PSYCHOLOGICAL PROBLEMS AFTER BURNS November 2000

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Burn injuries have long-term psychological consequences.

When a child is admitted to hospital with burns, she is suddenly separated from her familiar environment and placed in a strange, frightening place, where her parents are no longer in control and where strangers are hurting her. The burned patient is usually fully conscious at the time of admission, unlike patients with other severe trauma. With severe burns there is often deterioration after initial treatment, before improvement begins.

Frightening masks

The burned child in hospital feels shock, fear, bewilderment, and intense pain. It is easy for medical professionals to forget how frightening gowns, masks and ward equipment can be. Setting up drips and catheters can be the source of terrifying fantasies. During the weeks that follow, the frightening experiences continue as younger children try to come to terms with the pain and separation from their mother. Parents appear to be all-powerful to little children, and anything that goes wrong tends to be seen as the parents' fault. These children do not understand that their parents cannot control certain situations and this often makes them feel that their parents do not love them.

Frustration is added to emotions when the child cries for her mother and she is not able to be there. This sense of not being in control can lead children to start shouting and flinging things about, refusing to eat and talk, regressing to babyish ways, bed-wetting, rocking and thumb sucking.

After the burn injury, in the acute hospital phase, most of the attention of the medical staff is focused on the suffering patient. Family members remain in the background and few people are aware of their suffering and emotional needs. Just as the patient must adjust to her injury, so the family must go through understanding, accepting and adjusting to the illness and distress of the loved one.

Wound dressing

Burn care involves repeated painful procedures for dressing and skin grafting. It is difficult for young children to understand why the person who is supposed "to make

things better" hurts them in the process. Healing by inflicting pain becomes a conflict for the burns team who have to perform painful procedures daily on the child. This is worse in some hospitals where there is not enough money to buy the modern dressings that don't have to be changed so often.

Children in pain do not know if worse will happen, but they know they can do nothing about it. This is particularly the case where wounds are cleaned by scraping off old skin. For days, sometimes weeks and months, there is pain every day. Even after the pain subsides, when the wound starts healing, the memory of the pain endured during procedures is enough to make the child scream. The trauma of the burn injury remains continuously relevant in the child's mind.

For other child injuries and illness there is a trend towards shorter periods of hospitalisation, but patients with burns can be in hospital for many months, with frequent re-admissions for further corrective surgery. The patient becomes progressively more dependent on the hospital staff and loses a lot of freedom. Long-term hospitalisation may also contribute to rivalry between parents and staff over the care of the child and even to the child's reluctance to leave hospital. When patients are ready to be discharged from hospital, the trauma continues. The child still will have to face periods of great physical and mental suffering, particularly when she has to re-meet family, school, peers and friends. This is worst when scarring and deformities are visible.

The psychological impact of the burn injury on the child is not only prevalent during hospitalisation, but also during the long-term adjustment to the injury.

Developmental issues

Adaptation in burn-injured children is complex owing not only to the burn trauma, but also to age-specific developmental issues. Child patients, because of their limited life experiences, developing cognitive, emotional and social capabilities and dependence on others, are particularly vulnerable to influences fostering maladaptation.

Back home

Much of children's behaviour after discharge can be understood as testing out whether their parents love them and whether they can help to control aggressive feelings. Some children shout, swear and fight, unable to deal with underlying fears,

others are unable to sleep at night or do not want to be left alone. Other children seem to give up the battle, regress, cannot face school, cry at the slightest telling-off, cling to their mothers and show fear of any new or difficult situation. Outbursts of temper are often the child's way of trying to deal with intense anxiety.

The psychological effects of the burn injury remain long-term and often persist into adolescence and adult life.

Behaviour problems

Studies have shown after one year post burn injury with between 15-50 per cent total body surface area burns; boys aged between 4-11 years had behaviour problems in social interaction and sexual identity. Those boys also showed more delinquent behaviour and less competence in social interactions at school. Girls aged between 4-11 years also suffered problems in interacting socially, in thinking and in paying attention.

Sleep disorders are common in children long after burn injury and discharge from hospital. These disorders included bed-wetting, sleep-walking, nightmares, with daytime naps well beyond the normal age for napping. Recognising and studying these emotional, psychological and psychosocial variables in burned patients is crucial for intervention in hospital and at home during recovery.

Long-term childhood disorders may cause significant and permanent interference with the child's physical and emotional growth and development. This is particularly the case when the child suffers from depression and anxiety.

Eighty per cent are emotionally disturbed

Emotional reactions in burned patients such as fear, anxiety, restlessness, psychotic behaviour and depressive symptoms occur while working through the traumatic event. Separation anxiety is common as is regression to the emotional responses of young children after burn injury. A study of some 200 children under 15 years who had survived burns of more than 10 per cent of the body surface area, showed 80 per cent of the children were emotionally disturbed.

Most frequently this showed as fear and anxiety, lethargy, aggressiveness and psychosomatic disorders such as sleeping and feeding difficulties, urinating without control and stammering.

The behaviour of burned children is like that of other children who are hospitalised, but tends to be more extreme. Children of all ages who have a relatively large burn, commonly show extreme anxiety and pain, including body tensions, shivering and rhythmic movements. They sometimes grind their teeth or bite their lips or the insides of their mouths raw. Even survivors with just a small percentage of the body surface burned, experience prolonged disabilities, skin breakdown, itching, sleeplessness, reduced stamina, incomplete recovery of motion and strength, changes in body image and particularly depression. These problems are redoubled with more extensive burns or if the burns involve face, hands or lower legs.

Adolescent depression

When compared with the patient's description of their character before the burn, adolescent burn survivors with face and hand burns showed a significant increase in depression after the injury, while those with burns to other areas of their body do not show the same increase.

