normal phenomenon in bereavement. It is an active and conscious decision of a bereaved parent to 'forget' painful events directly related to the death of the child in order to be able to function. For example, the grieving mother who has to be able to function at a pre-loss level at work otherwise she may risk her position, decides to intentionally forget or de-memorize details related to her son's illness prior to his death. The attempt to forget painful memories is similar to what Nietzsche called: Active Forgetfulness and what Freud described as Repression (Krell, 1990, p. 107). But, Freud speculated that there is a neurotic resistance to remember unpleasurable memories. He called this neurosis: Repression and described it as an incomplete process; an inability to achieve complete forgetfulness. However, grieving is not a 'neurosis'. The grieving mother does not deny nor repress the *fact* of her son's death; she does not repress her emotions of grief and deep sadness although she may temporarily forget some occurrences that lead to his death. Nevertheless, these memories can be retrieved intentionally.
- Turning points occur when the parent identifies a mission, a goal, a new interest, a passion, a new focus that enables him or her to reconnect to life by discovering or reconstructing new meaning to the life that is left to live.
- Parental bereavement can be described as a process characterized by *Inward Steps* and *Outward Steps* taken simultaneously, and by combined *Steps – Vicarious Grieving-Living*.

- The Inward and Outward Steps are defined both by the bereaved parent's intention and purpose, and by the outside observer's interpretation.
- *Inward Steps* are introverted; private and sometime(s) invisible to the outside observer. Inward Steps are best described as motions of an inner search. A parent may or may not be fully aware of them. The intention is introspection and the purpose is a search for answers. For example, the parent may ask himself or God: Why was I punished? How can God allow the death of an innocent child?
- *Outward Steps* are extroverted, overt actions of intentional connection to the outside world, visible to an outside observer. These might be symbolic acts as well as actual. For instance, the bereaved parent chooses to join a support group, take a trip, go to work, answer a phone call or an e-mail. The intention and purpose are the same: Reconnection to life.
- *Grieving Vicariously-Living* is a transforming state expressed within in Inward Steps, and Outwardly in Steps representing symbolically or actually re-connecting to Life. A combined process of inner and intra motive Steps, enable the grieving parent to vacillate between the inner-isolating state, through Steps of direct- face-to-face or the indirect –virtual reconnections, to interaction with the Other. The ultimate intention and purpose are the same: Living a meaningful life.

In conclusion:

Grief processes are the function of who we are and of those we grieve. Parental traumatic bereavement is a lifelong, profound and complex process of adaptation to a world without the physical presence of the child; of re-learning a new 'language'; of

constant change and challenges of living with a self-defining loss and life-altering experience. This journey of discovery encapsulates both grief and the possibility of joy.

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