RECOVERY AFTER SUBARACHNOID HEMORRHAGE

Lisa T Hannegan, MS CNS, ACNP
Department of Neurological Surgery
University of California, San Francisco

I HAVE NO FINANCIAL DISCLOSURES TO REPORT

OVERVIEW OF RECOVERY AFTER SUBARACHNOID HEMORRHAGE
“People see you looking good and tell you that you are doing great. Yet you have to work so hard to appear normal (when you really aren’t) that it is exhausting.”

The Cooperative Aneurysm Study

- 1981
- Delayed operations
- Standard Medical Therapy
- Outcome
  - Favorable 46%
  - Unfavorable 18%
  - Dead 36%

The Cooperative Aneurysm Study
Memory

- Verbal- most often impaired (14-61%)
- Visual (14-49%)
- Short-term
- Long-term

Executive Function

- Frontal lobes
- Diffuse injury
- Variation in tests done and incidence

Executive Function

- MRI study done at one year
- 76 SAH survivors and 30 controls
- Reduced total gray and white matter volume that correlated with executive function deficits
- Significantly reduced hippocampal volumes bilaterally that correlated with visual memory impairment
  - Bendel et al. (2010)
Language

Functional Outcome

- Reflects the interaction of all the separate cognitive domains.
- This includes the activities of daily living and return to work

Activities of Daily Living (ADLs)

- Ability to care for oneself
- Impairments are not as common (4-12%)
- Deficits are related to visual memory, visuospatial function and psychomotor function

Instrumental Activities of Daily Living

- Complex daily functions
- Much more frequently impaired at 44-93%
- Driving
Quality of Life

Social
Emotional
Physical

Mood and Anxiety

- Depression in 5-50%
- Anxiety affects 27-54%
- PTSD

Sleep and Fatigue

- Daily fatigue in 31%

Sleep and Fatigue

- Daily fatigue in 31%
- Profound sleep disturbances in 37-45%
Sleep and Fatigue

- Daily fatigue in 31%
- Profound sleep disturbances in 37-45%
- Significantly lower quality of life scores

“...I mean there are times when I’m just bawling I am so tired at the end of the day. I realize I do a lot of covering up. I mean I’m blind from this side over--I have no vision here. And when I am really tired, I’m banging into things and I’m constantly having to reorient.”

Headache

- Daily fatigue in 31%
- Profound sleep disturbances in 37-45%
- Significantly lower quality of life scores
- No obvious improvement
• Cognitive function in SAH survivors with “good” outcome evaluated after 6 months
  • Impaired cognitive flexibility, planning, problem solving and inhibition
  • Intact judgment and estimation

Manning et al. (2005)

Long Term Outcomes

• Persistent headache, depression and forgetfulness
• Low return to work rate

Perimesencephalic Hemorrhage

Clipping versus Coiling

• Extensive cognitive and functional impairments
• More use of neuropsych testing
• Comprehensive rehab strategies

Conclusions
“Now technology is a huge problem for me. I had been back to work for 2 years and getting by doing my old job (except a little slower) when my computer software was updated to Office 2010. I couldn’t learn to use it, so I had to quit.”

SAH Survivor

• One of the most important aspects of real-life functioning

• 40% of SAH survivors are unable to return to their previous work
Return To Work

• Subarachnoid hemorrhage occurs during the peak productive years
  • Effect on the family structure
  • Effect on the family finances

Benefits of Work after SAH

• Financial stability
• Improved self-esteem
• Improved satisfaction and quality of life scores
• Social interactions
• Enhanced cognitive function and physical recovery

Barriers to Return to Work

• Cognitive dysfunction
• Depression
• Fatigue

Cognition: Challenges at Work

• Pace of activity
• Multi-tasking
• Lack of quiet time to recover
• Lack of understanding by co-workers
• Using energy to hide emotional and cognitive difficulties
Fatigue

Patients who experience fatigue after stroke are more likely to be unemployed or have lost or changed jobs compared with those with no fatigue after stroke (Lerdal et al., 2009).

Hidden Physical Limitations

- Preventing those around them at work from knowing their post stroke deficits
- Refusal to use assistive devices
- Not seeking assistance from professional resources for fear of losing more independence

POST-TRAUMATIC STRESS DISORDER

“I was taken to a baseball game as a special treat from my family. When we got there, I became completely overwhelmed by all the stimulation and jostling and the speed of the crowd. I had to go right home.”
Noble et al.

