



Research Article

Mourning, Bereavement and the Grief-Work of Traumatic Brain Injured Patients: Theory and Practice

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Abstract

Background: Grief, as a universal human experience, follows certain stages as described in different (at times overlapping) models, by various researchers. However, the completion of certain emotional tasks and processes is required for grief to be resolved, allowing us to return to full living. The dynamics and expression of grief and mourning in the traumatic brain-injured patient present specific challenges for therapeutic intervention since the mourner may be impaired both cognitively and emotionally by the sequelae of their injury and is often unable to work-

through their grief in a coherent and continuous process. In these cases, the therapist should take a very active role in the process, eliciting memories and emotions, and then integrating them together with the patient's associations and post-injury experiences, and grief reactions to the current loss. Moreover, when the loss occurs during, or after a rehabilitation program, the therapist's memories of anecdotes previously recounted by the patient may be elicited and offered by the therapist, and incorporated into the present treatment.

Procedure: A case will be presented illustrating the complexity of the mourning process in a traumatic brain injured patient.

Conclusion: While keeping in mind the general recommendations for the grief-work with traumatic brain injured persons, there is a clear need to “tailor” an individual approach for each and every single patient.

Keywords: Bereavement; Grief-work; Cognitive impairment; Mourning; Traumatic brain injury; Cultural aspects

1. Introduction

1.1 Grief and bereavement

Bereavement is the sense of loss of something precious [1]. That which is lost may be a person, a thing, a relationship, or the ability to do something, but the loss is real and is experienced as a loss by the individual [2]. Bereavement is a condition. Grief is the healing process through which the individual recovers from that loss. The reactions that follow bereavement encompass a wide range of symptoms that are usually predictable and include crying, sighing, sadness, anxiety, agitation, sleeplessness and loss of appetite. These symptoms are part of normal grief that was first described by Lindemann in 1944 [3]. However, it is possible to experience all of the physical and emotional components of grief without moving towards a resolution. When the reaction is inhibited, delayed, or prolonged the grief process can be destructive; the individual has all of the pain and all of the emotional and physical symptoms of grief, but these do not diminish with time. They do not allow the individual to progress and find renewed

energy, re-establish relationships and get on with life. Sometimes we are at a loss to understand why this happens. Other times the reason is clearer – for example, when the bereaved is a cognitively impaired person.

We have learned that grief, as a universal human experience, follows certain stages similar to these of the dying process as described by Kubler-Ross in 1969 [4] (shock, denial, anger, bargaining, depression and acceptance), although the concept of stages of grief is more safely viewed as a model than a fact. Lindemann [3] described three stages of grieving: shock, despair and recovery; Parkes [5] saw four stages: numbness and denial of the loss; pining and yearning for the lost one; depression, disorganization and despair; and recovery - reorganization and reintegration, beginning to pull life back together. It is clear that there is much overlapping of stages between the various models. Moreover, some prefer to conceptualize the grief process in terms of reactions rather than stages. Three broad categories of reactions are distinguished: avoidance (shock, denial and disbelief); confrontation (the grief is most intense and the reactions to the loss are most acutely felt); and re-establishment (the grief declines and a reentry into daily routine follows). These reactions are not rigidly sequential and the individual can move back and forth among them [6]. The completion of certain emotional tasks is required for grief to be resolved, allowing us to return to normal living. Unresolved grief frequently has long-term consequences, often apparently unrelated to the initial loss.

After having described the experience of grieving, let us address some of the more active tasks the grieving

person has to undertake to complete the grieving process. The tasks of grieving as outlined by Worden [7] are: to accept the reality of the loss; to experience the pain of grief; to adjust to an environment in which the deceased is missing; and to withdraw emotional energy from the past and reinvest it in the future. In studying grief over the years, we have come to know a great deal about what happens when one is bereaved and moving toward recovery from the loss through the grief process. We also know that a second loss can interfere with recovery from the initial bereavement. Multiple losses, one after another, can affect the way in which a person goes through the grief process. A person can, at times, be grieving many losses simultaneously, even though this may not occur on a conscious level [8].

