

disabled or disfigured. He thinks that disfigurement restricts people in what they can apply their talents to, because others are uncomfortable with it, thus limiting their opportunities. He finds that peer burn survivors can be helpful in dealing with this issue. On the other hand, he notes that, at least for a man, there is something "macho" about scars.

Years after the injury, when he felt he was recovered, he got involved in United Way volunteer activities. Then, about two years ago, he thought he should give something back for all the care he got in the hospital, so he became an active volunteer with the burn survivors group. He goes to the hospital once every two weeks and visits a few patients on the burn unit each time. He also takes phone calls from those in need of support. The support group has languished in the last few years because one person was doing all the work; when this individual died, they had to regroup, and Mr. Anders has been involved in this effort.

Impact on Family

Mr. Anders feels his support systems were extensive. People at work were very supportive, and support from family and friends was "unbelievable." They encouraged him a lot. His wife and daughters were helped by the employee assistance program (EAP) provided by his employer. The counseling there provided a place where his wife could express her anger. His injury was very hard on his children. His older daughter who was 11 at the time of his injury, still can't handle flames at all. His younger daughter smokes, but is not allowed to smoke in the house.

Getting through the injury was "a matter of will," for Mr. Anders and for his wife. They were determined to make it, and their marriage is stronger as a result. In fact, the injury strengthened the family; his children were very good through it all and everyone pulled together.

Costs and Lost Productivity

The cost of all of Mr. Anders' medical care was covered by his employer. The losses of his belongings were covered by his homeowners' insurance policy. Since he had just moved, there wasn't that much in his apartment. He is very grateful that no one else was injured in the fire. One loss not easily quantified is that he was about one-third through a book he was writing and the manuscript was destroyed in the fire. Due to his own recovery time, he was not able to complete the book, and since it was related to computer technology, the material was out of date by the time he would have been able to get back to it.

He probably lost nine months from work, since he wasn't very productive when he first went back. His wife was not working at the time, but she probably couldn't have worked because of the demands of caring for him and driving him to and from work. He estimates that he cost his company hundreds of thousands of dollars in lost productivity.

Mr. Anders indicated that his medical bills were about \$100,000 (early 1980s prices). The hospital bill alone for the first six weeks was \$57,000, which was covered almost completely by insurance. He estimates that his family paid about \$3,000 out of pocket.

Functional Capacity Limitations

Mr. Anders feels the residual effects of his injury are very minor--mostly a loss of flexibility and dry skin. He has all of his fingers, but there is some scarring which slightly limits his ability to spread the fingers of his left hand. For example, he can no longer play the guitar. There is a general loss of flexibility due to scarring, but by working hard, he maintains his flexibility. He joined a gym and works out a couple of times a week. He thinks the stretching through weight lifting really helped his physical recovery. Mr. Anders did have burns to his eyes and has residual scarring of his left cornea. However, this has not affected his vision. As for pain, he experiences very mild distress with no disability, and he does not take any pain medications.

Litigation

Mr. Anders did not undertake any legal action. The apartment building did not have a smoke detector, and there was only one way out of the building. But, he felt strongly that the fire was probably his fault, so he didn't want to pursue any litigation.

Quality of Life

The injury has had some positive effects. First, he quit smoking. Second, the injury has given him a different appreciation of life. He is more active and more persistent in trying to reach his goals. He feels more alive, and life is more precious. He is now involved in many things, so that if one goes wrong he has other interests. In contrast, before the injury, he was a "workaholic," working 10 to 12 hours a day and on weekends. Now he works fewer hours at his job, teaches, and does volunteer work.

Mr. Anders describes himself an unusually "upbeat" person, and says that "he works at it." He rates his quality of life as mixed to good before the injury. Six months after the injury, his quality of life was "terrible." Today he would rate his quality of life as "terrific." He no longer defines himself as a "burn survivor," and is looking ahead to deciding where he wants to go next in his career.

Other Comments, Findings

Mr. Anders finds that visiting other burn survivors is inspirational because many are doing very well. He found that some of the issues raised in the interview were hard to talk about, even after 10 years and a good recovery. "It's hard to predict how you will react to some things." For example, late 1984 was the first time he barbecued, and, to his surprise, it didn't bother him at all.

Mrs. Bailey (10 years post-injury)

Overview

Mrs. Bailey is a 49 year-old white woman. She is a married and has two children. She is a housewife and lives in a suburban area on the East Coast. She was injured in December 1983. She had second and third degree burns over 65% of her body, but has returned to her regular activities and feels that her long-term disabilities are minor.

Injury and Circumstances Surrounding the Injury

Mrs. Bailey was in her home in the kitchen around 11:30 or 12:00 at night. She was drunk and she was smoking a cigarette. She had either fallen asleep or passed out, and the cigarette ignited her clothes. The fire woke her up; she called for her husband and he came into kitchen and put the fire out himself with water. The fire department was never called. Mr. Bailey had first degree burns on his hands because at first he tried putting the fire out with his hands. No one else besides Mr. and Mrs. Bailey was injured in the fire. The only property damage was to the kitchen floor and chair padding.

Treatment and Services Received

Mrs. Bailey was taken to the to hospital right away. Her initial hospitalization, at a burn center, lasted three months. Physical therapy was started when she was still in intensive care at the burn center. She also received occupational therapy while hospitalized. The hospital team included a social worker, a physical therapist, an occupational therapist, nurses, and doctors. Special equipment included pressure garments, weights for exercising, and an exercising bar to reach up to. There was no psychological counseling at the hospital, and she feels she would have liked some had it been available.

It was hard for her to understand what was going on, especially during her initial hospitalization. Although everything was fine at the hospital, the nurses have to be "tough" with burn patients and she didn't understand this at first. They have to get the patient to move around, and she didn't want to because it hurt--now she understands that it was in her best interest.

Even with morphine, she was in constant pain. She was on morphine for about the first one and one-half months after her injury, and was still taking codeine when she went home. Mrs.

Bailey was discharged to her home, and returned to the hospital weekly for physical therapy. She has had plastic surgery about six or seven times since her injury.

Recovery and Adjustment Process

Mrs. Bailey noted that she went through "all of the stages that the terminally ill go through."¹ Initially, there was a tremendous amount of denial--she didn't believe what had happened to her and wanted to go home right away. The hospital didn't tell her how seriously injured she was (she found out later that she had a 2 out of 10 chance of survival). Even when a priest came in and gave her "last rites," she believed him when he told her it was just to pray for her recovery. Her husband didn't let on about how serious her injury was either.

The pain and disfigurement were the hardest parts of her injury to cope with. She continued to experience pain for three years. No one explained to her that it would go away--she thought she would be in that kind of pain her whole life. After three years, very gradually, the pain stopped. No one in the hospital talked to her about disfigurement. Due to her disfigurement, she didn't go out much, and only very gradually got back into activities outside the home. Psychologically, it was a difficult adjustment, especially because of the guilt she felt about the incident. She relied on her own strengths and the support of her family to get through this period.

It took her about three years to get back to her daily activities. Since she was a housewife before her injury as well, there was very little change in her activities or lifestyle. The main changes have been that she is much more concerned with improving her own health habits and those of her family (e.g., smoking and drinking). She is also probably a little less likely to participate in "fun" activities with family and friends since her injury.

Impact on Family

Mrs. Bailey's family was very supportive, but it was a strain for all of them. Her two children were 14 and 15 at the time of the injury, so they were old enough to help out. She was

¹ See, Kubler-Ross, 1969. On Death and Dying. The five steps identified and described by Kubler-Ross are: Denial and Isolation; Anger; Bargaining; Depression; and Acceptance.

able to manage at home alone, so no one needed to take off from school or work to care for her. Mr. Bailey took time off work to drive her to hospital appointments.

Costs

The costs of Mrs. Bailey's care were covered by the health insurance policy that her husband had through his employer. Homeowners insurance covered damages to the kitchen floor and furniture. There were some out-of-pocket expenses not covered by insurance.