The incidence of depression and anxiety is high in burn-injured patients of all ages. Mild depression occurs in about 58 per cent of burn-injured patients, while moderate depression occurs in about 23 per cent to 61 per cent of burn patients. Between 19 per cent to 30 per cent of burn survivors have severe depression.

Depressive symptoms are high with burn patients because the injury causes losses and separation. There is loss of health or loss of appearance and sometimes loss of physical and mobile ability to play and be active. Separation from the parents and loved ones and isolation in the hospital burn unit is also a loss for the child. For older children there may be a gradual awareness of what they have lost after being burned.

Losses and concerns

A study examining some of the losses and concerns of 60 child burn survivors aged between 6 -19 identified five major aspects of post-burn life. **Preoccupation with health**, refers to the child's anticipatory thoughts and feelings about treatment procedures. **Internal acceptance** refers to the increased awareness of the various long-term medical or physical outcomes. **Reconstruction of one's life map** is the process of redefining personal dreams, goals and plans. **Changing relationships** involves the process by which others and the burn survivor incorporate the effects of

the burn injury into their relationship. **Redefining the world** refers to attempts to make sense of the burn trauma.

Anxiety about the future is inevitable; not knowing what to expect, anticipating the worse, yet hoping it will not happen, all combining into anxious feelings. Older children are worried and anxious about themselves, about operations and being cut open, about dying, about change in their appearance and body and about losing control of their bodily functions and consciousness.

The anxiety that a burn patient may feel from the beginning of the impact of the event, through to hospitalisation and later long-term recovery is continuous traumatic stress. Although the traumatic event itself has ended, the patient still faces a period of severe psychological and mental suffering that may qualify for the definition of further or multiple trauma as well as post traumatic stress disorder.

Post Traumatic Stress

Burn injuries are of sufficient severity to meet the Stressor Criterion for Post Traumatic Stress Disorder (PTSD) of the American Psychiatric Association's Diagnostic and Statistical Manual. This disorder is defined as one caused by exposure to a traumatic event outside the range of human experience and that would be markedly distressing to almost anyone.

For the burned child, how she adjusts determines if she is at risk of post-traumatic stress developing. PTSD is much more common a year after injury than during the time in hospital.

Increasing attention has been given to factors that predict post-traumatic stress following burns. After discharge, burn victims respond to stressors, including pain, disfigurement and functional limitations, which can impede adjustment.

Continuous Stress

During this phase PTSD is associated with disfigurement and low self-esteem, avoidant coping style and poor social support. Some psychologists think burns patients have Continuous Stress Disorder, rather than PTSD, and say it has three phases: the event itself; an extremely difficult period of hospitalisation and a new encounter with the social environment, with all its concomitant difficulties.

Psychic trauma is when an individual is exposed to an overwhelming event resulting in helplessness in the face of intolerable danger and instinctual arousal. Children

suffering from psychic trauma resulting in a traumatic state of regression and helplessness, exhibit paralysis and immobilisation, ranging from numbness to an emotional storm; disorganised feelings, thoughts and behaviour and physical symptoms reflecting autonomic dysfunction. (The autonomic nervous system is responsible for control of bodily functions that are not consciously directed, like regular beating of the heart, sweating, salivating.)

Children can look panicky and submissive or can show frenzied over-activity, tantrums, rage or shock-like, stunned reaction and unresponsiveness, symptoms that could be linked to Post Traumatic Stress Disorder.

Re-living the burn

The way in which children are affected by post-traumatic stress affects their learning, behaviour and progress. A child with post-traumatic stress has at least one re-experiencing symptom: intrusive recollections of the event, distressing dreams about the event, sudden activity or feeling as if the event were recurring and intense physiological distress when exposed to events that symbolise the event.

Children's post-traumatic stress includes daydreams, fantasies, nightmares and behavioural changes linked to sudden sights or sounds that may remind children of the traumatic event.

Post-traumatic behaviour in pre-school children can include withdrawal, denial, anxious attachment and regression. In younger school age children: performance decline, behaviour and mood changes, psychosomatic complaints, and in older school-age children/adolescents: low self-esteem, displaced anger and pre-occupation with themselves.

Timing of Traumas

Traumas occurring during a specific developmental stage creates special vulnerability for the child, by not enabling successful resolution during that stage and leaving the child less able to resolve future issues successfully. The trauma produces anxiety, lack of psychological equilibrium and attempts at coping with this anxiety can block successful mastering of developmental tasks.

An important developmental concern is the interplay of the processes of trauma resolution and other childhood tasks. After psychic trauma in childhood, schoolwork, play and interpersonal relationships are hampered. The child's growing ability to take

an active role in dealing with changes in current life circumstances, may be eroded by traumatic anxiety. When there is continued reworking of traumatic memories, it can also have long-term effects on the child's abillity to learn and understand.

Feeling ugly

After enduring a long hospital stay and separation from family, children have to adjust to changes in their appearance and must learn how to tolerate others' reactions to their disfigurement. Some children learn to accept these challenges and adjust well psychologically; others isolate themselves.

The subsequent disfigurement can also place children at high risk for psychotic dysfunction. The best reconstructive efforts cannot erase the psychological marks left by this severest of traumas. Children with disfiguring conditions tend to try to protect the sense of self from complete disintegration by maintaining the mental image of a normal body. This has a devastating effect when at a later stage in life the child has to confront her severe scarring. The child with visible burn disfigurement has to deal with prolonged stress, shame, depression, apathy and ego restriction long after the trauma.

A premium is placed on physical attractiveness in society. Being unattractive can lead to depression - which is often associated with medical illness and is increased when the illness or disfigurement is visible to others. Children and adolescents with facial and hand burns, which leave extensive scarring to areas that are difficult to conceal, disappear socially rather than be ridiculed in public.