Hidden grief, more frequently than the grief of "acceptable" losses, can lead to incomplete resolution of these tasks and processes and result in: (i) delayed grief reactions where new grief may draw on the power of old unresolved grief; (ii) chronic grief reaction where grief is never resolved, life becomes stagnant and new emotional growth cannot take place; and (iii) masked grief reactions where grief may express itself in physical illness, psychological problems, or aberrant or self-destructive behavior [9]. Bereavement however, perhaps more than any other area of psychiatry, is likely to touch on the personal philosophy of clinicians working in the field. There are varying expectations as to what satisfactory resolution of bereavement means. Clearly, the range of what are considered to be phenomena following bereavement has broadened considerably since the syndrome described by Lindemann in 1944 [3], a syndrome which consisted only of somatic

disturbance, preoccupation with the image of the dead, guilt, hostility and disorganized behavior.

Zisook and DeVaul [10], in simplifying the evolving process of grieving, opted for a model of three partially overlapping but distinct stages of the grief process that were: (i) an initial period of shock, disbelief and denial; (ii) an intermediate mourning period of acute somatic and emotional discomfort and social withdrawal; and (iii) a culminating period of resolution. "Pathological" grief is thought to encompass delayed, absent, intensified, or prolonged aspects of what is usually described as "uncomplicated grief." Prolonged or chronic grief was found to be the most common form of pathological grief [11].

A central issue in examining the morbidity associated with bereavement is whether or not it is qualitatively different from morbidity that may occur in association with depression, post-traumatic stress disorder, adjustment disorders, or other forms of stress-related or stress-precipitated conditions. Is pathological grief an exaggerated or prolonged form of normal grief? And what would be considered 'normal' grief in someone who has limited ego resources or cognitive abilities or who concomitantly has features of post traumatic stress disorder due to the specific circumstances of the loss or due to a previous head injury? Moreover, the whole question of the expected course of time for the resolution of normal grief is yet unanswered. Zisook and DeVaul [10] propose a model of unresolved grief based on fixation at one of the three stages they have described, where fixation is equated with psychotic denial in the first stage; depression, hypochondriasis, or grief-related facsimile

illness in the second stage; and chronic mourning in the third. They conclude that unresolved grief is a "somewhat overly simplistic concept" in that "most, if not all, people never totally resolve their grief" and that "significant aspects of the bereavement process go on for years after the loss, even in otherwise normal patients."

Longitudinal studies of bereaved subjects have provided a linkage of descriptive syndromes of nonrecovery with specific, premorbid phenomena. This typology offers tangible descriptive and etiologic features and it clarifies the independent effects of specific forms of dying on the grief response [5, 12-14]. The typology refers to combinations of premorbid attachment behavior with specific forms of dying associated with prolonged, intense and dysfunctional grief responses. (i) Dependent grief syndrome links premorbid clinging or over-reliant attachment together with responses of immediate pining and chronic grief; (ii) Unexpected loss syndrome links unexpected loss with responses of immediate disbelief, avoidance and anxiety leading to chronic anxious withdrawal; (iii) Conflicted grief syndrome links conflicted ambivalent attachment with an initial minimal response and delayed responses of anxiety and pining.