Functional Capacity Limitations

Mrs. Bailey has less mobility in her legs. She also has trouble lifting her left hand over her head, and she has a little trouble lifting heavy objects, but otherwise she has no long term disabilities.

Overall Quality of Life

Before the fire and six months after the fire, Mrs. Bailey's quality of life was "terrible." Now, she is doing the activities she wants to be doing and her injuries do not hamper her. She rates her current quality of life as mixed to good.

Litigation

No litigation was pursued as a result of this injury.

Mr. Carter (16 years post-injury)

Overview

Mr. Carter is a 39 year-old white male. He was injured in 1977, sustaining second and third degree burns over 60 percent of his body. He is married and has a 21 month-old daughter. He also has two grown sons from a previous marriage. He holds a professional position in agricultural management in a midwestern city.

Injury and Circumstances Surrounding the Injury

Mr. Carter was injured when he went to investigate a brush fire on a dairy farm where he was working (milking cows). It turned out that the brush fire was caused by a downed wire--Mr. Carter was electrocuted (knocked unconscious), and his clothes caught on fire. In addition to the burns, his left hand was amputated from the elbow. He also lost the tip of the index finger and thumb on his right hand.

No one else was injured in the fire and, since the fire occurred outdoors, there was no loss to personal property other than his clothing.

Treatment and Services Received

Mr. Carter was taken to an acute care hospital that had a burn unit. He was in intensive care at this hospital for three to four months, and then was transferred to a rehabilitation facility when he became more independent. The burn center promoted independence, which Mr. Carter feels was very positive. He spent two months in the rehabilitation hospital. He received physical therapy and occupational therapy in the first hospital and in the rehabilitation hospital. Counseling was available at both facilities, but he was not interested in these services. He was provided with special equipment, such as a one-handed shirt buttoner.

After discharge from the rehabilitation hospital, he returned to the burn center monthly to work with the surgeon and talk about next steps in his treatment. They maintained an ongoing dialogue about his care plan. Mr. Carter has had about 30 reconstructive surgeries since his discharge from the rehabilitation hospital.

Mr. Carter doesn't recall any problems in getting access to all of the care he needed. At first, he didn't get much explanation about his treatment because he was too sick and medicated to participate in his treatment planning. At the time, Mr. Carter says, the care he received

seemed fine, but looking back now, he thinks he could have used more help in "dealing with the change in his life," although he indicates that he's not sure he would have accepted such help then.

Plans and preparations for obtaining a prosthesis were made after his discharge from the rehabilitation hospital. He was not satisfied with the prosthetics consultant used by the hospitals where he was treated, because he felt he was not involved enough in the decisionmaking process. He went to another city to obtain his prosthesis, and he was fitted for the prosthesis six months after his hospital stay.

Recovery and Adjustment Process

Mr. Carter indicates that he "went through the typical five steps described by Elisabeth Kubler-Ross for terminally ill patients."²

Initially, he never felt he wanted to die, so he just focussed on living. Everything was focussed on basic survival. The hospital didn't let him look at himself for four months. His wife was pregnant at the time of his accident. When his son was born, he couldn't see him for three months due to risk of infection.

The next stage, according to Mr. Carter, occurred at the rehabilitation hospital, where he was functioning, but in pain and realizing the impact of the injury. The hardest step was dealing with the scars, the need for many services, and "facing a society that doesn't accept disabilities." At this stage, he was working on getting better and getting out of the hospital. The nurses and his family were especially important in helping him through this phase of recovery.

When he came home, he had to "face the fact I couldn't do what I did before." Mr. Carter returned to school for his masters degree shortly after he came home. He was offered a teaching assistant position, and continued on to complete his doctorate. His family also suffered another tragedy during this period, when his infant son died. Through all of this, he was "determined to survive."

² See, Kubler-Ross, 1969. On Death and Dying. The five steps identified and described by Kubler-Ross are: Denial and Isolation; Anger; Bargaining; Depression; and Acceptance.

Mr. Carter says he spent the next 8 to 10 years trying to prove to everyone that he was "normal." He indicates that he had to "stifle" himself to do this, by not acknowledging his feelings or special needs.

At first, he didn't want to ask for anything special. Now he is beginning to ask for things like a voice-activated computer (he only has three fingers to type with). He thinks that some type of mentoring program to share experiences might have helped him to ask for special tools and other types of assistance earlier, as well as provided some practical advice for coping with his disabilities, since caregivers "just haven't been there."

In the past three years, he has been reassessing himself and his life. He has become more involved in issues related to society's view of diversity and differences. He is involved in a national leadership program through his employer, and has been running programs on "valuing the physically challenged." He is becoming more accepting of himself and is trying to get people to respect each other more.

Mr. Carter sums it up by saying, it has been a long process, and "all of the time there is a feeling of isolation—you look in the mirror every day and see the evidence of what has happened to you."

Impact on Family

Mr. Carter feels that his family learned a lot from his injury, and that he learned a lot about his family. His wife was very supportive and pushed him to be independent (although he has since divorced and remarried, Mr. Carter notes that his divorce was not related to his injury, but to "marrying too young" -- they are still "good friends").

Mr. Carter's mother "couldn't deal with his accident." She was overly protective, which made it hard. Mr. Carter describes most of his family as "tough-it-out" types, who tend to be supportive, but not introspective. His family doesn't treat him differently because of his disabilities. In fact, he believes it has been a good experience for his children because it has made them much more accepting of differences in people.

Costs and Other Losses

Mr. Carter couldn't go back to his work on the dairy farm at all. His wife couldn't work for six months due to his care and the care of their newborn. They lived on Social Security

during this period, on a very tight budget. Workers' Compensation covered the cost of his care because he was injured while on the job.

Litigation

Mr. Carter filed suit against the power company because of the downed wire. Mr. Carter's brother is a lawyer and he handled everything at the time. Mr. Carter was too sick to be involved, and remembers little of the specifics. The case was settled out of court after about 5 to seven years, and he receives an annuity payment.

Functional Capacity Limitations

Mr. Carter was a runner before his injury; now he does not have full motion in his foot due to the burn injury. He can't raise his left arm all the way over his head.

With a prosthesis on one arm and three fingers on his remaining hand, he can't hold small objects very well. Activities like buttoning clothes are awkward for him. To hold larger objects, he uses his right arm. One ear was also burned off, and he misses some sounds as a result, but the hearing loss is "not dramatic."

He no longer experiences any pain, and does not take any medication.

Quality of Life

Physically, Mr. Carter feels "OK." He is happy to be rediscovering things about himself-- he describes himself as an "optimist." He is trying to decide what he really wants to do next in terms of his career. He values things differently since his injury, for example, "family is number 1." He also thinks he is more of a risk-taker since his injury.

Yet, he feels the impact of the injury will never go away completely because society won't accept it. He is still stared at in stores, for example.

Ms. Clark (9 months post-injury)

Overview

Ms. Clark is a 29 year old white woman. She suffered third degree burns over 40 percent of her body nearly nine months ago, in 1992. Ms. Clark, a long-time heroin addict, was living in an abandoned house with 15 other people. After her hospitalization, Ms. Clark went to live with her mother, sister, and brother at her mother's house. She has many physical and emotional problems, and has no money or job. She is a high school graduate.

Injury and Circumstances Surrounding the Injury

Ms. Clark was alone in the house one day, and awoke to a fire. She was eight months pregnant at the time. The house was very hot, and there was fire and smoke everywhere. She ran through the fire to escape, and her clothes were burned. She then jumped out a third floor window, breaking many bones in the fall. She collapsed on the ground. Eventually emergency vehicles took her to the nearest hospital. She woke up in a different hospital that had a burn center, where she stayed for three months. Her baby died in the hospital.

The cause of the fire was arson. The house was destroyed. Police apparently caught the arsonist at the scene, and he was convicted. He since has been sentenced to prison.

Ms. Clark had third degree burns on both hands, both feet, the back of her arms (shoulder to elbow), and her whole back. She also broke her pelvis and several ribs, and punctured a lung and her bladder in the fall; her upper teeth were knocked out. A bone was shattered in her foot, and she now has arthritis in her leg and back.