Disfigurement during adolescence where body image is so important, is particularly devastating. Body image is a component of the self-concept that is formed from sensory and social experiences, with cultural and familial reactions to one's body having great importance in determining one's own attitude. Altered physical conditions such as disfigurement can be accompanied by changes in social interactions, leading to changed body image.

Breast scars

Girls and women with burns have a more negative body image than boys and men with burns. This is particularly true for adolescents who have breast scars and sometimes their breasts cannot develop properly due to tissue damage.

Physical attractiveness comes close to being sexually attractive, which is one of the major social areas that badly affects the burn patient.
Burn patients with facial scars are most readily rejected in the competition for sexual partners.

Hidden injuries

Burned children of all ages in peer group counselling, speak of guilt feelings associated with fear of discovery of hidden injuries. Younger children with concealable burns who may have made reasonable social adjustments, will often feel renewed social stress upon reaching the age when having to dress in front of other for physical education classes.
Visible scarring is thought to be more psychologically damaging than hidden burns but there is little evidence to support this.
Awareness is needed with child burns survivors who may appear superficially to be adjusting well, while harbouring grave self-deprecating feelings and those with visible scars who will need special support to enhance self-esteem.
For male or female, it is hard to keep a positive body-image and some sense of self-esteem in the face of continuous negative reactions from the public to disfigurement and scarring.

Lack of worth

We judge ourselves in relation to the community, and our sense of personal value always (to a degree) depends upon relationships with the outside world. A core sense of one's worth or lack of it, may be internalised in childhood and adolescence. This is an excessive burden for children who then have to confront and integrate their own feelings towards their body image as well as the attitudes of the people and culture around them. Society stigmatises individuals with deformities, denying them full social acceptance and adding disapproval, denigration and avoidance. Although this attitude towards scarred and disfigured people is not necessarily communicated visibly to the specific individual, it is an issue that burn-disfigured people all have to confront.
Willis-Helmich (1992) in an article on "Reclaiming body image" explored her feelings as an adult after a burn injury at the age of four years old that left 45 per cent of her body with permanent scars. In a burn survivors' self-help group, unclothed, she

expresses the sadness in the group members eyes and states that “perhaps in my burn injury they recognised the pain that I had been through.” The burn injuries are located on her chin, ears, neck, shoulders, upper arms, chest down to waist and large areas on her legs. Part of this support group's intention was to reclaim positive feelings about their unclothed bodies. Looking at her body in a full-length mirror, her focus was on her scarring and the confirmation of the physical and emotional pain that she had experienced with this burn injury. It took her several years to feel comfortable about her body before an integrated body image emerged.

This example identifies the years of struggling with issues that a serious burn injury at the age of four years can leave.

Social support

A study of some 120 patients, 14-27 years old burned within the past ten years, found that those who received social support, especially from friends, had more positive body image, greater self-esteem and less depression than others. Body image is influenced by social experiences and that social support can buffer the negative effects of physical trauma.

Social support is crucial during the long term process when burn survivors have to look deeper into themselves to find the sense of beauty and worth that was formerly obtained through physical appearance. It can lead to a better understanding of what it means to be a loveable human being, but it can also mean waves of grief, rage, anxiety and depression as the loss sinks in. The degree of support given to a patient will vary, according to resources available and this has an effect on psychological adjustment.

Psychosocial adjustment

Psychosocial adjustment is best achieved where disability doesn't affect function too much, where the child can join in with more recreational activities, has greater friend support, less use of avoidance coping and more use of problem solving.

Social support helps rehabilitation of burned children and training in such support should ideally be given to a suitable health care worker. The family is under considerable emotional stress, which makes it difficult for them to provide the best support for the child. Social support is valuable, even crucial, during the acute phase at hospitalisation, as well as during the long-term rehabilitation of the burned child.

Working out some kind of meaning and some sense of personal worth for the family as well, is part of the process of the long recovery from a burn injury. Recovery that cannot be made in isolation.

Two hard years

The first one to two years after the injury are the most difficult because of follow-up care, wearing of pressure garments, recurrent skin breakdown, itching, the strain of resuming normal activities and the emotional intensity of adjustment to changes.

Adjustment is the ability for a burns patient to resume her pre-burn level of functioning, accepting a change in body image and a loss of certain roles. It may involve returning to a different, lower level of functioning.

The patient goes through stages of shock and disbelief, grief, awareness and acceptance of loss where the child comes to terms with reality and returns to the best possible level of functioning. Each stage has to be worked through successfully before adjustment is reached.

Variables that affect the child's adjustment are the severity of the injury, compliance, and characteristics of the child and family.

Delayed grieving

A young child may not be concerned about her appearance, but may reactivate the grieving process during adolescence and young adulthood.

The pre-burn emotional state of the child may affect and prolong recovery, particularly if there were significant behaviour problems before the injury.

Each child, even the most independent, the youngest, the most outcast or the most mentally impaired, had a rich background of personal experience and a network of social relationships. Any serious emotional problems that occur during acute treatment for the burn injury, or even during the lengthiest period of post-burn adjustment, rarely arise simply as a result of the burn or what follows physically.

Before a traumatic event, the older child has a distinctive personality and coping skills that work for her, so adjustment to the burn injury is an interplay of previous personal experience and continuing social support.

Adolescent burn patients show a much poorer psychosocial adjustment when compared with younger children. Visible burns, emotional distress in the mother and

multiple home moves all add to poorer psychosocial adjustment in burned adolescents.

Hope

For a person to resume a normal life after a major burn injury, they need remain hopeful for the future. Without this, there is a sense of failure, an inability to cope and a loss of gratification from interpersonal relationships, as well as a sense of disruption in time.

Some people may never reach the final stage of adjustment, often remaining in the avoidance stage, using denial to cope and reducing anxiety and stress temporarily.

