



**What Will It Take to Make
Long-term Psychosocial Rehabilitation
for Burn Survivors With Permanent Disfigurement
a Standard of Care?**

**Scientific Progress in
Understanding and Facilitating
Psychosocial Adjustment to Appearance Changes**

Presentation Goals:

To Make the Following Points as Clear As Possible

- A significant proportion of burn survivors who sustain a change in appearance experience difficult and persistent psychosocial/body-image **rehabilitation** challenges.
- These **rehabilitation** difficulties are often under-appreciated, under-recognized and under-treated. Patients are very often left to deal with them on their own.
- The emphasis is on **REHABILITATION** not on psychopathology.
- There are many excellent methods already available for addressing these **rehabilitation** needs.
- There is much work to be done to empirically evaluate the efficacy of these interventions and the best way to disseminate them.
- Empirical evaluation of the efficacy of these interventions is the key to insuring the highest quality of life for the greatest number of survivors over the long-term.

Premise/Heart of the Presentation

- When our legs or spine are injured and we lose the ability to walk, we are mercifully and generously provided rehabilitation services so that we can learn to navigate through the world that is now quite different and which can be quite threatening.
- When our eyes are injured and we lose the ability to see, we are mercifully and generously provided rehabilitation services so that we can learn to navigate through the world that is now quite different and which can be quite threatening.
- **Why is the same not true when we lose our former physical appearance, and the limits of plastic surgery have been reached? With a change in appearance, it can be very difficult to navigate through the world that is now quite different and which can be quite threatening.**

**State of the Science:
Multiple Perspectives on Facial Disfigurement**

The “Outside” Social Perspective:
The Experience of Social Strain

VS.

The “Inside” Psychological Perspective:
The Experience of Body Image

Conclusion of Frances Cook Macgregor's 30+ year Qualitative Investigation of the Social Effects of Disfigurement

“In their efforts to go about their daily affairs they are subjected to visual and verbal assaults and a level of familiarity from strangers ... [including] naked stares, startle reactions, ‘double takes’, whispering, remarks, furtive looks, curiosity, personal questions, advice, manifestations of pity or aversion, laughter, ridicule, and outright avoidance. Whatever form the behaviors may take, they generate feelings of shame, impotence, anger, and humiliation in their victims.”

~Macgregor, 1990

Evidence for Empirical Efficacy of Social Skills Interventions for Individuals with Facial Disfigurement:

Immediate Need for Replication, Extension, and Massive Dissemination

- Blakeney, et al (2005). Efficacy of short-term, intensive social skills training program for burned adolescents. *JBCR*, 26, 546-555.
- Robinson, Rumsey, & Partridge (1996). An evaluation of the impact of social skills training for facially disfigured people. *Br J of Plastic Surgery*, 49, 281-289.

**Scientific Research Focus:
Multiple Perspectives on Facial Disfigurement**

The “Outside” Social Perspective:

The Experience of Social Strain

vs.

The “Inside” Psychological Perspective:

The Experience of Body Image

Burn Rehabilitation: State of the Science (2006)
Esselman, Thombs, Magyar-Russell & Fauerbach
American Journal of Physical Medicine and Rehabilitation

“The extent to which abnormalities in skin pigmentation and texture, scar visibility, amputations, and other changes in appearance affect an individual’s physical image of themselves **have only begun to be examined in burn patients**” (p. 339; emphasis added)

Examples of Empirical Evidence for Burn Survivor

Appearance-Related/Body Image Adjustment Challenges

- The reliability and the validity of the Perceived Stigmatization Questionnaire (PSQ) and Social Comfort Questionnaire (SCQ) among an adult burn survivor population (Lawrence, Fauerbach, Heinberg, Doctor, & Thombs, 2006)
- Development and validation of the Satisfaction with Appearance Scale: Assessing body image among burn injured patients. (Lawrence, Heinberg, Roca, et al, 1998)
- A test of the moderating role of importance of appearance in the relationship between perceived scar severity and body-esteem among adult burn survivors (Lawrence, Fauerbach, & Thombs, 2006).
- Coping with body image changes following a disfiguring burn injury (Fauerbach, et al. 2002).