Treatment and Services Received

Ms. Clark's treatment was complicated by her intravenous drug use, and by her advanced pregnancy. Medical personnel had a hard time finding veins for medication, and could not give too much morphine for her pain, "or it would kill the baby." The baby died shortly after she arrived at the hospital.

Ms. Clark had seven skin graft surgeries. She felt that her medical care was good--"they did a great job." She liked some of the nurses; she disliked others. She received several months of treatment in the hospital. She returned for follow-up every two weeks, then once a month,

then every two months, and now every three months. She described long waits to see the burn specialist and the orthopedist.

Ms. Clark also had physical and occupational therapy in the hospital. Special clothing was provided, although she apparently did not wear it very often. She used a walker at home a few times and returned it to the hospital.

The social worker at the hospital helped her to apply for SSI, which was denied (she is appealing this) and offered to arrange for drug treatment. She apparently received no counseling or psychotherapy, which she now regrets: "I should've had counseling...I got a mind like a kid."

Recovery and Adjustment Process

Dealing with her changed appearance has been the hardest part of recovery for Ms. Carter. She has many scars, and feels that her body is ugly. She noted, "I cry a lot over that." She feels no one will love her with her "messed up body". She is lonely and depressed, and has poor self-esteem.

Ms. Clark "thinks about it (the fire) all the time", how she jumped out of the window, and how no one broke her fall. She wishes that the incident never happened. She blames herself for being in an abandoned house, and for her drug habit. Ms. Clark started using alcohol, pills, and marijuana when she was 12 years old. At age 13, she started shooting up. She noted that "I've been in 20 different rehabs since 1981". While she has tried to stay off drugs, she has had relapses since the fire. She attended an outpatient drug program after she left the hospital, and was recently in a rehabilitation facility. The first time she relapsed, her mother "threw her out", and she went to her sister-in-law's house. Her mother invited her back "right before Mother's Day."

The death of her baby was a loss for Ms. Clark, but the impact of the loss was not clear. Ms. Clark has four other children who live with relatives. The father of the baby who died is in prison.

Impact on Family

Ms. Clark's injuries affected her family a great deal. Her mother, a cashier, was "really upset" and visited her every day at the hospital. Her mother's employer gave her one week of paid leave. She took off from work at other times, and visited evenings and weekends. Her parents are divorced, and her father, a longshoreman, lives in another city. He, too, came every

day to see her. Her sister also helped take care of her. Ms. Clark is closer to her sister than to her brother.

Her mother's boss sent her flowers, which truly amazed her. Her godmother and some friends arranged a benefit for her and raised \$1,500. Much of this money was used to buy clothes (she lost all she had in the fire).

Due to her drug habit, and many unpleasant incidents in the family, her mother previously "threw her out of the house". Her injuries helped bring her and her family back together. She always thought they would not want her back. She noted, "I never thought I would see that day."

Costs

Ms. Clark receives a modest welfare check. She also has a Medicaid card, which covered some of her medical expenses. She recently has been getting a number of doctor and hospital bills, which she cannot pay: "I have no money."

Litigation

Both Ms. Clark and her mother "wanted to sue someone", but the idea was dropped. Ms. Clark felt that she was "in the wrong" by being in an abandoned house. No litigation was involved.

Functional Capacity Limitations

Ms. Clark currently has many physical disabilities, most stemming from the fall. While her burns are not currently painful, she suffers from intense itching. Her pain varies from mild to severe, depending on the day and time. She feels worse on a rainy day. She cannot stand or walk more than fifteen minutes, and cannot run at all. Her foot is "locked" (stiff) from the fall. She can walk from one room in the house to another, but must rest after doing so. It takes her a long time to climb a flight of stairs. She can walk 150 feet, but must sit down and take a break. Though she gave the walker back to the hospital, she still needs it. She estimated it would take her about fifteen minutes to walk one third of a city block.

While she can hold a pen, her hands "get tight" after a while, and she needs to rest. It hurts to lift her left arm over her head. Ms. Clark cannot bend and touch her hand to her foot. While she dresses herself, it is not easy and takes "a while". It hurts her to take off her slacks. She is only able to lift light objects.

Additionally, her vision has been affected. She sees spots and "blurry things" now. Also, she has experienced some gynecological irregularities, and has some problems with bladder control.

Ms. Clark has short-term memory loss, but thinks that this may be due to the drugs. She has a problem making decisions, and needs help with finances and other aspects of her life.

Quality of Life

Ms. Clark is grateful to be alive, to have a place to live, and to have food and clean clothes. However, she likes to be on her own, and come and go as she pleases. She would rather be somewhere else, though she cannot afford it. Her boyfriend, who is black, is not allowed to come to her mother's house. She blamed her mother for being prejudiced, but also noted that he is a crack addict. She currently is not using drugs, but indicated "I don't know about tomorrow." She is not attending outpatient drug treatment although it is available. Ms. Clark rated her quality of life as "terrible" before the fire, as "bad" six months afterward, and as "mixed" today.

Mrs. Davis (2 years post-injury)

Overview

Mrs. Davis is a 52 year old black woman. In 1983, she quit her job to be a full time foster mother, primarily for children with special health care needs. Mrs. Davis was burned in a house fire nearly two years ago, in 1991. She suffered first and second degree burns on her legs, back and arms. After discharge from a burn center, Mrs. Davis and her family lived with her grown daughter while searching intensely for new housing. Mrs. Davis, her husband, five foster children, and one grandson now live in a different county, far from the site of the fire.

Injury and Circumstances Surrounding the Injury

One summer afternoon, Mrs. Davis was sitting on the front steps of the house her family had rented for 20 years. A neighbor told Mrs. Davis that smoke was coming out of a window. She immediately went into the house. Two of her foster children, aged 11 and 4, were in an upstairs back bedroom. She remembers "trying to get the baby out" of the bedroom. She has no memory of anything after that, until she awoke in a hospital bed.

People have told Mrs. Davis that she was overcome with smoke and burns and collapsed. She also was told that her neighbors "dragged her out of the house." The older child apparently survived by crawling out of an upstairs window. He also may have been helped by a neighbor. The 4 year-old died in the fire.

The cause of the house fire is unknown. It may have resulted from children playing with matches. The house was 90 percent destroyed.

Mrs. Davis was burned on her hands, arms, legs, and back. She had minor blisters on her face, which have since healed. She currently has no pain or physical limitations due to the burns, although she has some itching. She has a great deal of scarring, and "dark and light spots" on her body.

Treatment and Services Received

Mrs. Davis felt that her medical care was good. She had no surgeries--"they said I didn't have to do it." She had physical therapy in the hospital, but no counseling or other support services.

Upon discharge, she received medications and cream for the burns. She was given self-care instructions about bathing, skin care, and staying out of the sun. She returned to see a burn specialist, who said she was "doing okay." She then told him she could not afford to pay him for future visits. He said she looked okay and told her it was all right not to come back to see him.

Recovery and Adjustment Process

Family and friends helped care for Mrs. Davis after she was released from the hospital. A woman friend, who was in a wheelchair, cleaned the wounds on Mrs. Davis' back as she showered. Mrs. Davis noted that her family, friends, and neighbors all have been very supportive. She did not participate in any support groups.

While not facially disfigured, Mrs. Davis has many scars on her body. She "covers up more with clothes", and no longer wears sun dresses or shorts. If people inquire about her appearance, she hesitates, unsure if she wants to tell people what happened.

Mrs. Davis felt the hardest part about her experience was accepting things...the fire, the losses, the burns. She is filled with hurt and pain. She still feels guilty about losing the child she took care of for nearly three years..."somehow I could have done more".

Another source of sorrow for Mrs. Davis was that she felt "cut out" of anything related to his death. Caseworkers did not let her know when the funeral was. She "could not send flowers or say goodbye." As she was unable to express her sorrow, she has no sense of closure. She avoids the site of the fire, though the family lived there for 20 years. She "still hears the baby cry."