Good adjustment is likely in a family environment in which commitment to each other is strong and where communication allows expression of conflict and encourages independence and active mastery of the environment. The role of parents in a child's adaptation to a major burn injury is critical.

Family trauma

It is hard for parents and family who need to provide support, as trauma affects those closest to the family and friends as well as the survivor. Disruption of these relationships, whether temporary or permanent, affects all these people. Witnessing the traumatising of a person one cares about, often seriously affects the family. Parents feel pain from the trauma of the accident but also by watching helplessly as their child endures the pain of the burn and the medical treatment. It is hard to be supportive while at the same time having to endure their own emotional trauma.

There is no correlation between the depth or extent of a burn and the stress it induces in the family. Most parents suffer the same process of guilt, anxiety and anger, whether the burn is large or small and irrespective of how the burn was caused. Parents of a burned child have prolonged disruption to ordinary family life with a child who requires time-consuming daily attention for months after leaving hospital.

The impact on the siblings of the burned child is also a primary concern to parents whose daily routine is disrupted by the injury, hospitalisation and rehabilitation process of the burn survivor. Financial hardship can be a big worry for the family; the mother having to sometimes stop work to visit the child daily or even sleep at the hospital.

Attention to the family as well as the total care of the patient is needed to promote emotional and physical healing. Lack of family and social support is linked to poor recovery for burned children.

Shock and acceptance

Relatives of the burn patient go through an adjustment process similar to that of the patients. The first stage is one of acute shock and grief like the acute physical and emotional trauma experienced by the child. In the second or convalescent stage, the relatives overcome shock and disbelief, accept the injury and begin to help the child to recover.

As parents cope with the initial shock, the distress of their child and the new information they are being given, they are also coping with great fears for the future, namely “will my child live?” Parents can think this even with a superficial 2 per cent burn. They ask: “Will my child be scarred?” as they worry about acceptance for the child. “Will my child be able to live a normal life?” and “What changes will be needed in our family for us to deal with this terrible situation?”

Six sad stages

Some researchers list six stages of grief in both the burned child and the family. At first there is emotional numbness, when nothing seems real, followed by denial that the burn injury could be as bad as it is. Then comes the anger and guilt, when one asks “why me?”, “why my child?”, “why now?”, “what did I do wrong?”, “how could I have let this happen?”. During this stage, both the child and the family re-experience the burn accident in their minds, trying to work out why it happened and what they could have done to prevent it. Although these stages tend to occur one after another, there is a shifting back and forth between emotions and stages. This occurs because burn patients, especially growing children, often need extensive or reconstructive surgery involving repeated adjustment to a new appearance; the process of adjustment for the child and family can be prolonged over many years.

Separation anxiety

Parents’ and children’s reactions interact following burn injury. Frank separation anxiety was apparent in the mothers’ disregard for the needs of other family members. The anguish experienced by many mothers seemed to represent an

identification with the child and an attempt to take over her physical suffering. The grieving, withdrawn mother mourns the loss of the intact child (replaced by a damaged and angry child) and anticipates the feared death of the injured child. There is also a grief for the loss of her own image as a good, loving mother, replaced now by her image of herself as harmful, bad and unworthy.

Other emotional and psychological post-burn effects on the family were identified as crisis, control, commitment, consequences.

The first phase (crisis) begins when the family member realises that the child has been injured and exhibits "behavioural disorganisation" consistent with feeling shock.

The second phase (control) is trying to regain control of her life and the routines of daily living after the disruption of the burn injury.

In the third phase (commitment), the family member must decide whether or not to make a temporary, but possibly prolonged commitment to continuing the relationship with the patient in an altered form, through the child's recovery and rehabilitation.

In phase four (consequences), the family member has to negotiate a renewed relationship with the child that has the potential to meet the child's emotional, social and economic needs.

Poor home, poor parent

The process is slow because the burn patient’s slow recovery and rehabilitation can cause persistent family distress, stimulated by constant reminders of the traumatic event, such as clinic visits or the patient’s visible disfigurement. Chronic distress can also occur in reaction to continued demands on parents’ coping resources, such as financial concerns, the patient’s rehabilitative exercises or the need to help with the often painful application of pressure garments.

For some children with burns, a variety of psychological factors can make the burn trauma especially devastating, for example, many children who sustain burn injuries come from low income homes and have depressed mothers with poor parenting skills who are unable to aid the child in coping. Adolescents with emotionally distressed mothers, show a markedly poorer psychosocial adjustment.

Burn injuries are more common among families of the lower social classes, where poverty, poor housing, inferior diet and overcrowding interact and can lead to sudden tragedy, particularly in the one-parent family.

Positive psychological adjustment happens most easily with greater family cohesion, independence and more open expressiveness within the family. This will be more difficult for a child in a family with social problems and lack of family commitment and cohesion. The worst psychosocial adjustment will be in a family environment characterised by conflict and diminished cohesion, which can also be predictive of alcoholism, delinquency and other disturbances.

Emotionally disturbed mothers

Follow up studies of children who have recovered physically from severe burns have revealed that emotional disturbances not only in the children but also in 60 per cent of their mothers. Most mothers thought that the disturbances in their children were the result of the burn experience, pain and the separation from home during the hospitalisation, but some studies report a high incidence of psychopathology in the family unit before the burn incident.

Many mothers were preoccupied with some unresolved problem at the time of the accident. This preoccupation appeared to divert the mothers' attention away from the child and delayed reactions that could have prevented injury.

Whole-family counselling

Chronic relationship problems may be most easily seen at the time of the children's burns. These maladjustments are related to the trauma of the burn and with mothers interviewed at 4½ years after the injury, it showed that the trauma was still not worked through adequately. It is essential for both the injured child and the mother (ideally the whole family) to get counselling over this traumatic period. This is needed to reduce emotional maladjustments later in life, particularly because of the important role the mother plays as caregiver in rehabilitating the child.