The specific phenomenon of bereavement and mourning and individuals' psychological response to it have been studied across cultures [15-17]. A number of queries that are of importance in considering cross-cultural bereavement and mourning have been delineated. Among these would be whether within a culture, bereavement was viewed as an illness, what types of mechanisms and behaviours

could be seen as facilitative of grief resolution and what type of therapeutic activities existed within the culture for helping with "bad" grief. These questions in themselves suggest that culture may play a significant role in symptom expression, inasmuch as culture influences thoughts of suffering and pain and impacts on their expression and articulation. Various cultures and religions provide the bereaved with rules of conduct before the burial (or cremation) and with clear prescriptions as to what should be done and observed on holidays and anniversaries [18]. In Orthodox Judaism, for example, the funeral takes place before sunset of the very same day the person has died and the entire period of grief is composed of several sub-periods; During the first seven days following the funeral (called "Shiva"), the bereaved is confined to the house and required to sit on the ground. The whole day is dedicated to lamenting and to the memory of the deceased. During these seven days clothes are not to be changed. At the end of this defined period the whole family gathers at the grave for a prayer. During the first month after the funeral the bereaved is expected to pray twice a day in the synagogue and men to express their acute grief by not shaving. On the 30th day the tombstone is set in place, after which the families are expected to go to the synagogue twice a day for the remaining 11 months, then four times a year thereafter [19].

1.2 Traumatic brain injury

The psychological long-term effects of traumatic brain injury are typically conceptualized in terms of neuropsychiatric sequelae (cognitive, emotional and behavioral disturbances) of TBI [20]. But brain injury is also a frightening experience in itself and the circumstances of the injury may range from the

moderately distressful to the horrific [21]. Brain-injured patients are usually thoroughly worked-up from a medical and to a lesser extent from a neuropsychological point of view, but much less attention is paid at times to the emotional and psychodynamic effects of brain injury.

The coexistence of post-traumatic stress disorder (PTSD) and traumatic brain injury (TBI) has been disputed for decades, however the overlapping symptoms impose the need of a careful evaluation and differential diagnosis, but do not impend the possibility of a dual diagnosis, as brain injuries are often sustained in traumatic experiences. The effect of TBI on PTSD may manifest as a missing memory of the traumatic event itself if consciousness was lost at impact, but may actually be of the first experiences of the patient upon regaining consciousness (unable to understand what has happened and why he/she is in unknown environment). In cases of concussion (mTBI), evidence suggests that impairment secondary to mild TBI is largely attributable to stress reactions after TBI [22].

Chronic sequelae of head injuries include residual neurological dysfunction, psycho-social and psychological deficits, each of which can be a major source of disability to the survivor and of stress to the family [23, 24]. The most frequent changes that may occur in the head-injured patient are:

- Cognitive changes - problems with higher cognitive functioning may be among the most subtle manifestations of brain injury. Changes may occur in the capacity for concentration, use of language and

abstraction, calculation, reasoning, memory and information processing [25-28]. These intellectual changes, even if not perceptible to others, impose the use of unusual psychological approaches to treatment [29] and influence the social rehabilitation of the head-injured patient [30]. Moreover, because of the vulnerability of the prefrontal and frontal regions of the cortex to injury, specific changes in personality within the "dysexecutive syndrome" are not uncommon.

- Personality changes - the most frequent and prominent behavioral traits may include disorderliness, suspiciousness, argumentativeness, isolation, disruptiveness and anxiousness [31, 32].
- Affective changes - head injured patients may develop manic-depressive or major depressive episodes de novo subsequent to the brain damage [33-35]. Depression has been more frequently associated with a left hemispheric lesion [36-39]. Right hemispheric lesions may too cause depression [40] but the "quality" of the symptoms is different: while patients with 'left depression' manifest mostly anxiety, 'right depression' may be characterized by low mood with otherwise very few depressive symptoms, as compared to major depression affected patients without head injury [41, 42]. Moreover, the depression in the right hemispheric injured tends to develop slowly, tends to be chronic and is resistant to treatment. Major depression with anxiety has been linked to lesions of the left

basal ganglia [43]. Depression following lesions to the cerebellum or the brain stem develops through a mechanism that differs from that associated with left frontal lesions or left basal ganglia, manifesting after a much shorter period of time than the "hemispheric" impairment [44]. One of the possible reasons for the delay of appearance of "right depression" may be the fact that the patient affected by a right lesion is not aware of it. Another possible explanation is a different neuropsychological manifestation of sensitivity of the hemispheres to catecholaminergic pathways [45, 46].