Mrs. Davis' biggest frustration was being homeless. She "got no help from the city" on housing. After visiting several housing agencies with long waiting lists, the Davises finally obtained a list of houses. She and her husband looked all over for houses. Since her old neighborhood was drug infested, she felt she should find a better area for the children.

The Davises moved into a house in a more rural area about two months after her discharge from the hospital. Mrs. Davis has experienced extraordinary stress and loss, and has been quite depressed. She had five grown children of her own, in addition to her foster children. The same month as the fire, one of her natural sons was shot and killed.

Mrs. Davis described herself as "a fighter", and said she puts her children first. She noted that she is the one who has to be "real strong" and keep the family together. She stays very busy, is active in church and community, and enjoys caring for children. However, the tremendous

stress she has experienced has certainly taken its toll. She recently went to a medical clinic with chest pains..."feeling depressed...feeling like I was having a heart attack." She was given medication, and the pains went away.

The foster children she cares for receive regular visits from a psychiatrist. During one of these visits, he told Mrs. Davis that she needed to see a psychiatrist herself. She felt unable to afford this.

Impact on Family

Mrs. Davis' husband is a construction worker. As he was looking for housing, helping with the children, and visiting his wife at the hospital, he lost his full time job. Since the fire, he has not been able to find steady work, only day work. He has been very frustrated about this situation, which has added much stress to their marriage. Mr. Davis previously had a drinking problem, but had quit drinking. After the fire, he started drinking again, but has since stopped. During this time, he "was picked up on a DWI" (driving while intoxicated).

The Davis' foster children were very worried about Mrs. Davis. They "thought they had lost me, too." They needed a lot of reassurance and calming while she was hospitalized. Mrs. Davis' natural daughter, with whom the family stayed, was very helpful. She took off work "a lot" to help care for the children and to visit her mother in the hospital. She used accumulated paid leave.

Additionally, the Davis family lost virtually everything in the fire... furniture, possessions, important records and pictures. They were able to salvage only a few pieces of furniture.

The Davises had three smoke detectors in their former house. They now have six in their new residence. In addition, the family has "regular fire drills--how to get out of the house in case of fire."

Costs

Mrs. Davis had no health or home insurance, and owes \$10,000 to the hospital. She informed the hospital of her financial situation, and "they are not bothering me." The hospital provided medication for her. She bought some pain pills on her own. Her biggest out-of-pocket costs were moving expenses. The Davises used their savings for rent and a security deposit; they also had to buy basics like linens, furniture, and kitchenware. She estimated it cost them \$6,000 to move.

Functional Capacity Limitations

Mrs. Davis has no physical limitations stemming from her burns.

Litigation

No litigation was involved.

Quality of Life

Mrs. Davis rated her quality of life as "good" before the fire, as "terrible" six months afterward, and as "mixed" today.

Ms. Deale (27 years post-injury)

Overview

Ms. Deale is a 52 year-old white woman. She was injured in November, 1966, when she was 26 years old. She was burned over 35 percent of her body (3rd degree) mostly on her hands, arms, and shoulders. She is divorced and lives alone with her dog. She works as a secretary for a state government agency in an Eastern state.

Injury and Circumstances Surrounding the Injury.

The year prior to Ms. Deale's injury was a very difficult one. She had gone through a painful separation. She was pregnant and her husband was physically abusive, so she left him. Since she was emotionally fragile and had no financial resources, she gave her son up for adoption.

At the time of the injury, Ms. Deale was working two jobs, and was on tranquilizers, prescribed because of her emotional state at the time. She had taken a sleeping pill and was smoking a cigarette—she fell asleep and was found on the kitchen floor with the melted telephone in her hands. Her arms and hands were severely burned. The little finger on her right hand was later amputated due to contractures.

Ms. Deale was sharing an apartment at the time of the fire, but her roommate was at work; apparently someone outside the building saw the smoke and hit a fire alarm box. All of her belongings were destroyed in the fire, but she especially remembers that her "hope chest" was destroyed. The only thing she remembers about the fire is being carried downstairs on a stretcher.

Treatment and Services Received

Ms. Deale was transported to a nearby community hospital. A tracheotomy was performed right away and she remained in intensive care at this hospital for two to three weeks. Ms. Deale did not have health insurance, but she was eligible for care through the Veterans Administration (VA) because she had been in the Marines from 1962-1963. She was moved to the VA hospital in a nearby city.

Ms. Deale remembers very little about the first few weeks after her injury. The mirrors were covered in her hospital room, and she was very sedated.

Her first stay at the VA hospital lasted nine months. Ms. Deale was the only woman in the VA hospital at the time, and they had never had a burn patient before. She was "helpless" because she was bandaged from her fingertips to her shoulders. She felt that the staff at the VA hospital was "wonderful," but that her scarring was worse because of how dressings were changed there. She attributes this to staffing limitations, lack of experience with burn care, and just the fact that this happened 27 years ago, and burn care has advanced since then. Dressing changes, especially, were very painful. But, she remembers the itching even more than the pain. Her care consisted primarily of pain relief, tranquilizers, and physical care. Once she was less sedated, her medical care was explained to her and she was able to understand her treatment. She received a limited amount of physical therapy at the VA hospital, but no other special therapies. There was no special clothing (i.e., pressure garments) at that time. No counseling was offered to her at the VA hospital. Ms. Deale feels that counseling might have helped her to adjust to her changed appearance.

She felt more comfortable at the VA hospital because of her military background. Also, she felt that patients and staff at the VA hospital were more accepting of appearance because they were accustomed to seeing disfiguring war injuries that were much more severe. She feels the staff did everything possible to help her at the VA hospital. She was especially fond of one nurse that cared for her. This nurse had a heart attack and died while Ms. Deale was still a patient at the hospital. Her doctor was understanding, and had the "best bedside manner." When she started feeling better, Ms. Deale tried to help with the care of the other patients.

She returned to the hospital every year for five years for reconstructive surgery. This included the amputation of her finger, which was so skillfully done that it is "hardly noticeable" to others. Although she can't make a fist, the surgery saved her hand. In 1983, she went back for more surgery on her right hand to get full extension of the thumb from the forefinger. She has had at least 23 operations since her injury. In fact, in August, she is going back for surgery on her left arm to release skin under the arm so that she can have a fuller range of motion with that arm.

Recovery and Adjustment Process

After discharge from the VA hospital, Ms. Deale got her own apartment in the city where the VA hospital was located, so that she could continue her care with the same doctors. She was able to manage on her own. She was unemployed and lived on social security disability

payments. Since she was new to the area, she spent all of the time during the week alone in her apartment. Family and friends visited only on weekends. Ms. Deale describes herself as "a hermit" during this period.

After the injury, her "self esteem was zero." She was seeing a psychiatrist in 1970 who was not all understanding. She attempted suicide with pills. She fell in her apartment, received a gash in her head, and was in intensive care for three weeks. She was treated at the VA hospital again and got excellent care—this was probably the turning point for her. She was treated by a wonderful female psychologist at the VA who encouraged her to go back to school and get a college degree. Her military benefits paid for her education. She completed a bachelor's degree in police science and joined the National Guard in 1972. This was her first job since her injury. She chose the National Guard because she wanted to be in the military again and the National Guard offered part-time positions. She was the only enlisted woman at the time, but she felt she was accepted.

Ms. Deale feels that doing well in school really helped her self esteem. She later became a state employee, and continues working for a state agency today. She taught herself to type again, and now works as a secretary and types 80 words per minute. However, she can no longer take shorthand quickly.

Ms. Deale indicates that it took her years to accept how she looked. Even though the scars have faded, she is still self-conscious. She doesn't mind talking about her injury, but she hates when people stare. Her arms were "bright red" for years—she wore long sleeves, even getting special permission to wear a long-sleeved uniform all year-round. She continued to wear only long sleeve blouses until about 1980. Outside of the military, she feels she has faced job discrimination due to her appearance. She rarely dates because of her self-consciousness. In addition to the scarring on her arms, she has scars all over her body from skin grafts. She goes to very quiet beaches only, and is much more of a loner than she was before her injury. Ms. Deale is much less willing to ask her family or friends for help since her injury, and tends to keep to herself.

