Caregivers as Clients: Who’s Caring for the Caregivers

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Objectives:

- Who are the caregivers?
- What are the stages of recovery?
- What are the risks to caregivers’ health & satisfaction?
- What is the impact of caregivers’ wellbeing on the patients’ wellbeing?
- How can caregiver support & assistance be improved?
Caregiver Demographics

- Unpaid family member, friend, neighbors
- 44 million people over age 18
- 40% are male
- Average age is 47
- Working at least part time
- In need of support
If you’ve seen one brain injury, you’ve seen one brain injury.

Each case is unique and every caregiver needs case-specific guidance.
With Brain Injury there is an Increased Survivability
Earlier medical intervention
but, shorter medical rehab
Individuals with greater disabling conditions being sent home

“sicker and quicker”
17 days of acute medical care in 2012 vs. 57 days in 1990 for high moderate to severe injuries

Ashley, M. Santa Clara Valley Brain Injury Conference, 2012
Occurrence of Severe TBI:

- 50,000 to 75,000 people per year
- \(\frac{1}{3}\) to \(\frac{1}{2}\) of those will die
Cost of Severe TBI:

$15-17 million over the course of a person’s life
Cost of free caregiver services:

$375 Billion per year

National Alliance for Caregiving and Evercare. March 2009
When the Unthinkable Happens...
Every Survivor is a Miracle!
But as Time Goes By...
The Feelings Come...

Exhaustion
Anxiety
Anger
Sadness
Guilt
Stages of Recovery
The Family’s Initial Response
Stage 1 – One to Three Months

➢ Shock
➢ Hopeful, relieved
➢ Denial
What are the needs at this stage?

- Support from friends and family
- General information from nurses and doctors – factual without too many details
- Listen
Adjusting
Stage 2 – Three to Nine Months

- Realization of the Situation
- Anger, Anxiety, Fear, Depression, Loss
What are the needs at this stage?

- Ongoing support
- More specific information
- Allow for venting anger, frustration, fear, loss
Annoyance
Stage 3 – Six to Twenty-Four Months

- Discouragement
- Depressed
- Reviewing the Information
What are the needs at this stage?

- Information about resources for brain injury
- Support groups for caregivers
- Validation of feelings
Exhaustion
Stage 4 – Ten to Twenty Four Months

- Realism sets in
- Less Time Spent with Loved One
- Grief
What are the needs at this stage?

- Counseling
- Social Support
- Time off
Sadness
Stage 5 – Twelve to Twenty Four Months

- Ambiguous Loss
- Accepting the "New Normal"
What are the needs at this stage?

- Expression of grief
- Family- Community-Based Interventions
Acceptance
Stage 6 – Two to Three Years

- Greater Understanding
- Accepting the Person as They Are Now
- From Patient Focus to Family Focus
What are the needs at this stage?

- New Social Networks
- Help with Daily Activities to Avoid “Burnout”
- Recognition
I need a vacation so badly, I've resorted to plotting my own kidnapping.
It’s not a sprint –
It’s a Marathon!
Challenges Facing the Caregiver:

- Financial
- Social
- Psychological
- Physical
Financial Resources:

- Private Funding
- Insurance
- Medicaid
- Medicare
- Waiver Programs
Social Isolation:

- The Family
- The Caregiver
- The Patient

Increased social support leads to decreased distress in caregivers.

Ergh, Tanya C., et al. 2002
Predictors of Caregiver Burden: Care receiver characteristics

- Global Handicap
- Level of Executive Function

Signs of Caregiver Burden

- Depression
- Somatic symptoms
- Anxiety
- Substance abuse

Physical Impact of Caregiving:

- Increased Health-Risk Behavior, i.e. smoking
- Sleep Disturbances
- Lower Immune Functioning
- Slower Wound Healing
- Increased Insulin Levels & Blood Pressure
- Increased Risk for Cardiovascular Disease
- Changes in Sexual Roles for Spouses

Reinhard, Susan C., et al.,
Predictors of Success:

- Behavioral & Cognitive Function of Patient
- Premorbid Function
- Social Support
- Economic Status
Caring for the Caregiver:

- Caregiver as the client
- Individual as opposed to group Counseling
- One-to-one telephone calls
- Home visits
Goals for Caring for the Caregiver:

- Improve Confidence & Competence
- Home Care Team
- Problem Solving Strategies
- Safe Plan for Caregiver & Patient
Caregivers as Providers:
Potentially Harmful Behaviors

- Abuse & Neglect
- Medication Errors
- Abandonment
Positive Consequences of Caregiving:

- Increased Mutuality
- Sense of Meaning
- Developing New Relationships
Areas of Vulnerability for Caregivers:

Lack of:

- Funding
- Facilities
- Social Support
- Therapeutic Services
- Understanding...community, family, friends, professionals
Issues Identified by Caregivers

- Changes in family roles
- Social isolation
- Expectations of behaviors & recovery
- Identity blurring

Fay, Aimee, 2012
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Assisting Caregivers

Healthcare Providers

Family & Friends

Support Groups

Caregiver Receiver

Counselor

Home Care Team
Resources:

- Caregiver.org
- www.mentalhelp.net
- Caregiveraction.org
- www.caregiver.va.gov
- www.helpguide.org
References:


Questions?
Comments?