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# The Burn Survivor Perspective

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The burn survivor's perspective is critical in helping focus the priorities for burn research during the next 10 years. The goal of medical science is to improve outcomes and the lives of those we serve. As individuals who have experienced a burn injury, burn survivors can provide an important and unique perspective. There have been numerous advances in burn care and, as was discussed in the first 2 days of this State of the Science conference, yet there is a lot of work yet to be done. Each of us survivors has tremendous respect and gratitude toward the burn team, and the following comments are made with the goal of improving care for current and future burn survivors. Real progress can happen if we work together to develop the goals, knowledge base, and then ultimately implement the available and proven interventions as a standard of care.

The purpose of the burn survivor panel discussion was to provide a personal perspective of the priorities in burn care research. The collective burn survivor community is a wealth of information—if we listen. Both Erin Mounsey and Chris Gilyard are burn survivors with a point of view that will help demonstrate some common themes we hear across the country at the Phoenix Society for Burn Survivors. They are two individuals burned some 20 plus years apart and both believe that psychosocial rehabilitation of patients should be the priority in patient care and thus the priority for research.

The first thing I must tell you is that I am not a researcher, but I do value the importance of a scientific approach to the care we provide. I will share my perspective from several vantage points to demonstrate some of the themes that are common for many people that I speak to regarding burn recovery. First, as someone who has been in the bed as a patient receiving burn care, I learned that the burn team

helps to lay a strong foundation for the healing necessary both physically and emotionally. Not only were compassionate care givers key to the progress physically, but they helped to create a safe place for emotional healing to start. I only wish I could have taken the burn team with me out into the world as I transitioned back into my community and my peer group. It is there that I stumbled and lacked the necessary information, tools (to manage stares and questions) and support. The psychosocial reentry was the most difficult part of my personal recovery.

I also spent 7 years at the bedside as a burn nurse working to meet the needs of patients and families. At times I felt very inadequate as patients and families asked the tough questions about their future and how to handle the reality of their disfigurement. The easy part for me was providing the “physical care.” I did not receive specific training during my orientation, nor was I prepared for the psychosocial issues that the burn patient and family may experience. As a caregiver I lacked the tools to support this part of recovery beyond what I learned in my nursing program. Because I had “been there,” I was able to offer some hope and examples of how I handled life after a burn injury though it was just one perspective. It was interesting to me that the patient and family would receive this information from me in a different way (than from other staff members). It was my first experience of the power of peer support.

One of the most dynamic educational experiences for me as a new nurse was attending World Burn Congress. I learned there is not one way to do this thing called “burn recovery” and that many types of resources are needed at different times in the recovery process. I realized that my own personal biases of what was needed for successful burn recovery could get in the way of what I provided for the patients I cared for. An example of this was the belief that corrective cosmetics were just a way to hide and not deal with the reality of the burn. That was my perspective. After attending World Burn Congress, I met Barbara Kammerer Quayle and many others who shared that for them it was a necessary tool to take that first step—it was a tool to help them gain confidence to get

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back out there socially. Shortly after that experience, we trained several staff on the burn center to assist in this area of psychosocial rehabilitation.

I transitioned to the manager of the burn center and fought the battles to keep the burn program and used tools such as verification to improve the quality of care on our center. We were able to incorporate several programs to assist with social reentry. We had burn camp, burn survivor reunions, monthly support groups, image enhancement, a social skills program, and sent a group each year to World Burn Congress. From this perspective, it appeared like we were meeting the needs of the patients and families. Like many units these psychosocial rehabilitation programs were a “add on” to staff roles above and beyond their hours. No one was ultimately accountable for the success, evaluation or the succession of these programs. If the staff who took this on left the unit, so did the support programs. The programs were not embraced by the whole team and often were not offered.

Then I took the role as the Executive Director of the Phoenix Society for Burn Survivors. Despite tremendous progress in the medical care of burn survivors, I quickly realized there are a substantial number of individuals who experience significant long-term psychosocial adjustment difficulties, particularly those individuals who have changes in appearance. Although these adjustment difficulties (eg, coping with staring and teasing when out in public, body image changes, relationship issues) do not necessarily meet diagnostic criteria for psychopathology, they do significantly affect quality of life.