Impact on Family

Ms. Deale feels that her family was very supportive. Her sister lives in the same city as the VA hospital, so she visited often and helped her when she was discharged from the hospital. Her mother lives in another city, and came to visit monthly, as did an aunt and uncle. The injury

did not cause much change in her relationship with her family. Her parents were divorced and she didn't get along with her father before the injury. He didn't come to see her and he rejected her attempts to keep in touch after her injury.

Ms. Deale did get to meet her son and reestablish contact with him a number of years ago. He committed suicide one-and-half years ago, which has caused Ms. Deale considerable emotional pain.

Costs

The VA covered all costs of her care except for the stay in the acute care hospital, which she didn't pay because she had no money. She presumes that the hospital wrote off the bill.

Functional Capacity Limitations

Ms. Deale has some permanent limitations as a result of her injury, mostly affecting her arms and hands. She has difficulty cutting her food, her arms tire easily, her hands cramp up, and certain actions, such as opening car doors, are awkward. She can't hold the steering wheel of the car with her left hand. Because her fingertips are very smooth, she has difficulty turning pages.

Since the burns also destroyed glands in her armpits, she doesn't sweat and heat affects her tremendously. She can lift one arm up all the way over her head with some pulling. Scar tissue prevents her from lifting her other arm all the way (the surgery scheduled for August should correct this).

She still has phantom pain in the amputated finger and itching. Her level of discomfort is mild or worse, but she takes no pain medication.

Litigation

Ms. Deale did not pursue any litigation because she felt the fire was her fault.

Quality of Life

Ms. Deale indicates that her quality of life before the fire was "bad;" six months after the fire it was "terrible," and today her quality of life is "good." She is much more self-confident, and has improved her own health habits. She quit smoking in 1977 due to an ulcer. She started smoking again in 1983, but is now trying a nicotine patch, and has gone from smoking two packs of cigarettes a day to less than one pack a day.

She is seeing a psychiatrist now to resolve problems related to her son's suicide and her relationship with her father.

Ms. Deale indicates that she has "always been for the underdog," and her injury has made this more so. She is much more understanding of others with disabilities.

She spends a lot of time by herself, but she is content with her life. She is interested in genealogy, reading, and computers. Her dog is a good companion. At the time of this interview, Ms. Deale was about to leave on a vacation trip to Scotland.

Mr. Engle (4 months post-injury)

Overview

Mr. Engle is a 55 year-old white male. He was injured in February, 1993, and was interviewed while still an inpatient at a burn center in an Eastern city. He was burned over 55 percent of his body (third degree), mostly on his hands, legs, and face. He is divorced, and has one grown son. Mr. Engle has a college degree and had worked in the area of city planning and development. He is an alcoholic. At the time of his injury he was unemployed and sharing a house with a woman friend.

Injury and Circumstances Surrounding the Injury

The fire occurred late at night. Mr. Engle had had a few drinks and was sitting on the couch with the newspaper when he fell asleep. The cigarette fell on the newspaper and started the fire. The smoke detector woke up his housemate. The neighbors had already called the fire department. He was transported by ambulance to the nearest hospital, but because of the severity of his injuries, he was immediately transported by helicopter to the burn center. Because his teeth were "in bad shape," they all fell out when a breathing tube was inserted in his mouth at the time of the injury.

No one else was injured in the fire. The house was severely damaged, but not destroyed. His belongings were completely destroyed.

Treatment and Services Received

Mr. Engle remained in intensive care at the burn center for almost four months. He is now in a "step-down" unit of the burn center. He has been on this unit for about two weeks, and will probably remain in the hospital another three to four weeks. He is receiving physical therapy and social services at the hospital. The staff have been very helpful so far and have explained his treatment plan to him. He notes that his schedule in the hospital is "very busy." "They work you hard so that you will be able to do things for yourself."

He has had some surgery, and more is scheduled while he is still in hospital. The injuries are very painful, and he is still on constant medication.

Mr. Engle was not aware of any support group at the hospital. He has talked with a chaplain, but there "has been no follow-through."

Recovery and Adjustment Process

Mr. Engle has been a member of Alcoholics Anonymous (AA) for many years, and he has contacted them from the hospital. He also says he would not smoke again. Mr. Engle is very uncertain about the future. His housemate had to move elsewhere and "won't take him back," so he has no place to go upon discharge. The social worker at the hospital is working to help him find a place. He has no family in the area. His son lives in California and his brother lives in Texas.

Impact on Family

Mr. Engle's injury has had a financial as well as an emotional impact on his family. His family is, of course, concerned about him. His son came to see him from California. His son got him new glasses, since his were lost in the fire. He ordered and purchased them outside of the hospital because the hospital "was taking too long," and his son paid for the glasses. Mr. Engle has been in touch with his brother, but he has not seen him since the injury.

Costs and Other Losses

The only insurance Mr. Engle has for his medical care is Medicaid. The rental house he was living in is being reconstructed by the owners. Mr. Engle assumes that the landlord's insurance is paying for this. However, the lease apartment in his housemate's name and Mr. Engle's name was never added to the lease. As a result, his belongings are not covered by any insurance, because, technically, he was not a tenant. Mr. Engle indicates that he was not aware that his name was never added to the lease and expressed some anger at his housemate for this oversight.

Functional Capacity Limitations

It is too early to adequately assess the long-term impacts of Mr. Engle's injuries. He is just starting to stand with a walker. He should be able to walk by the time he is discharged. He can hold things in his hands and move his hands and fingers, although his right hand is more severely burned than his left. He has limited ability to lift his arms, but this is being worked on every day with the physical therapist. He can't tell yet if his vision has been affected because he just got new glasses. He is wearing pressure garments on one hand and on his arms.

Litigation

No litigation is planned.

Quality of Life

Mr. Engle indicates that his quality of life was not satisfactory before the injury. He had not been working for several years. Now he just feels he has lost everything and is uncertain about the future--no home, no clothes, no money, no job.

Mrs. Green (7 years post-injury)

Overview

Mrs. Green is a 35 year-old white woman. She was burned over 43 percent of her body in a house fire in 1986. While the cause was uncertain, investigators believed it was either an electrical or cigarette-caused fire. She suffered some second degree and some third degree burns (most were third degree). Her husband died in the fire. She remarried and had a baby 18 months after the fire. She and her husband now have two children.

Injury and Circumstances Surrounding the Injury

Mrs. Green and her husband were asleep in an upstairs bedroom of their rental house in an Eastern city. The house had no smoke detectors. She "smelled something"--or something woke her--and she tried in vain to wake her husband. She tried to leave the room. As she opened the bedroom doors (there were two doors that opened in), heat and smoke rushed in and burned her. She put her arms up in front of her face, and her face was not burned.

Rescue personnel found her under a window, on the floor, inside the same room. Apparently, a neighbor heard some glass crashing, or saw smoke, and called the fire department. She was taken to the nearest hospital, which had a burn center. She has no memory of the early events after she opened the bedroom doors. Mrs. Green's face, hands, and feet were not burned, but she sustained serious burns to her upper body, from the knees up.

Treatment and Services Received

Mrs. Green was unconscious for about two weeks after the fire, was "drugged out" and on a respirator. She "almost died" in the fire. Mrs. Green had nine graft operations. She recalled the burn treatments as very painful. She remained in the same hospital for about six months. She saw a social worker at the hospital a few times. The social worker offered her counseling, but Mrs. Green felt that she "didn't need it," and did not have a problem dealing with her burns, or accepting her injuries.

Mrs. Green believed that the hospital had a good burn unit, and that she received good care. She still keeps in touch with the nurses, who she said "helped pull her through". She described the nurses as very caring, and "very special people".