Family members need to be prepared for what to expect during all phases of recovery and supported in dealing with their own reactions to the injured child. Family members who have psychological difficulties should ideally be offered counselling and therapy. Joint family sessions can be very helpful during and/or after hospitalisation.

Few systematic studies of the needs of family members of burn victims have been undertaken. And there has been little description or measurement of the mother's response in the early stages of the child's rehabilitation process, when the mothers'

mental and physical resources are most needed to cope with the child's care. This void of information is particularly significant when one considers that psychosocial and perhaps physical recovery from burn injury, as well as compliance with follow-up care, is associated with support from loved ones.

Most studies that examine the mother's response to their child's burn, look only at retrospective descriptions and interpretations of mothers' emotional disturbance. Post-traumatic stress disorder is prevalent in parents of burn-injured children. It can be disruptive to a mother and interfere with her caring for her child.

Change

Change creates stress for the family and sometimes these changes can be for the better, by drawing closer together. Often the crisis brings the opposite reaction as families become fragmented and are unable to re-establish closeness.

The family's first reaction on arriving at the hospital is that of relief because the patient has not died or been burned more severely. Rationalisations that "it could have been worse" provide an affirmative basis from which to begin coping with the stress that they face. Soon after admission, severely burned patients experience confusion and disorientation and sometimes can be abusive orally or physically. Relatives find this stressful and frightening and find it hard deciding whether this behaviour represents the patient's true feelings, or whether it is a result of delirium or sudden mental illness.

Regression

Another source of stress for relatives is the psychological regression of patients who become complaining, demanding and dependent. For the family that is unaccustomed to this behaviour, they want to respond, but are confused by demands that seem out of character.

The pain that the patient must endure also results in a sense of helpless frustration in the relatives; as well as their anxiety over frequent skin grafting operations.

Later during recovery, pain is replaced by itching as the skin heals. Some relatives become overwhelmed by the emotional stress of sitting at the bedside of a loved one, sharing their suffering. This can lead to anxiety and depression in the relative.

Disruption

Normal family functioning is disrupted when one or both parents spend a lot of time at the hospital or leave home to be with a child who is being treated at a large burn centre far away from the home community. If there are other children in the family, they are often without a mother or given to other relatives or friends to look after. These siblings are often upset by the burn injury and separation from their mother and brother or sister. They may even have nightmares or behaviour problems of their own; it also common for parents to have difficulties sleeping and eating. Previous physical problems that are stress related, such as hypertension, ulcers, headaches and asthma can often be aggravated by the added stress.

Recoil

Families often don't know how to manage this stress, as well as the restructuring necessary for the changes brought about by the burn injury. Restructuring can be in three stages. “Recoil”, following the critical incident, where family members respond by allying themselves to meet the threat. This stage has increased intimacy, trust and communication. In the second stage “reorganisation,” when the situation has stabilised, old patterns of communication and old conflicts reassert themselves. This may lead to polarisation and fragmentation. In the third stage, “restabilisation,” family members are unable to rebuild the relationships exactly as before. A new period of stability characterised by deteriorated or increased levels of intimacy occurs.

Anxiety about death

A burn injury is a traumatic experience for the uninjured relatives. They must cope with anxiety about death, communication difficulties with the medical staff, fear of deformity and the boredom of a prolonged hospital stay, as well as enduring the trauma of watching a loved one suffer. It often seems that total recovery will never arrive and that one discomfort is succeeded by another.

If the mother is in a state of shock and suffering from stress and anxiety, she could pass on these feelings to her child, increasing his distress and impairing his adaptation to the hospital setting and adjustment process after discharge. There is correlation between the mothers’ anxiety and the amount of upset behaviour shown by the children after they had been in hospital. An overly distressed parent could

significantly impede the child's ability to tolerate burn pain, hamper therapy and affect rehabilitation.

No preparation

Depression, hopelessness and stress response symptoms of intrusion and avoidance were significantly more prominent in the parents of burned children. Burns allow no time for psychological preparation. Burn injury may irreversibly alter the appearance of a child and trigger mourning to this loss. Burn injury is frequently associated with actual or perceived parental neglect.

Visual reminders

Sensory reminders trigger distress in re-experiencing reactions, it is more likely that parents who must adjust to a visibly altered child, will suffer from stress response symptoms.

Big burns are more strongly related to parental post-traumatic stress disorder.

Mothers with more than one child burned and those mothers who were burned themselves, are severely traumatised and usually less able care for her child with burns after injury.

Unbidden ideas

Signs and symptoms of response to a stressful-like event are expressed in two predominant phases: the intrusive state, characterised by unbidden ideas and feelings and even compulsive actions, and the denial state, characterised by emotional numbing and finding it hard to think. The intrusive state includes rushes of feeling, sleep disturbances, confusion, intrusive, repetitive thoughts, disorganised when thinking about themes related to the event.

Some of the symptoms that emerge during the denial phase of stress-response syndromes are amnesia (complete or partial), numbness, fatigue, headaches, muscle pain, disavowal of meanings of current stimuli in some way associated with the event, loss of a realistic sense of appropriate connection with the ongoing world and withdrawal.

Troubled parents

Parents of burned children often see their children as troubled and having an increased number of behavioural problems. Parents who report their children as troubled, are themselves stressed, not only by their children's behaviour, but in areas unrelated to their children. These mothers report often feeling depressed and guilty.

Parents report significantly higher depressive symptoms two years after the child's burn injury and lower than normal levels of depression in years four and five after the child's injury. Parents of recovering children with burns seem to develop a focus on the child as their new primary source of stress, whereas parents of children who do not have burns and parents of children with acute burns, perceive their stressors to be more evenly divided among personal characteristics and their children.