Prospective study
Evaluated at 3 and 13 months
Neuropsych battery:
- Cognition
- Physical disability
- Sleep
- Fatigue
- Coping
- Quality of life
- Global mental status
- PTSD

Study Outcomes

- Only 4.1% of patients had physical dependence
- 8% demonstrated impairment in attention
- 12% impaired cognitive function

“Neither physical nor cognitive impairments, on average, seem severe enough to explain the QoL reduction”

Study Outcomes

- Only 4.1% of patients had physical dependence
- 8% demonstrated impairment in attention
- 12% impaired cognitive function
  - With regard to QoL, patients scored significantly worse than the norms across all domains ($P < 0.006$).
Study Outcomes

- At 3 months
  - Moderate to severe PTSD in 37.1% (norm 8%)
  - Functional impairment in 75%
- At 13 months
  - Persistent incidence of 37.1% PTSD
  - Functional impairment in 82%
  - 59% pathological fatigue and 45% pathological sleep disorders

Criteria for PTSD Diagnosis

- Trauma
- Re-experiencing
- Avoidance
- Hyperarousal
- Fear and guilt

Treatment of PTSD

- Psychotherapy
  - Cognitive Behavioral Therapy
  - Exposure Therapy
- Pharmacology
  - sertraline (Zoloft)
  - paroxetine (Paxil)

Post-traumatic Growth

- Transformative powers of suffering
- Positive change arising from struggle
- Change of perspective
- Appreciation
- Transition from “why me?” to “what for?”
“I’m always fatigued. Not sleepy, but just bone-tired. Sometimes it’s really hard to get out of my chair, so I don’t like to get into it.”

“At work, to be on the phone when someone is talking or to…be on the computer and phone. That just was not going to work! And I couldn’t be on the computer for more than a certain amount of time. That was also very hard for me.”

“I feel like an alien. I can’t move at warp speed like everyone else does. Simple things like grocery shopping or walking down a busy street are overwhelming.”
“I can’t watch medical or hospital shows on TV any more.”

“Some of the problems and quirks I had before are magnified by the hemorrhage”

“I am still not able to travel anywhere that is away from my hospital and my doctors.”

“As the caregiver, I have post-traumatic stress. When my wife sleeps at night, she has nightmares that wake me up and scare me when she calls out. But it is even worse when she sleeps soundly and quietly. I wake up and can’t hear her and startle wide awake to check and see if she is still alive.”
“I feel bad for my husband. He’s my caregiver. My aneurysm caused huge changes to our finances, our marriage, and our relationship.”

“I was an investment banker. Now I have lost two jobs and each time I look for a job I need to decrease my expectations further. I am interviewing for a job tomorrow that I would never have considered taking before. Now I just hope I get it.”

“No one prepared us for how to recover from this.”

“We need more information, more resources, lists of what to do for disability, unemployment and the DMV. We need referrals to advanced therapy like cognitive therapy or vocational therapy. We need social workers.”
“A life coach would be great, but I can’t afford it, and I know that most could not.”

“The hardest thing to understand is how long the healing process is.”

“Tell people to get out of the house and not be so isolated”

“You have to do more everyday so you can relearn things.”
“Find something that brings you joy.”

“Focus on coping and on what you have.”

“Life is just different.”

“You can’t spend all your time complaining.”
“You can go from depression and feeling bad to accepting and giving back and being happy.”

“It’s a matter of reassessing yourself and finding your calling.”

“Support groups are a huge help. Everyone needs sharing and support.”

“Sometimes hardship is just hardship. It’s like that joke about the little boy who looks through a pile of s… hoping to find the pony – and clearly the pony isn’t there. To look for the gift when you are in the midst of suffering doesn’t really work….”
……Instead, being with the hardship and acknowledging the ‘yuck’ in our lives might be the point. The courage to stay with the ‘yuck’ and create something from that seems to be the lesson. No pony rides for me today!”

“I am glad this happened to me and people think I am nuts. I am glad because if I was still working I wouldn’t have done these things… now I travel every year…I write about my experience and at my old work one of the bosses asked me to speak at a stroke convention.”

“I have the sense that I am lucky to be alive and I need to pass the gift on…..”

• With great appreciation for all you have taught me
  • Jeanne Scanlon
  • The San Francisco Aneurysm and AVM Support Group
  • Michael Lawton and Charles Wilson
  • Wellcome Images

Thank You