- Changes in reality testing ("induced psychosis") - posttraumatic psychoses can occur either immediately following brain injury, or after many months of apparently normal functioning. Left-sided injuries were found to be more often associated with psychiatric illness, in particular with psychosis [47].
- Aggression - in brain-injured patients, irritability and aggressiveness are a major source of disability for the survivors and of stress for their families [24, 48].
- In order to illustrate the complexity of bereavement and grief-work, and the necessary adaptations of treatment of the bereaved brain injured patient, we shall consider a patient referred for assessment about 12 years after he had suffered a head injury during his military service.

2. Case Example

Mr. R. was at the time of referral a 34-year-old unmarried man, the eldest of 4 adult children, who lived with his parents. He was not working at the time of referral and in fact had not held a steady job since his medical discharge from the army some 10 years earlier. He described taking many jobs in various fields, none lasting more than several months. He held a high-school certificate, had enrolled in several vocational training programs but dropped out each time.

2.1 Background

Mr. R. was injured in combat while on active military duties. He vaguely remembered sitting in a parked jeep outside a high-rise building that then exploded. The jeep overturned, he was apparently thrown out and lost consciousness. There were many casualties as a result of the explosion, including several of the soldiers sitting with him in the jeep. Mr. R. was evacuated by helicopter to hospital. He regained consciousness at about the time of admission, probably about 2 hours after injury. He was diagnosed as suffering from an open depressed skull fracture in the right parietal region, and underwent a decompressive craniotomy. Other physical contusions did not require surgical intervention. He was referred for counselling but did not follow through.

At the time of his present referral, Mr. R. claimed that other than occasional headaches, he suffered no sequelae to his injury. He attributed his unstable work history to the fact that he had really wanted to become a steward for the national air-line, and since he had been - unfairly, in his opinion - rejected on medical grounds, nothing else was suitable. Every job he had

held had ended for reasons that he considered to be beyond his control, (e.g. the boss was mean, the pay was too low, the work was too boring, and so on). In similar vein, all his relationships with women had ended because they had all disappointed him, or had not been up to his standards. He lived with his parents, he said, for financial reasons. When asked about his injury, he said that he had had nightmares for some time during the first year, but now rarely thought about it. And he didn't remember the soldiers who had been with him in the jeep and had been killed. He considered himself lucky and healthy.

Neuropsychological evaluation demonstrated that while Mr. R. was of average general intelligence, there were significant discrepancies between various cognitive functions. These indicated deficits consistent with a diffuse head-injury and with particular evidence of impaired right-hemisphere functioning in a right-handed young man. Among these were constructional problems, difficulty with integration and visual coding, inattention, and problems in self-monitoring and social judgment. In addition, his behavioral instability, his fragmentation of affect and perception, and his denial of difficulty were seen as reflecting mainly right hemispheric neuropsychological dysfunction.

Mr. R. began an individualized rehabilitation program that stressed concrete goals along with cognitive and individual treatment. He was offered mild medication, but rejected this. He was not interested in participating in group therapy. He was, however, very eager to achieve vocational goals and was willing to engage in a gradual process that was suggested to him. With the co-operation of the rehabilitation branch of the Ministry of Defence, Mr. R. began to

work part-time in a small clerical department in a large hotel. His work was structured and closely monitored by his therapist and immediate supervisor who agreed to take on "mentor" status. He was slowly allowed more responsibility, although all of his tasks were carefully structured. He was gradually included in social activities in the hotel, especially after several social "gaffes" of lack of judgment were tactfully explained to his supervisor and also addressed very clearly during therapy sessions. His co-workers became quite fond of him and he in turn adjusted his vocational aspirations ("Yes, I would still prefer to be an air-steward, but you know, it's fun working in a fancy hotel"). His relationship with his therapist became more open and trusting. Mr. R. also showed more maturity and judgment in his relationships with girl-friends.