Parents of recovering burn survivors describe their children as very demanding, dependent and unhappy. These parents see their children as overly active and restless. They are disappointed in their children and do not experience them as a source of positive reinforcement.

Family stress is rife, particularly when the mother is not coping due to stress. This affects the children. Family stress increases the risk of burn hospitalisation in children. In some studies 74 per cent of mothers were at home when their child was burned but were temporarily distracted. Single mothers living alone were at increased risk of having a child hospitalised for a burn, compared to married couples. There are more childhood burns in families with low maternal education and low family income.

Epidemiological studies reveal that burn injuries and trauma to children occur more often in families that are already more stressed than the general population; particularly single-parent families with little money and lots of children.

Even if stress is not a cause of burn injury, it would increase as a result of the injury. Hospitalisation of a child is stressful to any family and distress increases when parents are expected to provide or supervise the daily baths, exercises and wearing of splints.

Psychological distress not only has an emotional impact on the family, but it has also been shown to have a physical reaction on the body. The stress profiles of spouses and parents of patients with burns greater than 20 per cent total body surface area, measuring depression, anxiety and cell-medicated immunity, show that immune function declined as depressive symptoms increased.

Maladjustment

A study on mothers of ten children who had long recovered from severe burns indicated the existence of lasting emotional maladjustment in both children and mothers, related at least in part to the trauma of the burn. They contained evidence of adjustment problems of sufficient magnitude to justify in ordinary clinical practice, their treatment in an outpatient child psychiatric clinic. All but two of the mothers in their samples were described as depressed by the two interviewing psychiatrists; six of the seven mothers cried openly during the interviews whenever the children's burns were mentioned. Feelings of guilt were common with all.

Close relatives of patients hospitalised for burns showed specific stress syndromes characterised by intrusive and avoidant responses to the post-burn trauma. The intrusive-avoidant stress responses could not be predicted by demographic information, severity of the burn, facial disfigurement or actual responsibility for the burn; but by the mothers blaming themselves for the injury to their child.

Self blame predictor

Self blame is a predictor of a stress syndrome and its presence in relatives should be assessed shortly after the burn, to target people needing primary prevention. As a mother attempts to rationalise the cause of the accident, she will ask herself "whose fault is it?" Although the accident was completely unintended, she will usually consider that the ultimate blame rests with her. The failure to protect the child from the burn results in guilt. Most mothers had a strong desire to protect the child from any further harm.

Guilt

Parents feel guilty about the burn accident, whether they were actually involved or not. They feel that they have failed in their role as protector. There is also the fear that the child will never forgive the parents and blame them for the accident. They go through a process of imagining what they could have done, or not done, to prevent the accident. If a patient dies during the first phase of post-burn adaptation; that of crisis (soon after the injury), certain family members will be at a higher risk for developing problems during bereavement with self blame for the patient's death.

Most relatives carry this additional burden because they feel that they have contributed to, or caused the accident in which the patient was injured.

Even when relatives have had nothing to do with the injury, some feel guilty. They explain this feeling on the basis of not having foreseen the possibility of the accident and not having taken steps to prevent it.

Some mothers are so filled with horror over their child's burn injury that they are unable to acknowledge blame for the accident or will make excuses to account for the accident to soothe their guilt feelings. This denial of guilt is usually a temporary response and acceptance of some responsibility occurs in time, whether it be minutes or months.

Anger

In view of their child's visible injury and obvious physical distress, many mothers feel too guilty to show the anger and resentment that they feel towards the injured child. Some parents feel that their child grew up or away from them during hospitalisation and some maintained this detachment in their relationship after discharge. These were particularly the parents whose anxiety and guilt after the accident were denied or unresolved.

Relatives who are rated as guilt-ridden, demonstrate more dramatic stress response symptoms than those who were either troubled by guilt (had mild guilt) or expressed no guilt. Most of the relatives who were quite distressed and guilt-ridden at the time of the burn injury, also were significantly distressed after six months and all showed at least moderate distress.

Time to adapt

Memories and effects of burn accidents are often recalled in detail by parents and do not decrease significantly with time

One and a half to five years is enough time for a reasonable, stable mother to adapt to a burn crisis, and if she still shows signs of disturbance at that point, she may have been chronically disturbed before the burn crisis. If so, her disturbance may have in some way contributed to the accident.

When the child is burned, most researchers report that the primary parental reaction was fear for the survival of the child, but that this was quickly followed by guilt and general anxiety about the future. Typically 60 per cent of mothers had upset nerves and 16 per cent suffered nervous breakdowns, which was felt to be related to guilt and a loss of mother image. These mothers possessed unconscious hostility towards

the burned child. Such hostility stems from guilt and alienation, causing parents to fluctuate between rejection and overprotection of the child. Failure to protect the child from injury results in guilt and this leads to a desire to protect the child even further. This involves spoiling the child to repair the damage done to her and anxiety at any further potential danger to the child, resulting in the mother becoming protective with the child to the extreme, and having a strong desire to warn others of the dangers of burns.

Over-protective

Mothers' feelings during the period when the child first comes home involve two contrary emotions, namely "shame and guilt" and "angry". The mothers' feeling shame and guilt are the ones who try to "make it up" to their children. They spend more than they can afford and are unable to say no in any form. Often they develop an over-protective attitude that is aimed at safeguarding the child from the risk of further accidents, but it is also associated with reducing their own guilt feelings. **The mothers that are angry with their children are the ones who feel that their child has let them down. This hostility is not easily expressed openly, but sometimes shows itself in a crippling possessiveness, and encouraging the child to be dependant, which can only be harmful to the child**.

Parents of burned children in their study experience a loss of appropriate perceptions and have an unconscious hostility towards the child due to the role perception loss. The parents tend towards both anxiety and hostility and pre-occupation with physical injury and/or deformity, as well as poor self-concept.. Mothers of burned children possess very low perceptions of themselves in general and in their ability to fulfil the role of a mother in particular.