After her release from the hospital, Mrs. Green returned a few times to see the plastic surgeon, and to have her pressure garments checked. Overall, she had fairly minimal follow-up care. She received one month of physical therapy after leaving the hospital. Her arm, especially her elbow, was stiff, and stuck in a bending position. She was unable to eat with that arm. Physical therapy included exercises, which helped to loosen up her arm. She recently consulted a plastic surgeon about her arms, who told her it would not be productive to have further surgeries--that it "would just be trading one scar for another."

Recovery and Adjustment Process

Though she sustained serious burn injuries, and lost her husband in the fire, Mrs. Green indicated that she was able to deal with these tragedies in a largely positive way. In her words, "I'm pretty much a survivor; I had to accept it; why be depressed?" She had a very supportive family, who helped her through difficult times. Caring friends also made a difference.

She was not told that her husband had died until one month after the fire. She believes that her mother's decision to delay telling her the truth was a very good idea.

The hardest part about her recovery was having to "start over." She had no husband, no job, no house, and no belongings. "I went back to being 18-20 years old." She moved back in with her parents, and "felt like a little kid". She was unhappy being so dependent on her family, yet they provided a great deal of emotional support. She coped with her new situation by staying very busy--going to school, seeing friends, and later getting a job. She is now employed full time as a dog groomer.

Mrs. Green has always been open about her injuries and her scars. "I never tried to hide it--never covered it up; I wore shorts when I wanted to". She also wore her pressure garments out frequently. "People accepted it," she remarked. She did not receive any professional help dealing with her losses--"I didn't need it." Her family and friends helped her get through the rough times. Knowing that people still cared for her, "no matter what", had a big impact.

Mrs. Green was not involved in a formal support group. However, there was informal support among the patients in the hospital. They kept track of each other's progress through their families, who would check on other patients and report back.

Impact on Family

Throughout her recovery, Mrs. Green grew closer to her mother, who became quite protective of her daughter. She felt that her experience brought her parents closer together. She also got much closer to her brothers, who "helped her through everything". Her brothers checked up on her more often, calling frequently. She lived in a two family house, with her aunt and uncle next door, so someone was always around.

Costs and Other Losses

Mrs. Green's health care expenses were covered 100 percent by private insurance through her husband's employer. She was unaware of any out-of-pocket expenses incurred. Renter's insurance covered damages, but not the full value. She estimated compensation at about one-third. She also received her husband's life insurance.

Mrs. Green was a homemaker at the time of the fire. Her whole life changed after the incident. She lost her husband, three dogs and one cat (one cat survived), and all her possessions. Her mother took a great deal of personal leave, vacation time, and finally a leave of absence from her job to be with her daughter. She had accumulated much leave time over the years.

Functional Capacity Limitations

While she currently has no physical disabilities, Mrs. Green has extensive scarring and nerve damage. This is not painful now, but is uncomfortable. She suffers from itching, tingling, and gets welts/hives. She is in good health currently.

It hurts Mrs. Green to lean on her elbows. If she squats, she has trouble getting back up, and is uncomfortable. Also, her skin is thin, and is easily damaged. She must be very careful, use high sunscreens, and cannot sit in the sun. She currently has more discomfort than pain at this time.

Litigation

An attorney settled the estate of her husband, but there was no involvement in litigation related to the fire.

Quality of Life

Mrs. Green described herself and her family as "survivors". She currently is very happy with her life. She remarked, "there must be a reason why I'm still here." Mrs. Green indicated that her quality of life before the injury was "mixed," six months after the injury, it was "mixed," and today her quality of life is "terrific."

Mrs. Hall (9 years post-injury)

Overview

Mrs. Hall is a 48 year-old white woman. She suffered third degree burns over 86 percent of her body nine years ago, in 1984. Several years later, Mrs. Hall returned to school for a college degree, and has been employed for about one year as a social worker in a midwestern city. She is divorced, and has nine children and six grandchildren.

Injuries and Circumstances Surrounding the Injury

Mrs. Hall was alone in the basement of her mother's house, and was using flammable cleaning liquids. She lit a cigarette, and the fumes ignited. While she has no memory of what happened next, people have told her that she ran up the steps, and neighbors broke in a door to help her. An ambulance took her to a local hospital; then a helicopter took her 20 miles to the nearest burn center. About two months later, she was transferred to another hospital that had a burn center, as it was affiliated with her insurance coverage. She has little memory of the first two months following the incident. She later was transferred to a hospital rehabilitation center.

Several months before her injury, Mrs. Hall suffered a nervous breakdown and was hospitalized for 30 days. She received shock therapy prior to her discharge. Once home, she took anti-depressant medication and began seeing a psychiatrist. She was discharged about two months before the fire.

Mrs. Hall's face was severely burned. She lost the end of her nose and the outer ear lobes. Her eyes, however, were not burned. She had no breast tissue left. She also has adhesions under her chin, and permanent hair loss. Due to these bald spots, she always wears a wig. She has many scars all over her body.

She also suffered from calcium buildup in her elbows, which virtually locked in place. She was unable to bend her arms, and used a special utensil with a long extension to feed herself. As her skin is so thin, it is easily damaged, and she still gets skin infections easily, such as "cellulitis."

Mrs. Hall has had many surgeries, including breast and nose reconstruction. Yet, her nostrils are not even, and she has trouble breathing. She could have more surgery, but, in her words, "you reach a time when you say that enough's enough."

While she had very little memory of the earliest events, she gradually became aware of dressing changes, surgeries, and "indescribable pain". She remembers that doctors took tissue for skin grafts from her lower legs, which were not burned. She indicated that this process was extremely painful, and "gruesome" to look at. As she started to heal, her nerve endings got "reconnected", and for about two years, she suffered intense pain. Even today, she has some residual pain, although she describes her health as good.

Treatment and Services Received

While she believes her medical care was good, Mrs. Hall did not like one of the hospitals, and felt staff did not address her emotional needs.

Eventually, she started going home on weekends, but returned for skin grafts to her head. She was released from the hospital a little over eight months after the injury. She was unable to wear the typical pressure garments, due to a head infection. Instead, she wore a total body suit, for 23 hours a day. It left only her toes and hands out, and was "very uncomfortable to wear".

After Mrs. Hall was out of the hospital, she returned to the burn clinic weekly for follow-up. A visiting nurse came to do dressing changes, and she saw her doctor every week. Her follow-up medical care lasted about one and one-half years. She remarked that, at this time, she thought she would "never go out [of the house] again."

Mrs. Hall received physical therapy and occupational therapy, at the burn center, the rehabilitation hospital, and later, at home. She felt that medical and support services were all good.

Recovery and Adjustment Process

The first time she saw her reflection---an "80 pound skeleton"---she did not recognize herself. The hospital called in a psychiatrist, with whom she met weekly for about two months. She indicated that these sessions were not helpful, but admitted that "I wasn't ready (to talk about it)".

At first, the burned parts of her body were always wrapped up, and there were no mirrors in her room. "The only thing I could see myself in was the television screen." Later, another hospital had a mirror in the room. A social worker asked her if she wanted the mirror draped. Mrs. Hall told her no, but avoided looking in it. She feels strongly that she did not get the

professional help she needed to cope with facial disfigurement and self-image. Disfigurement was "only dealt with in a support group."

One day, a burn survivor visited her in the hospital. He was burned facially "as bad or worse than I was". Mrs. Hall recalled that meeting this person was an important step in realizing that "it could get better." A plastic surgeon also talked with her around this time about reconstruction. While he did give her some hope, he "didn't let me think he would perform miracles."

The burn survivor/visitor got her involved in a support group that met monthly. At first, all her family attended. Her family's attendance tapered off, and she started going to the group by herself. She found the group's support very helpful. By the third or fourth year after her injury, Mrs. Hall started visiting other persons with burn injuries in the hospital.

She did see a social worker three to four years after the incident, and received counseling for about two and one-half to three years. She found these sessions helpful.

At first, Mrs. Hall isolated herself, doing only "what was necessary." Her life started turning around about three to four years after her injury. She improved with each surgery, and made some "wonderful friends" when she started attending college. She described her return to school as a turning point.