“The role of shame in encounters between the disfigured and the non-disfigured is one that has been greatly neglected by psychologists. Yet the research reveals that it is a predominant feeling associated with facial deviance....”

~Macgregor, 1990

Barbara Kammerer Quayle:
Behavioral & Enhancement Skills Tools (BEST) Program
Summary Observations Based On Decades of Experience

Chapter 26: *Behavioral skills and image enhancement training for burn survivors: Essential interventions for improving quality of life and community integration. In Auchauer & Sood's Burn Surgery, Reconstruction, and Rehabilitation (2006)*

- “1. In terms of long-term quality of life, **social and psychological rehabilitation is**, for the vast majority of survivors, **profoundly more important than recovery of physical function.**
- 2. Personally meaningful rehabilitation and recovery from significant burn injuries can be greatly facilitated by learning behavioral and image enhancement strategies.
- 3. Currently, there is not a standard and systematic way to address the critical and pressing social and psychological rehabilitation needs of burn patients.”

Burn Rehabilitation: State of the Science (2006)
Esselman, Thombs, Magyar-Russell & Fauerbach
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“No controlled treatment studies for body image dissatisfaction have been published for burn survivors” (p. 399)

Examples of Scientific Evidence for Efficacy of Body Image Intervention: Reviews of the Empirical Literature

- Jarry, J. & Ip, K. (2005). The effectiveness of stand-alone cognitive-behavioural therapy for body image: A meta-analysis. *Body Image: An International Journal of Research*.
- Cash, T.F. & Strachan, M.D. (2002). Cognitive-behavioral approaches to changing body image. In T. F. Cash & T. Pruzinsky. *Body Image: A Handbook of Theory, Research and Clinical Practice*
- Winzelberg, A, J. et al (2002). Psychoeducational approaches to the prevention and change of negative body image. In T. F. Cash & T. Pruzinsky. *Body Image: A Handbook of Theory, Research and Clinical Practice*

Progress in Scientific Understanding of Body Image

- Many thousands total PsychInfo & Medline references
- Development of integrative theories which guide:
 - Conceptualization of body image
 - Assessment of body image
 - Interventions to treat body image psychopathology
 - Interventions to enhance quality of life and prevent future body image problems
- Publication of seminal texts summarizing the area
- **Innovative modes of evaluation/intervention (e.g., web-based, self-help)**
- Publication of multiple, psychometrically sound measures; e.g., Body Image Quality of Life Inventory
- Publication of *Body Image: An International Journal of Scientific Research* (Elsevier)
- Publication of the first edited text integrating Psychology and Plastic Surgery

Data Which Will Really Make a Difference in the Lives of Long-Term Burn Survivors

- Replication, extension, and dissemination of the social skills program evaluated by Dr. Blakeney and colleagues (2005): Evaluating efficacy in child, adolescent and adult populations using multiple methods of dissemination, evaluation, and follow-up.
- Cognitive-behavioral body image intervention for burn survivors with permanent disfigurement: A comparison of group and web-based/self-help intervention formats for children, adolescents, and adults.
- An empirical evaluation of the efficacy of the Behavioral Enhancement and Skills Tools (BEST) program for burn survivors: Assessing the unique contributions of Social Skills Training and Image Enhancement for improving patient quality of life.

Additional Constructive Directions for Enhancing the State of the Science

- Develop long-term collaborations with burn survivors/patient advocate groups (Phoenix Society) to design, implement, and empirically evaluate highly accessible psychosocial rehabilitation programs
- Constructive steps to maximize dissemination of the CBT Body Image, and BEST programs for burn survivors: **What are the impediments to dissemination? When is the best time? What is the best venue? Who are the best providers?**
- Evaluate the effectiveness of short-term “one shot” group interventions (e.g., at World Burn Congress or burn camps) that would include post-intervention web-based follow-up
- A long-term (3-5 year post-injury) evaluation of the social skills and body image adjustment of burn survivors with residual disfigurement
- Concerted study of resilience and post-traumatic growth in the wake of disfigurement: What do “high coping/thriving” survivors have to teach us?