Protest at withdrawal

Aggressive reactions occurred among children whose mothers consciously blamed themselves for the accident and who responded to feelings of guilt with depression and withdrawal from the child. Their children countered this loss of support with provocative, anxiety-arousing behaviour in protest against the mother's withdrawal and an attempt to restore her interest and evidence of her care.

The interaction of stress symptoms after a burn injury affects the whole family

and often marriages are threatened. Typically four out of ten mothers had marital problems, two had been divorced within one year of the accident, seven out of ten were depressed and most felt they had to suppress these feelings in order to help the child. These mothers said they did not display or even discuss their feelings with their doctors at the time of the accident. They refrained from making their emotional state known because of the irrational fear that their action would distract the doctor from the care of the child. Also because of a guilty sense of selfishness over their own sense of need. For mothers carrying this guilt burden alone, it causes a tremendous strain on the family.

Marital conflict

Marital conflict can follow when a child is severely burned. It generally arises when the father blames the mother for the accident and by projecting all the fault on to her, he escapes from his own guilt feelings. The removal of his support seems to be one of the major factors in causing a breakdown in the mother.

The burn accident often happens when the father is not there and his experience depends on information given by others. His early reactions often reflect the marital relationships. When he is critical he uses the accident as a pretext for expressing anger at his wife. Where the marital relationship was mostly warm and supportive, he more often showed concern and tolerance. Many fathers isolate themselves by visiting the children less often and leaving responsibility with their wives.

Critical atmosphere

Too often parents don't visit their burn-injured child in hospital. Parents felt useless and helpless in the presence of specialist skills. Parents are acutely sensitive to what sometimes seemed to them a critical atmosphere and some failed to return to visit the child because of this.

Most mothers experience great anxiety and guilt and often the conflict centres around frustration at losing immediate responsibility for their child. This is shown by repeated requests to take home a severely burned child, by a mother who, at the same time, feels the accident is already evidence of her inability to be responsible and knows that in reality she could not nurse the child at home.

Burns units

Going to any burns unit can be a great strain for most mothers, even if their own child is not badly burned. Mothers describe nightmares that they have and some worry about other burned children that they have seen in the ward. One mother is even described as feeling so ill after two visits to the unit that she could not return, although her own son's burn was a slight one.

It is an added strain to see other children suffering and crying in pain. Added to this, are her ever-present guilt feelings to work through.

Burned to death

For the family of the fatally burned child, the mother's guilt has a devastating effect. Six out of seven mothers felt guilt arising from their absences at the time of the accident and from an ambivalent relationship with the child before the accident. Guilt had a punitive effect; of three mothers who showed suicidal tendencies, two received psychiatric treatment; three others suffered from severe depression and said they too, felt partially dead.

Inadequate

When these parents gave up the hope that their child would survive, they could no longer feel like good parents, but only inadequate bad parents with no chance now to change this situation. This feeding the guilt feelings and self blame even more and adding to parental stress responses.

In one study, in 19 instances mothers consciously blamed themselves for the accident, while 27 mothers projected their feelings of responsibility on to other objects, including the child, other people and external circumstances, such as particular housing conditions and specific domestic practices.

God's will

Eventually relatives (i.e. usually the mothers), resolve their guilt feelings and achieve rationalisation, that relieves them from full responsibility for the accident. They do this for example, by thinking or claiming that the accident happened because it was God's will or because it would draw the family together, or because of the carelessness of others.

The guilt and self blame apparent in most mothers with burned children cannot be compared to the self blame found among adult burn patients. Adults have the added anxiety of death because of the expectation of punishment, with the patient always tending to blame himself for his burns. Behavioural self blame for the burn accident is a significant predictor of poorer compliance with nurses, more pain and greater depression.

Controllable

The attribution of undesirable events to one's behaviour allows a person to perceive the occurrence of similar future events as more controllable. Attributions to stable aspects of the self are the dominant force in "characterological self blame", where negative events are seen as the result of personal inadequacies or failings. Characterological attributions may result in subsequent motivational deficits and greater distress.

Behavioural self blame appears to explain why the event happened to the victim in particular because of something he/she did or failed to do. While characteriological self blame would also be a satisfactory way to respond to "Why me?" This self-attribution would be detrimental to the rebuilding of assumptions about personal invulnerability and positive self-esteem.

Therapy

Individual therapy during and after a child's hospitalisation can help mothers to reduce stress and to develop better coping skills. Counselling can assist parents to express their grief and to work through their guilt and self blame.

The mother seems to be a neglected victim of her child's burns. Her plight needs recognition.

Psychological support and intervention for burn patients and their families, by health care professionals, although urgently required, is not offered in Southern Africa. There is a shortage of burn professionals in terms of psychologists and psychiatrists. Rehabilitation with a multi-disciplinary team offering psychological assistance does not exist at any of the main burn unit hospitals, so long term follow-up of the burn patient is almost impossible. Future intervention is urgently needed in Southern Africa, as well as a protocol to follow.

Very little effort has been devoted to the development of intervention methods to assist child patients to cope with hospitalisation and repeated exposure to highly invasive medical procedures.

There is a need for post-traumatic stress debriefing, the support of family and friends, psychotherapy, behavioural therapy, psychiatric approaches, as well as social skills training. Consultation is needed with well-trained social workers and mental health professionals to allow mothers to express overwhelming feelings of helplessness, anxiety and guilt. Child psychologists and psychiatrists may also provide information to mothers about their child's changed behaviour and emotional state after the burn. An understanding of how children react to a burn injury may help mothers regain some control of their parental role.

Parent groups

Parent groups help people adjust to their children's burns as fears relating to a child's survival, possible deformity and future adjustment can be discussed openly..