She now "feels normal" and forgets about her burns. Her family and friends are accepting of her. However, sometimes strangers stare at her, which reminds her of her injuries. She mostly wears long sleeves, but said "you can't cover up your face." She does use special cosmetics, but scars are still apparent.

Impact on Family

Mrs. Hall felt that her family could have used more help in coping with the injury and its effects on their lives. She felt that their need for emotional support was not met. It was very difficult for them to deal with her changed physical appearance. She didn't look like she did before, and the younger children were "scared to death" of her--"they didn't know who I was". It took about a year for them to accept her. Her children are very protective of her, and get upset even now if someone stares at her.

Mrs. Hall's mother devoted herself to caring for her daughter, and was very supportive--"like a rock". For one and one-half years, she took over the family and household. Mrs. Hall felt extremely dependent on her mother for virtually everything. Previously very self-reliant, she

became angry and frustrated at being so dependent on someone. Mrs. Hall remembered "a blow-up --a big argument" that she had with her mother. "I told her it was my house, my kids, etc." After this argument, her mother stayed away for three days.

Mrs. Hall and her husband had marital problems prior to the fire. Her injuries "added additional problems" to their relationship. Moreover, her husband was resistant to getting counseling. The Halls divorced three years ago, in 1990, following an eighteen-month separation. Their four oldest children are married. The five younger ones, four girls and one boy, live with their father. At the time of the divorce, Mrs. Hall could not afford to care for the children. However, she has joint custody of them, and sees all her children often. She also has six grandchildren.

Costs and Lost Productivity

Mrs. Hall's expenses, both inpatient and outpatient, were covered by a Health Maintenance Organization (HMO), through her husband's employment. All costs were included until her divorce. She had minimal out-of-pocket expenses, such as for a wig and cosmetics. Her counseling sessions required a co-pay, but this was reduced. She received SSDI for herself and the children, and also Medicare. After the divorce, she had only Medicare. She is currently covered through an HMO at her job. Also, the state Vocational Rehabilitation agency paid for part of her college education.

At the time of the injury, Mrs. Hall was working part time in a restaurant. She was physically unable to return to work. Mrs. Hall's mother quit her job and "practically moved in" to care for her. Her former husband and her children also provided care, especially at night and on weekends. Mrs. Hall remarked that she "lost three to four years of her life" due to her burn injuries, and that she has "begun to reclaim them in the last five years."

Functional Capacity Limitations

Mrs. Hall's injuries have slightly reduced her ability to walk or run. She also has problems lifting her arms over her head. She has some trouble bending over. She can dress herself, but has trouble with zippers and buttons. As a result of her injuries, Mrs. Hall currently experiences mild pain.

Litigation

No litigation was involved.

Quality of life

Though she went through several years of physical and emotional suffering, Mrs. Hall stated that currently, "I have never been better." She has a job, a supportive relationship with a man, caring friends, and enjoys life--"I even go dancing!" She is "physically and emotionally healthier than ever before." She credits her support systems and caring people. She "drew strength out of a bad situation", and turned it into something positive. She commented, "I had a second chance--I am happy to be here."

Mrs. Hall did not resume smoking after the fire. Mrs. Hall rated her quality of life as "mixed before the fire, as "terrible" six months afterward, and as "terrific" today.

**DATA COLLECTION PACKET:
IN-DEPTH INVESTIGATIONS/CASE STUDIES OF BURN INJURIES**

Contract CPSC-C-93-1118



Dear :

National Public Services Research Institute and The Urban Institute are conducting a study for the U.S. Consumer Product Safety Commission in support of a report to Congress on the Fire Safe Cigarette. The purpose of this study is to provide information on the costs to society of burn and anoxia injuries.

One important part of this study is to report on the personal impacts of burn injuries. Through interviews with individuals and families, we hope to gain an understanding of the recovery and adjustment process, help provided by family members and others, and the effects of the injury on the individual's and on the family's outlook on life. We are interested in both the short-term and long-term impacts of the injury.

With your permission, we will be contacting you to arrange a convenient time for a telephone interview. We can schedule the interview for after work hours, if necessary. The interview will take about two hours of your time. In addition to talking with the interviewer, you will be asked to complete some brief questionnaires. A postage-paid envelope will be provided to return the questionnaires. Respondents will be paid \$25.00 per family for participating in this study. The identity of respondents will be kept confidential. The interviews will be written up as "case studies" with no individual identifying information.

Reports on injury costs and medical data do not fully describe the impacts of injuries. You will be providing important new information by participating in this study. We hope you can assist us.

I have enclosed some additional information about the study. Please feel free to contact me at (202) 857-8523 if you have any questions about the interviews. Thank you.

Sincerely,

Nancy M. Pindus

Nancy M. Pindus
Senior Research
Associate
Human Resources
Policy Center
202-857-8523 Telephone
202-223-3043 Fax

Project: ESTIMATING THE COSTS TO SOCIETY OF SMOKING FIRE INJURIES

Sponsor: U.S. Consumer Product Safety Commission

Contract No.: CPSC-C-93-1118

Purpose and Approach

In support of a Consumer Product Safety Commission Report to Congress on the Fire Safe Cigarette, this study examines the costs of fire-related burn and anoxia injuries. The research focus is on costs per incident. Study tasks include:

- Estimation of Medical Costs
- Literature Review, Data Analysis, and Conference on Trends
- Case Studies of Burn Victims
- Estimation of Quality of Life Losses
- Analysis of Jury Verdicts on Pain and Suffering
- Analysis of Litigation Costs
- Estimation of Emergency Transportation Probabilities and Costs

Case studies will provide qualitative information on the psychosocial impacts and functional capacity loss associated with burn injuries. Data collection for the case studies will include individual interviews with victims and their families, administration of selected instruments which measure impacts, review of individual patient records, and focus group discussions with patients and their families.

Project Contacts

Government Project Officer:

William Zamula

U.S. Consumer Product Safety Commission

5401 Westbard Avenue, Room 656

Bethesda, MD 20816

(301) 504-0962

Principal Investigator:

Ted R. Miller, Ph.D.

National Public Services Research Institute

8201 Corporate Drive, Suite 220

Landover, MD 20785

(301) 731-9891

Subcontract Manager (case studies):

Nancy M. Pindus

The Urban Institute

2100 M Street, NW

Washington, DC 20037

(202) 857-8523

CPSC Cigarette Fire Injuries: Case Studies

COVER SHEET

Age:_____

Sex:_____

Race/Ethnicity:_____

Date of Injury:_____

Occupation:_____

Nature of Injury

Narrative description of injury:

Part(s) of body injured:

Degree of burn:

% of body burned:

Treatment

Initial treatment:

Hospital length of stay:

Discharged to:

Disabilities at discharge:

Subsequent hospitalizations:

Payment source:

Charges:

CPSC CASE STUDY DISCUSSION GUIDE

I. Introduce Study to Injured Person/Family Member

- * Introduce self to individual/family member and let them know that we will be asking about their experiences with the burn injury; explain we are doing this for CPSC.
- * Assure them there is no "right" or "wrong" answer. Let them know we will not be sharing the information with the burn center, etc., and that no names will be used with the information.
- * Tell them we hope to gain understanding about the effects of burn injuries on injured persons and their families.
- * We are primarily interested in long-term effects; interested in short description of incident and current situation.

II. Discussion Topics and Probes

1. Initial "get acquainted, get comfortable" discussion (tell me about yourself, your family, who lives with you, etc.)
2. The Incident: How, when, where it happened (probe substance abuse)
(Probe) Pre-incident conditions: e.g., unusually tired, upset, awareness of danger, safety precautions taken, etc.

Who was involved; who was injured;
Type of injury
Body part(s) burned, degree, % body burned
Residual impairments; prognosis
Perceived health status; pain
Losses due to fire: house? belongings?
3. Medical care received--acute; long-term
Frequency of visits to health care facilities
Any access problems?
Understood medical terms, procedures, treatments?
4. Support services received--therapies (p.t., o.t. etc.), special clothing, equipment, mental health services/counseling, social services, vocational rehabilitation, housing, transportation, etc.