At this point, after about a year of working at the hotel, Mr. R. and his family suffered a devastating loss. The sister to whom he had been closest since childhood was killed suddenly in a freak accident. Mr. R called the clinic to cancel his appointment (this in itself was unusual since he never cancelled - he either forgot completely or attended as scheduled) without mentioning the reason. However, the accident and his sister's death were reported in the news media, his therapist telephoned him and, with his ready consent, paid a condolence call. Mr. R. was physically involved in the family's rituals, (the "Shiva", the prayers) but he seemed emotionally absent and at times behaved in a somewhat inappropriate manner: he played the role of the gracious host, inquired as to visitors' well-being, and behaved as if this was a purely social event. Moreover, he seemed to ignore his parents and their grief, while constantly issuing

orders to his surviving siblings. At times he would retire to a corner and sit there quietly, detached from his surroundings. This behavior was interpreted by his family as expressive of grief since “he’s been so sensitive since his own accident”. He continually muttered “What a loss, what a loss” in a detached way, and said that he never wept, not after his own injury, and not now. After the days of mourning of the “Shiva” were over, Mr. R. stayed at home. He would daily announce that he was returning to work the next day, but he did not. At first, his co-workers were very supportive and kept in touch with him, but gradually they stopped. He described agitated outbursts with his parents and fist-fights with his siblings that he claimed were provoked by them. He was having trouble sleeping and suffered severe headaches. However, therapeutic contact with him at this point was maintained mainly at the therapist’s initiative.

During therapy sessions he completely ignored the issue of his sister’s death and its impact on his life. When the therapist raised the subject, he reacted in a matter-of-fact manner and said that his sister’s death was indeed a tragedy, “but what could one do”. However, he was vociferous in expressing disappointment with the vocational program that he had previously appreciated, along with its aims and potential pay. He expressed a great deal of anger towards the Ministry of Defence, and reverted to his pre-rehabilitation goals (“They can at least find me a job at the air-port - the Ministry of Defence can do anything it wants”). When the therapist actively directed the content of the sessions towards grief-work Mr. R. at first complained that he could not remember much about his and his sister’s shared lives. He did, however, wear her watch and said that it

helped calm him. He reported that he had convinced his parents to move to another apartment, and that he wasn’t getting on with family members, including his late sister’s boy-friend, but he did not connect this to his feelings concerning her death. Mr R. spoke frequently of his own injury, which he had rarely mentioned previously. He expressed anger with the hotel staff and management at his previous job, and was completely detached from his previous affection for co-workers and his involvement in the hotel’s activities. He reverted to his former vocational mode: he would find a job, work many hours with great enthusiasm and hopes, and within several weeks he would either resign or be let go. Each time, he expressed bitterness and feelings of hopelessness and rage. Three days later he would find another obviously unsuitable job... Each time he found a new job he would announce: “I’m fine, this is just the chance I’ve been looking for, I don’t need therapy any more.” He would re-establish contact in-between jobs. He invested effort into maintaining the therapeutic alliance, and differentiated between his anger towards the Ministry of Defence and feelings towards his therapist. This was considered prognostic and positive.