Most patients would welcome regular support meetings after discharge; even two years post-injury. All patients or parents wanted additional information or support groups, hospital talks and social meetings. Expression of emotions is part of the healing process so **patient education forms an essential part of treatment**.

By providing information to patients with burns and their families about the importance of social support, it may lead to more positive psychological responses to the burn injury. Adolescent and young adult volunteers could lead peer support groups for young people with burns in the hospital, to provide education, the opportunity to explore feelings and the experience of acceptance.

A psychiatrist could help manage disruption and despair of the families as well the care of the patient and staff issues, as an integrated member of the burn team. A psychiatrist can co-ordinate communication with the primary physicians. **The unique expression of emotions by many patients from various backgrounds and in various states of health must be considered by the staff**.

There are specific interventions burn staff can make with family members to resolve the issues faced and to facilitate appropriate post-burn adjustment.

Early treatment is recommended to improve social ties and maximise access to available support mechanisms. With early intervention for stress-response syndromes; immediate distress is reduced, chronic or delayed responses may be prevented, and pathological responses may not be fixed, making allowing shorter intervention.

Dynamic therapy

Brief dynamic therapy for stress disorders is one appropriate modality or if the patient fails to progress well through the adaptive phases (within a few weeks); further intervention is needed.

The trauma of a burn injury to a loved one and the subsequent reminders, cause more persistent distress in some family members than would be anticipated by a standard crisis model. It is important to identify the relatives at risk early in the development of the stress response, to enhance their compliance with psychotherapeutic treatment and perhaps also the medical rehabilitation of their relative. **Relatives should be assessed shortly after the burn to target individuals requiring primary prevention**.

Family problems must be anticipated and addressed by the medical and mental health professionals caring for the patient. Family members' need to be prepared for what to expect during all phases of recovery and supported in dealing with their own reactions to the injured patient. **There is a need to optimise parents' potential to provide adequate physical and emotional rehabilitation of the burn-injured child. Parents who are supported,**

encouraged and counselled during the inpatient phase can reinforce treatment goals for their child.

Home visits are critical to determine family and social functioning, as well as family dysfunction.

The absent parent (at the time of the accident) is angry with the parent involved. Working through the second parent's anger often assists them to acknowledge that they in fact could have been the one involved in the accident.

There is a need for a hospital psychiatric social worker to get to know the child and mother in the early stages of inpatient treatment. The social worker can help the mother to appreciate that her own confusion is largely due to the sudden and unexpected quality of the new situation. She can help the mother with suggestions as to what to do during this early stage. **When the child is home the social worker can help the mother to appreciate how the accident has upset the child's previous expectations of life being safe for him/her**.

Ideally the social worker and psychiatrist should work closely with other members of the team to help the patient and family cope with any emotional problems present at the time of the burn. They also work with issues arising from the trauma of the accident and treatment. Crisis intervention is offered during the acute phase where support around life and death issues are dealt with. Help is also offered to the family in making plans for the long hospitalisation. Later there is counselling for family members to be supported and encouraged to express their feelings in their own time. By allowing parents to assist in their child's care and management, it can result in positive feelings and enhanced self-esteem.

Skin anatomy

Few units prepare patients and their families to cope with the years ahead. The Frank Robinson Clinic in Manchester (U.K.) specialises in guidance and support for the patients and parents. Parents are educated in the anatomy of the skin, what problems will be met in the years ahead and how these can be overcome. Such interactive emotional support for the family is rare.

Increasingly high-technology burns unit can offer life to the extensively burned patients, who only a few years ago would have died of their injuries. But the corresponding need to increase the availability of aftercare nurse specialists to meet the challenge of helping such patients and their families return to a fairly normal existence, is denied.

Hospitals should prepare a simple pamphlet for relatives of burn patients to be given to them on arrival, explaining simple facts about injuries from burns and the operation of the unit. A second way of helping understanding among relatives would be the establishment of group information meetings, composed of family members of patients with a psychiatric social worker and a nurse or physician from the burn team.

Association and identification with other parents of seriously ill children, is helpful to many parents.

Problems of parent psychology and preparation of the parents for contact with their children, are of fundamental importance. Psychological disorders in children may persist for a long time after leaving hospital and often require the advice of a psychologist and psychiatrist, as well as having a supportive, understanding family.

Contact must be maintained on an ongoing or as-needed basis, to help families resolve many of the practical concerns that follow discharge. Interim telephone contact with anxious families can be very supportive and allow an opportunity to clarify instructions received in the clinic. Many Southern African families are too poor to have telephones though. For good rehabilitation, the family needs to be involved in and be aware of both intermediate and long-range medical and social rehabilitation goals and the importance of their roles in this process.

Sophisticated rehabilitation programmes, long-term follow-up services and community outreach assistance to both patients and families are sadly lacking in Southern Africa.

A planned approach to comprehensive rehabilitation for the burn patient should incorporate pre-injury, significant life events and post-injury adjustment.

The immediate survival of the patient with burns depends mainly on the skills of the surgical, anaesthetic and nursing staff. But the patient's long-term adjustment depends on personality and family support.

Research would be helpful on nursing interventions to reduce stress in-patients with burns. There is an acute shortage of allied health personnel trained in burn rehabilitation in Southern Africa. A large number of occupational therapists and physio therapists have left the hospital setting to work either in private practice or with home care agencies. There is no staff psychologist or psychiatrist on the multi-disciplinary team at the sole children-only hospital in Africa.

Severe burn patients' lives are being saved and then they are being put back into the community with little or no support, resulting in social withdrawal, depression and even suicide.

By understanding the many facets of rehabilitation, children surviving severe burns can have the best possible recovery of function and appearance, and regain quality of life, so reducing the burden on the survivor, the family and the community.