With the reality of decreasing length of stays and the limit of human resources, it is clear that the burn center is just the starting line and that much of the recovery happens out in the community and long after our contact with patients and families. When I started answering the 800 line and e-mail requests at the society, a whole new perspective of the long-term issues (beyond 2 years) of survivors was realized. The other thing I found as I worked with numbers of organizations around the country—efforts are being made in the area of psychosocial support within burn centers, nonprofits, and rehabilitation centers, but often they occur in isolation and without the support of research. At this time, there seems to be a disconnection between those who are doing research in this area and those who ultimately provide the services and interventions to assist in the psychosocial rehabilitation.

The Survivors Offering Assistance in Recovery (SOAR) program was developed to increase the access of peer support to the burn survivors and their families. This type of support is not offered consis-

tently in the rehabilitation of those with burn injuries. For nearly 30 years, our organization has been providing peer support based programming. In my 25 years in burn care, I have been sold on the power of peer support. Do we have the research to support the efficacy of these efforts? The answer is no. We need to partner with the research community and are willing to do so as we move forward to set goals for research in the next 10 years. The SOAR program is now in the process of implementation in more than 30 burn centers, and it provides a standardized model to study. What we need is to work together to complete the research on this program. We need to know if it has a positive impact on the psychosocial rehabilitation, when is it best to offer peer support and a whole host of other questions.

A resource that we are about to launch is another significant opportunity for multicenter research. “The Journey Back” is a school reentry resource that was developed based on an identified need. Parents, teachers, and burn care professionals all have contacted us for information and resources to assist in the important transition back to school after a burn injury. School Reentry is not a new concept. Is it a standard of care offered to all burned children? It is not.

Many burn centers and foundations have been providing school reentry for years, yet there is not a well documented, accepted program out there for general use. We approached many of our partners in burn care to try and identify a tool we could provide to our members. When we could not find one packaged and ready to use, we worked to develop a resource based on agreed best practice. The content has been reviewed by more than 20 burn care professionals, mental health care providers, parents, and teachers. Would it be beneficial to have a standardized approach within burn care based on research? Definitely. Again, we hope to partner with those who are experts in the research area as we implement this program. It will only improve the resource and the justification for school reentry as a standard of care offered for burn injured children. Like many of you, I assumed that this was offered to most of the children who are treated in burn centers in our country. The reality is that it is not.

Social challenges, the impact of changed appearance as well, as the effect trauma has on relationships are critical areas for research in the next 10 years. There are a number of high-quality interventions out there. We need to accomplish a collaborative approach to research the psychosocial rehabilitation interventions already available. Only then can we make progress toward making psychosocial rehabilitation a standard of our care. If we move beyond our own

organizational boundaries and explore the most practical and efficient way to deliver these types of interventions, we will have a tremendous impact on the quality of life of those we serve.

Herein the personal perspectives and experiences of two burn survivors are presented. The purpose of their stories is to articulate current limitations in burn care and identify areas for future research which may positively impact the life of burn survivors.

## Erin Mounsey

My story is presented as an example of the harsh reality that can exist for some burn survivors after hospitalization and highlights several areas that could truly benefit from research and program development. It is imperative that more research be conducted in the fields of psychosocial rehabilitation, recovery from facial disfigurement, and the effects of intervention programs. The importance of conducting this research is exemplified by how disastrous my recovery became when these tools were not applied. It is also interesting to note how significantly my recovery improved as I became exposed to the burn community and some of the psychosocial skills and programs available at events like World Burn Congress.

Seven years ago, on a beautiful, sunny Tuesday in late October, I awoke with every intention of changing things in my life. Little did I know what an absolutely devastating and life-altering change was in store for me. Throughout that summer I had been working on a home remodeling project that had begun to stagnate as other priorities took precedence. That day, I was focusing on refinishing the oak hardwood floors in the living room.

After sanding the floors, my partner and I started using lacquer thinner to remove any remaining varnish and to tack the floor before applying polyurethane. We properly ventilated the house, wore respirators, and took precautions to dissipate the fumes. When I was just about finished with the process, I poured out the last of the thinner that was left in the can, making a larger puddle than previously. The puddle crept across the floor and towards a wall mounted gas heater. The fumes that roiled off the front of the puddle ignited off the pilot light and instantly the interior of the house was engulfed in flames. The air itself was on fire. The air was fire.

