Scarred for life?
Social and appearance rehabilitation after burn injury

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Overview

- Social and appearance outcomes after burn injury – the evidence
- The experience of being visibly different
  - Impact on self-perceptions
  - Impact on social processes
- Implications for the care we provide

Social and appearance outcomes after burn injury

Summary of the evidence

Adults

< 6 months
  - Raised general anxiety (28%) and depression (13%); normal levels of social anxiety

6-24 months
  - Significant social anxiety (29%)

2 years
  - Significant depression (96%), general anxiety and social anxiety (44%)

Castle (2005 – Ladbroke Grove Rail Disaster, 1999)

18 months
  - 63% reported feelings of inadequacy and low self-confidence
  - 63% reported under-confidence in social settings

4 years
  - 15% reported residual psychological distress

Children and their parents
Phillips and Rumsey (2008)

< 6 months
  - 11% of parents reported clinically significant depression
  - 11% reported unhealthy family dynamics

6-24 months
  - 22% of parents reported clinically significant depression
  - 11% reported unhealthy family dynamics
  - 38% reported that their child had thoughts/images about the accident and 26% reported that their child still had nightmares about the accident

Across time bands
  - 33% of parents reported clinically significant levels of anxiety
  - 43% reported feeling that their child’s burn was unattractive to others
  - 27% reported that their child was teased and 23% reported that people stared
  - 36% felt that their child was bothered by the reactions of others
Impact on family members

- Siblings of burn-injured children:
  - 20% reported some form of disturbance after the accident (e.g. sleep, nightmares)
  - 27% reported still being bothered by their sibling’s burn scars
  - 20% reported feeling social discomfort when people talked about their brother/sister.

- Children with a burned parent:
  - 10-14% reported some form of disturbance following their parent’s accident (e.g. sleep, loss of concentration)
  - 33% reported still being bothered by their parent’s scars
  - 14% felt social discomfort when people noticed their parent’s scars.

- Partners of burned adults:
  - 36% reported actively trying to avoid looking at the injury initially
  - 57% reported a negative impact on themselves or their life (e.g. anxiety, low mood, giving up work)
  - 38% reported still being bothered by their partner’s scars.

**Summary**

- First 6 months post-injury, focus is on **survival**.
  - Anxiety and depression reduce from the in-patient to early post-discharge period

- 6-24 months post-injury - **socialisation**
  - As the permanence of the residual scarring becomes apparent social anxiety and depression emerge.

  The whole family is affected.

  Time is not a great healer for patients still in the burn care system 2-3 years post-injury.

Outcome predictors

- Not TBSA or HDU episode
- Still being in the burn care system >2 years post-burn

  Adults:
  - Lower social functioning (family/friends, sexual relationships) and personality (lower emotional stability)
  - Perceived severity and perceived visibility.

  Children:
  - Lower parental emotional stability
  - Poorer family functioning
  - Younger age of mother

- Provision of accurate information about the long-term rehabilitative process
- Availability of specialist counselling and peer-support post-discharge.

**Summary**

- Objective measures of burn severity are not stable predictors of adjustment levels.

- Family dysfunction and social factors are important.

- Children are reported to have more problems with peers and with the reactions of others to their appearance with increasing age.

Visible Differences are…

“Disfigurements are… potentially noticeable differences in appearance that are not culturally sanctioned.”

Kent and Thompson (2002)
The case of shame: Kent & Thompson (2002)

Internal shame or body shame
- Negative views about oneself – affecting self-perceptions

Leanne (aged 15 years) talked about her burn scarring to her chest and arm. She described it as “a thing” attached to her that did not feel part of her body. When asked to describe what it looked like she said it was “vile, disgusting” and unbearable to look at. When a therapeutic homework task was agreed which involved Leanne looking at her scarring in the mirror in order to more objectively describe its physical characteristics to the psychologist, Leanne found that she was unable to do this. She reported that she could not look at the scars for more than 2-3 seconds because it caused her too much distress.

External shame or social anxiety
- Negative views about how others perceive you – affecting social interactions

Hannah (aged 14 years) described a recent trip out: I had such a terrible time in Blackpool at the weekend. I was queuing up to go on one of the rides and everyone was staring at me – I could feel their eyes burning into me because I looked such a freak. I couldn’t bear it – I was stood in a queue so there was no escape from their glares. I ended up leaving long before I got to the front of the queue. I’m never going somewhere like that again.

Impact on social interactions
Not surprisingly, the majority of problems stem from social encounters and the reactions of others – particularly strangers.
- Many feel that they are avoided and rejected by others.
- Frequent exposure to these negative reactions can lead to: social anxiety, lowered self-confidence, negative self-image, depression and lowered self-esteem - all of which can have a cumulative effect on future interactions.
- Feelings of self-consciousness can take over and people can become preoccupied with their disfigurement and the effects this may be having on others.
- This in turn can lead to withdrawal from social situations.