Mr. R.’s emotional detachment and erratic and displaced pattern of anger were interpreted as significantly reflecting his cognitive disabilities. Hence therapy was aimed first at eliciting expression of appropriate emotions and then at providing cognitive and emotional structure for fragmented and concrete feelings. For instance, Mr. R. was asked to bring old family photographs and memorabilia, such as letters and recorded music, to therapy sessions. The therapist took a very active role in eliciting childhood

memories and emotions, and then in integrating these together with associations of Mr. R.'s own army and post-injury experiences, and grief reactions to the current loss. The therapist's memories of anecdotes previously recounted by Mr. R. were offered and incorporated into the fabric of the session. Mr. R.'s frantic and agitated reversion to dysfunctional behavioral patterns was seen as a concrete expression of the process of bereavement (a different kind of "acting-out"). Mr. R.'s behavior expressed at first numbness, then confusion, anxiety, overwhelming feelings of loss. Lacking the ability to express or integrate his fragmented feelings by himself, isolated within a metaphor of loss, Mr. R. reacted with relief to the interventions. He was also encouraged to find concrete rituals of expression, that were considered conducive to "working through" various stages of integration. He was encouraged, for example, to participate in family religious rituals of mourning. He was supported in taking decisions concerning his sister's personal belongings and personal memorial ceremonies.

Gradually, the behavioral pattern described calmed down. He started crying during sessions, and although he himself felt worse, his condition was considered improved. A year or so later, Mr. R. was encouraged to take a municipal job that while very structured in its criteria, allowed a certain amount of leeway and non-demanding social interaction. He was directly responsible to a supervisor, a family friend, who voluntarily took on the function of "mentor". Mr. R. held the position for over two years and, at the time of discharge from therapy, intended to keep it. He resumed an active social life, his mother reported that the home atmosphere had calmed down, and that he

was getting on very well with his siblings. Mr. R.'s therapy came to an end two years and a half after the bereavement.

3. Discussion

Grief work is a complex psychological process of withdrawal of attachment from the deceased and working through the pain of bereavement. In normal mourning the loss is clearly and unambivalently perceived and the deceased person is eventually, through the grief work, internalized as a loving and loved object [49]. Following loss or disaster, the adjustment and restoration process includes a need to give meaning to what has happened [50]. In order to accomplish these complex tasks, both normal cognitive functioning and maturity are crucial.

Traumatic brain injured patients often have difficulty with integration and coding, they may have problems in self-monitoring, fragmentation of affect and perception, and behavioral instability. Moreover, they can frequently be concrete and unable to engage in the sophisticated cognitive process of separation through a symbolical transformation of the "tangible" lost object into an internalized soothing memory and feeling [51, 52]. As cumulative traumatic events may frequently deplete resources and render coping significantly more difficult, recent bereavement may re-activate previous losses, triggering late awareness. In fact, following the loss of his sister Mr. R. began talking frequently about his own injury, something he had completely denied previously.

The patient described above managed to accomplish some important achievements during neuro-rehabilitation therapy. He underwent a severe

affective, cognitive and behavioral regression following his sister's death, to the point where it seemed that 18 months of rehabilitation achievements were lost. Following the loss, he participated in the traditional-cultural grief rituals, but did not seem to be helped by them: he was emotionally absent and at times behaved in an inappropriate manner. His behavior was interpreted by his family as an emotional consequence of his own injury, and not as an impairment of his cognitive abilities. When other family members returned to work he stayed at home, unable to gather the resources and skills needed to reintegrate [53, 54].

During therapy sessions he was unable to relate to his feelings of loss, his grief-work was fragmented and not effective, and required external direction and organization [55, 56]. However, it did not qualify as "complicated (or inhibited) bereavement", since it did not manifest fixation at any one of the three stages of the "unresolved grief" model described by Zisook and DeVaul [10]: psychotic denial (the first stage), depression hypochondriasis or grief-related facsimile illness (the second stage) or chronic mourning (the third stage).

Following active and directive intervention of his therapist, the patient was able to proceed towards the completion of his grief-work and re-integrate into the rehabilitation process he was undergoing when his sister died. The unique challenge presented to the clinician by the traumatic brain injured bereaved patient requires an integrated approach that accommodates both the psychological needs and the neuropsychological deficits of these patients. Further research is needed in order to develop a

comprehensive model of the way in which traumatic brain injured patients cope with life crises.

Conflict of Interest

All authors declare no conflict of interest.

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