The experience of being burned alive was truly surreal. So surreal that I almost laughed as I tried to wrap my mind around the life-threatening situation that had instantaneously appeared all around me. The empty can of lacquer thinner exploded. The compression

from the explosion tossed my partner through the glass-paned front door. Even though I was peripherally able to comprehend her exit I, reacting to my flight response, darted to the back door. When I grasped the brass door knob, it was already far too hot to touch and I watched as the skin of my fingers seared off.

I was trapped by the large oak door, which had a complex locking mechanism in addition to the door knob. I turned to look back to the front door, feeling the amazing heat across the left side of my face. The site of the air throughout my house boiling with the wicked hues of orange, purple, and red with such an intense area of concentration directly between me and the front door, has been a long standing image of emotional trauma. The utter desolation and desperation that accompanied that sense of being completely trapped by certain death, with no one to save me but myself, resonated in flashbacks for years to follow.

I snapped from my desolation and doubled back into a bathroom to my left. Knocking out the high window and boosting myself up off the rim of the toilet, I made a hasty and harried escape. As I dangled, straddling the glass-sharded sill, I screamed out to the world that I needed help. My bellowing caught the attention of some neighbors. I fell to the ground. And as I rolled out the remnants of my fire-torn clothes across the lawn, paramedics were called and neighbors came to the aid of my partner and me.

Just like that my world was turned upside down, inside out and spun all around. I was unable to even imagine at that point the depths of change and uncertainty that had consumed my reality. In a moments time, I had suffered severe burns over 80% of my body, mostly full-thickness.

My experience with what was modern burn care was for the most part positive. At least that is the way I seemed to perceive it at the time and the way I continue to consider it today. The pain management and amnesiac medications made what must have been a horrifically difficult seven months of severe burn recovery seem like a surmountable challenge without precedence. I just simply awoke each day, after the medically induced coma, to the unknown and did as I was told. Or, at least submitted to what I was instructed would be happening to me.

It was an experience filled with excellent pain management techniques, amazing burn care, exceptional therapy, and superb management of infections and collateral reactions. Over the years, I have had the opportunity to go back and review medical records from those months with family members that were there. In my reflections, I am consistently amazed

that all of the varied and multiple life-threatening obstacles were managed in such a way as to provide me, once again, with an opportunity at life.

While still in the hospital, there was an excellent timing and environmental set-up to the advent of me seeing my facial scarring for the first time. The response to my adverse reaction to that experience was also exceptional. There was a trained mental health professional in my ear for about a week afterwards until I had sufficient opportunities to grieve and begin to accept this new reality.

My hospitalization went as well as could be expected under the circumstances, and I learned to cope with my facial disfigurements while there. But, the hospital was a safe zone where artificial forms of acceptance and untried coping skills were relied upon.

With the loss of my face, I felt as though I had lost my identity and suffered a sincere disconnect with my sense of self. This was one of the most difficult losses to grieve and accept. I suffered a tremendous amount of long-term psychosocial adjustment difficulties as I struggled to overcome this loss.

Seven months later when I was healthy enough to leave the hospital, I felt that everything was going to be just fine. Just fine considering I was recovering from a severe burn from head to toe. I was too medicated and my family was too worn out from the trial of the preceding months to comprehend what we were in for. There were struggles as I assimilated into the urban community around the hospital, but nothing that I was not able to overcome.

It was then time to return to the small rural town in southern Colorado that was my home. I had goals of returning to operating my business, rebuilding my house, and dreams of a happy reunion with my fiancée, friends, and family. This was not to be the case. My goals and dreams quickly dissolved into a bottomless nightmare.

While I was still in the hospital, my fiancée had fallen out of love with me when faced with the prospect of disfigurements and disabilities. By the time I returned home, bandaged and still healing in so many different ways, she had already begun taking steps to sever ties. Everything in my world, once again, fell apart and I began a spiraling descent into that nightmare. Far from the safety and security of the burn care team and my hospitalization, I slipped away.

Posttraumatic stress disorder (PTSD) became more and more a part of my reality as it slowly entered my psyche under the guise of "a normal reaction to a series of unfortunate life events." A year after my burn, when I moved into an apartment of my own, the severe trauma, tremendous loss, and subsequent isolation became too much. It was more than my limited set of

coping skills could handle. I suffered a form of insanity. It is possible that PTSD was identified, but there was no effective intervention. All the right conditions for PTSD were present for quite some time, but when it was identified that my psychosocial reaction was not a positive one, it was too late.