Developmental issues

Children burned before the age of 2 require minimal body-image adaptation because the injury becomes a part of their “normal” body image.
The school-age child has a much clearer conception of body image and is aware of cultural standards of appearance. Children at this age are therefore likely to have to mourn the losses sustained.
- Teacher’s expectations of pupils’ academic achievements have been shown to be influenced by physical appearance, with more attractive children being regarded as cleverer, more likely to achieve and more likely to possess positive personality characteristics.
- Attractiveness is also a major influence on peer relationships.

Developmental issues
Adolescence is an especially challenging time with respect to body image adjustment, and some children may evidence problems at this stage of development even if they have not done so earlier in life.
Leaving school presents a further major social challenge with the need to seek work and attend interviews, as may thinking about sexual relationships.
However, many studies have found the majority of burned children to be coping well at follow-up.

Implications for the care we provide
Survival: The first 6 months
Support in Hospital

- Support around practical issues – lessens the emotional load.
- Normalising reactions on first seeing the burn.
- Answering questions, providing information and establishing realistic expectations of rehabilitation and outcome – *Burned skin will never look like unburned skin and there will always be some scarring, but appearance will change with time.*
  - Access to a photographic bank?
- Realistic short and long-term goal setting.
- Re-establishing sense of own competence.
- Prompt referral for specialist psychological support when required.
- Support for *all the family.*

Preparation for Going Home

- 3-2-1-GO! (James Partridge, Changing Faces). Get the patient to plan for uncomfortable social situations by thinking of...
  - 3 things to do when someone stares at them
  - 2 things to say when someone asks them what happened
  - 1 thing to think if someone turns away from them
- Contact from the Burn Care Team within the first week of going home.

Support in returning to work

**Important outcome:**
- Economic reasons
- Associated with good psychological outcome

**Recommendations** (Mackey, in press; Fitchett & Hickerson, 1995):
- Personalised rehabilitation targets
- Engage family
- Multi-disciplinary support:
  - Medical/nursing
  - Therapies: Individualised exercises; goal setting/pacing
  - Psychological: managing adjustment reactions; developing coping strategies e.g. managing difficult questions; managing fear and avoidance
  - Employer liaison service: education and advice; employee rights; welfare benefits.

Support in returning to school

Again, getting back to school as soon as possible is a key outcome. School reintegration programmes can include:

- Written information for teachers
- School visits by the burn care team involving pupils, teachers/teaching assistants, burn-injured child and parents/carers to:
  - *Educate* – causes of burns, treatments and prevention of injuries
  - *Explain* – the physical and psychological needs of a child who has had a burn
  - *Encourage* – an informed and confident acceptance back into the school environment.
- Important that the school is seen to be pro-active.

Living with scarring

Visibly different individuals face two challenging tasks:

- Dealing with others' negative reactions
  - Social skills based interventions to develop coping strategies
  - Reducing avoidance of social situations.
- Developing a healthy sense of self not dominated by the scarring.
  - Personal photographic diaries can assist with body image adjustment
  - Systematic desensitisation to areas of body that provoke distress
  - Challenging unhelpful appearance-related assumptions
  - Undertaking positive activities to develop a positive body image
  - Peer support interventions.

Socialisation

6 – 24+ months

**Socialisation**
Medical Interventions
Reducing the severity of visible differences can have substantial beneficial effects…
… but can be insufficient in themselves.
- Ensuring realistic expectations of process and outcome are key.

Support in the longer term
- Opportunity for support should be available for "old hands" as well as new patients.
  - Regular psychosocial screening throughout the patient’s journey

Advocacy
Given the crucial role that the reactions of the general public play, it is surprising that there are few reports of interventions at a wider, societal level.

Educational Initiatives
- Cline et al., (1998) developed a pack aimed to increase awareness and understanding of facial disfigurement for 9-11 year olds in schools.

Societal Interventions
- Changing Faces
  www.changingfaces.co.uk
Conclusions

- Time is not a great healer for patients still in the burn care system 2-3 years post-injury.
- Objective measures of burn severity are not stable predictors of adjustment levels.
- The experience of being visibly different can have a significant negative impact on:
  - Self-perceptions
  - Social processes
- Research findings have a range of implications for the burn care we provide – throughout our patients’ journeys, and beyond.
  - Importance of managing expectations and uncertainty throughout
  - Levels of support required differ markedly
- Multi-level approach provided by the whole MDT is needed!

Further Reading