Was an individual care/service plan developed with you?
Any difficulty obtaining services? Quality of services?

5. **Unmet needs**--physical, emotional, social/recreational; educational/vocational, community; barriers
6. **Recovery/Adjustment process:**
 - a. **Timing and level of reactions** to initial trauma, coping, stages, daily activities, stress; What has been the hardest part of the recovery process for you/for your family?
 - b. **Psychosocial status:** Self-esteem; loneliness; isolation
 - c. **Thoughts about injury** (blame, regret, life unfair, guilt feelings [re: the fire; burden on family; survivor's guilt])
 - d. **Effect on family/caregivers:** Loss of former roles; renewed dependence on spouse/parents/children; role strains; marital/sibling relationships; family cohesiveness/breakups; tensions, communication; positive changes in health habits
 - e. **Support:** What has helped you/your family the most through the recovery process? How could services be improved for other injured individuals/families?
7. **Disfigurement** (If applicable): Dealing with changed physical appearance (especially facial); self-image; reactions of others; community re-entry; acceptance vs. discrimination; emotional problems; any professional help dealing with this? where/when?
8. **Support systems:** Relationships with family, friends, neighbors, professionals, community; self-help support groups
9. **Activities:** school; work; housework
 - Time lost by the injured
 - Time lost/spent by other family members
10. **Cost information:**
 - Payment source for initial stay; for follow-on care
 - Care costs to the family (out of pocket); support services --Other care/services (received/needed) not covered by insurance (probe: respite care; special educational services; supplies; special equipment; etc.)
11. **Quality of Life Status**--injured and caregivers: instrument

What is your life like these days--the good things, the bad things?

12. Litigation/Compensation

Did you or anyone in your household hire a lawyer to help you get compensation for your injury?

Did you file a lawsuit because of your injury?

**Who did you sue (multiple defendants are important)?
(post-code)**

- Own insurance company**
- Someone else's insurance company**
- Person who caused fire**
- Building owner**
- Supplier of defective product**

Is the lawsuit still pending?

- Yes**
- No**

If no, did you settle the lawsuit?

If no, did the lawsuit go to trial?

If Yes, did you get some compensation?

If no, so you dropped the suit?

If yes, how far did you pursue it?

Purpose of above series is to determine disposition of the claim.

13. Any other comments?

Thank you very much for your time!

FUNCTIONAL CAPACITY SCALES

"I want to know if your injuries affected your physical abilities. In this next set of questions, just tell about things that resulted from your injuries."

EATING

Because of your burns/injury, do you have any restrictions on what you can eat, or how food has to be prepared?

No limit

Dietary Restrictions

Tube Feeding

STANDING, WALKING, RUNNING

A. Have your burns made you less able to stand, walk, or run?

Yes

No

(Probe: I'm interested in any change, even a minor one)

B. Can you walk around your home? Yes No

IF NO, SKIP To HAND/ARM

C. Can you climb a flight of stairs (12 steps)?

Yes No Needs assistance; takes long time

IF NO, SKIP To HAND/ARM

D. Can you walk one-third of a city block (150 ft.) ? Yes No

IF NO, SKIP To HAND/ARM

E. Do you need help from someone else to walk that far? Yes No (refers to C.)

IF YES, SKIP To HAND/ARM

F. Do you need a brace, cane, crutch, or walker? Yes No

IF YES, SKIP To HAND/ARM

G. Does it take you a long time to walk one third of a block?

Yes No

IF YES, SKIP To HAND/ARM

HAND AND ARM FUNCTION

A. Because of your burns, do you have trouble holding on to small objects like a penny or a pencil? No problems

Yes left hand right hand

Big objects like a basketball? No problems

Yes left hand right hand

B. Do you have trouble moving either hand to your mouth enough times to eat a meal?

Yes-Left hand **Yes-Right hand** **No problems**

C. Do you have any problems lifting either arm over your head?

Yes-left arm **Yes-right arm** **No problems**

(If Yes): Can you lift that arm over your head?

Yes-left arm **Yes-right arm**

BENDING AND LIFTING

A. Because of your burns, do you have any trouble bending over and touching your hand to your foot? (Demonstrate)

Yes No Some difficulty

B. Can you get dressed by yourself?

Yes No Some difficulty

C. Do you have any trouble lifting heavy objects?

Yes No

(If Yes): Can you pick up a bag of groceries? (10 lbs.)

Yes No

VISION

A. Do you have any vision loss due to your injury?

No Yes-right eye Yes-left eye

B. If you got new glasses/contact lenses because of the injury, how well can you see now?

Normal vision Visually impaired Legally blind

Profound loss (gray blind) Totally blind

HEARING

A. Do you have any hearing loss due to your injury?

No Yes-right ear Yes-left ear

B. Do you use a hearing aid?

Yes No

C. If yes, how well can you hear now?

Normal hearing Hearing impaired Profound loss

SPEECH

(Primarily through observation)

No problems

Speaks slowly, hesitates

Trouble articulating

Hard to understand

SEXUAL FUNCTION

Have your burns/injury affected your physical ability to have sexual relations?

No limitations

Some difficulty

Sex not possible

EXCRETORY FUNCTION

Due to your burns/injury, do you have any trouble going to the bathroom?

No limitations

Some problems with control

Incontinent

COGNITIVE FUNCTION

(Ask caregiver as appropriate)

- No limitations
- Can be left alone for several hours
- Needs 24 hour supervision
- Vegetative state

A. Did your burns/injury affect your memory or your ability to think clearly?

Yes No

B. If Yes, do you need others to help you manage your life (e.g., financial matters)?

Yes No

PAIN

- A. How would you rate the level of pain you currently experience as a result of your injuries? (circle the number that best applies)**
- 1. Mild distress with no disability. No or occasional use of non-narcotic drugs and/or other non-invasive therapy.**
 - 2. Moderate to severe distress with no disability--normal function may require the use of non-narcotic drugs and/or other non-invasive therapy.**
 - 3. Can function normally only with the use of narcotic drugs and/or invasive therapy.**
 - 4. Due to pain, cannot function normally even with narcotic drugs and/or invasive therapy.**

EFFECT OF THE INJURY ON FAMILY AND OTHER RELATIONSHIPS

For each item on the list below, think about how it has changed since your injury. Put an "X" in the box that best describes the change. If things are the same as before the injury, mark "No Change" for that item.

	Much Worse	A little worse	No change	A little better	Much better
1. Your place in the family.					
2. Relationship with spouse/parent/child.					
3. Feeling close as a family.					
4. Family communications.					
5. Arguments with spouse/parent/child.					
6. Trying to improve your own health habits (e.g., diet, exercise, quitting smoking, etc.).					
7. Trying to help other family members improve their health habits.					

	Much less	A little less	No change	A little more	Much more
8. Doing fun things together as a family.					
9. Family members helping each other with household chores.					
10. Family members helping each other with personal problems.					
11. Willingness to ask other family members for help.					
12. Doing fun things with friends.					
13. Willingness to ask friends and neighbors for help.					
14. Willingness to seek help from other outside agencies or providers.					

EFFECTS ON OVERALL QUALITY OF LIFE

Many things affect quality of life. These include how you feel about yourself and your family, your housing, your job, your health, and your neighborhood. They also include how much fun you are having, how fairly you get treated, and how pressed you are for money and for time.

Here are three lines that run from terrible to terrific. In between are bad, mixed, and good. On the first line, make an X to rate your quality of life today. On the second line, rate your quality of life a few days before the fire. On the third line, rate your quality of life six months after the fire.

Quality of Life

TODAY

!!!!!!!!!
T		B		M		G		T
e		a		i		o		e
r		d		x		d		r
r				e				r
i				d				i
b								f
l								i
e								c

BEFORE THE FIRE

!.....!.....!.....!.....!.....!.....!.....!.....!

6 MONTHS AFTER THE FIRE

!.....!.....!.....!.....!.....!.....!.....!.....!