By January, I was in the county jail facing a 4-year sentence in state prison. It was too late. Psychosocial interventions or behavioral enhancement programs that may have been an option to help treat the PTSD and my difficult psychosocial adjustments had not been tried.

Within a couple months of the start of my incarceration, the Phoenix Society sent me a package containing information on the burn recovery process, PTSD, the path of other survivors' recovery, and other burn resources. Before that point I was convinced that I had suffered the worst burn ever and I was suffering on a level never experienced before. My eyes had been opened to a whole world of burn survivors. I was able to read about survivors that had suffered in ways that I could relate to. The tools that they had used in their recovery were right there for me to glean. Finally, the resources that I needed to help me through my grief and recovery process were available to me. During the next 3 years, I studied the resources that I was able to find through this organization and I made great strides in my recovery.

When I started my reintegration process after leaving prison, some of the same psychosocial problems began to resurface. Things were much more manageable with some of the new coping skills that I had developed, but I was still struggling.

One of the areas that was causing the greatest distress was intimacy. I had learned to love myself as a burn survivor and I was rejoicing in some of the amazing personal gifts that were a byproduct of this tragedy. Yet, I was feeling an emptiness from experiencing this life alone. The scarring and severe changes allowed so many doubts to alter my body image. I had no idea how to even approach the possibility of developing a relationship. I had met some people that I would have liked to ask out but I recoiled in fear. I was genuinely concerned that someone might be insulted to be asked out by someone like me.

I began attending World Burn Congress that year. That first experience was absolutely revolutionary and life changing. Within a 5-day conference, I had been transformed. I was sent away with so many new tools and a sense of such utter self confidence. Break-out sessions on relationships and intimacy provided some of the simplest but absolutely necessary tips, techniques, and messages on overcoming my struggles.

Today life is so different than the devastation and desolation that overwhelmed me after leaving the hospital. I know from many acquaintances in the burn community that my psychosocial rehabilitation difficulties are not isolated. This is commonplace in the lives of burn survivors. These struggles don't often manifest themselves with the extremes that occurred in my life, but the difficulties and the pains are just as profound.

I share my story to help illustrate that the struggle to survive a burn injury continues long into the posthospitalization stage. It is not enough that the burn care profession researches to improve the survival rate for severe burns or to minimize scarring. There must be some collaboration with the burn community to improve research into the fields of psychosocial rehabilitation, recovery from facial disfigurement and the effects of intervention programs.

### Chris Gilyard

I am a burn survivor of 28 years and have worked as a burn care professional for the past 6 years. I want to mention a few things about my burn experience, primarily as a reference point for the progress that burn care has made in the past 30 years.

Soren Kierkegaard said, "Life is lived forward, but understood backward." It is looking back to the past that we understand the impact of education and research on the future of burn care. Twenty-eight years ago burn care was, from a patient's perspective, archaic. I was 17 years old when I was burned and had deep second- and third-degree burns to 21% of my body, primarily to my back and face. Here are a few notable examples of progress:

- Twenty-eight years ago, drug therapy was relatively conservative. I can still recall vividly the pain and trauma of the tub room. Today, we are much more proactive, liberal, and understanding with pain medication and pain management.
- Twenty-eight years ago, grafting was performed weeks and months after the initial burn injury. My face was grafted after three and half weeks, and my back was grafted two weeks later. Today, with the same burns, I would probably be totally grafted by two weeks after the injury.
- Twenty-eight years ago, I was an inpatient for 2 months. Today, I could easily be discharged before the end of a month. It's easy to see that, in the past 28 years, the science of burn care has progressed by leaps and bounds.

But although the physical pain my burn caused was unbelievable, the emotional pain was equally devastating. I remember the first two times I saw myself.

The first time, a nurse asked me if I wanted to see myself before I was grafted. She caught me as my knees buckled and I almost fainted. The second time was a week after I was grafted. I looked at myself and thought, "Who is ever going to love me?"

A few days later, the occupational therapists came in carrying a transparent face mask and said this is what we use to keep facial scarring to a minimum. They told me I would have to wear it for 1 to 2 years. I laughed at them. I knew how people were treated who had any cosmetic difference; they were laughed at, teased, and stared at. But, I was afraid to not wear it. So they made me a mask and I went home.

Everything I was afraid of happened. No one prepared me for what I would experience. No one talked to me about being stared at, teased, laughed at. I didn't meet another person who wore a face mask, or even had a facial burn close to what I had, for over a year. Today, 28 years later, when people go home with facial or other visible burns, they often times are still NOT prepared for what to expect or how to deal with it.

Twenty-eight years ago, there were no school or social reentry programs, there were few support groups, newsletters, or camps. Websites and chat rooms were unheard of. Conferences for adults were a dream. I truly believe that if I had had those resources available to me then, 10 years after my burns, I would not have started having flashbacks of the burn unit, suicidal thoughts, and panic attacks for fear of getting burned again. But, as previously quoted, "Life is lived forward, but understood backward," and by looking back, I was able to address the issues that needed addressing and I was able to begin looking forward and using my experience to make a difference for others.

Today I work as a Burn Support Representative at the Regions Hospital Burn Center, offering support, education, and coaching for our survivors and families, as well as implementing programs that promote positive psychosocial reintegration. My duties and programs offered are as follows:

- Burn Support Representative: Offering consistent support, education, and coaching for our burn survivors and families. Implementing numerous psychosocial rehabilitation programs, such as three support groups (burn, electrical injury, and necrotizing fasciitis), the Behavioral and Enhancement Skills Training (BEST) program, and SOAR.
- The BEST program, which deals with social reentry, staring, questions, and teasing. The program offered a formatted way to address these problems. It is an invaluable tool when working

with survivors who are struggling with some of these psychosocial adjustment issues. As burn professionals, knowing what we know today, we have no excuse to not offer this material to our patients.

- The SOAR program. Although I try to visit with as many of our inpatients as I can, I am only one part-time representative. Additionally, there are just times when a man would rather meet with a man, or someone from a house fire would rather visit with someone burned in a similar manner. That's the beauty of this program; we can match people up.
- The Sexual Considerations and Intimacy Needs (or SCIN). Our goal in this program is to address patient sexuality and intimacy issues, as well as train staff to evaluate their own values and beliefs and find their comfort zone with the subject.

These programs provide support and education for patients and their families, including specific training for school reentry, dealing with teasing/staring, and dealing with issues surrounding intimacy. These programs involve all members of the burn team in one way or another—including occupational and physical therapy, pastoral care, child life therapists, and nurses.

Although these programs have been successful in establishing better patient education programs, support systems, and improved rehabilitation programs, there have also been many challenges, including staff reluctance to having a burn survivor as part of the burn team, difficulty for burn survivors making the transition from patient to burn team member, and getting “buy-in” from the entire staff for these programs.

Life is lived forward and understood backward. It is as we look to the past of burn care that we realize how these psychosocial programs truly do help people move forward in their recovery and forward in their lives.

A final saying to conclude: “Success is the child of audacity.” Twenty-eight years ago, it was an audacious

**Table 1.** Priorities for burn research (survivor's perspective)

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Development of a collaborative approach to research the psychosocial rehabilitation interventions already available
Improvements in the management of facial disfigurement
Development of relevant metrics and conduct of studies to assess the effectiveness of burn rehabilitation programs
Development of effective programs focused on the transition from burn center to home
Development of effective educational programs focused on psychosocial rehabilitation and social reintegration issues for the burn injured person as well as burn center staff

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group of burn professionals who worked to change the science of burn care so that it would be what it is today. They are our role models. Let us be audacious as we pursue psychosocial rehabilitation as a standard of burn care, so that we, too, can say we have succeeded in pursuing the best that burn care has to offer. Be audacious.

## CONCLUSION

On the basis of our experiences, we believe five priorities for future burn research should be as follows (Table 1):

1. The development of a collaborative approach to research the psychosocial rehabilitation interventions already available;
2. Improvements in the management of facial disfigurement;
3. Development of relevant metrics and conduct of studies to assess the effectiveness of burn rehabilitation programs;
4. Development of effective programs focused on the transition from burn center to home;
5. Development of effective educational programs focused on psychosocial rehabilitation and social reintegration issues for the burn injured person as well as burn center staff.