



AHA/ASA's SUPPORT NETWORK

Presented by
Debbie Hill, FAHA
Lombardi Hill Consulting Group
www.lombardihill.com

THE IMPACT OF
SOCIAL SUPPORT
ON SURVIVORS
AND
CAREGIVERS

Disclosures

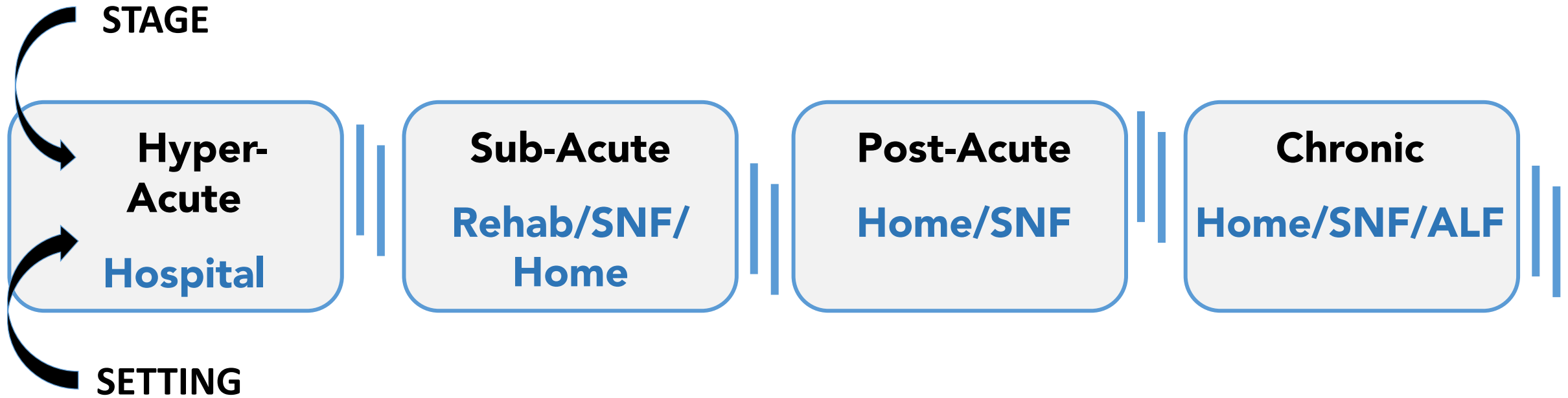
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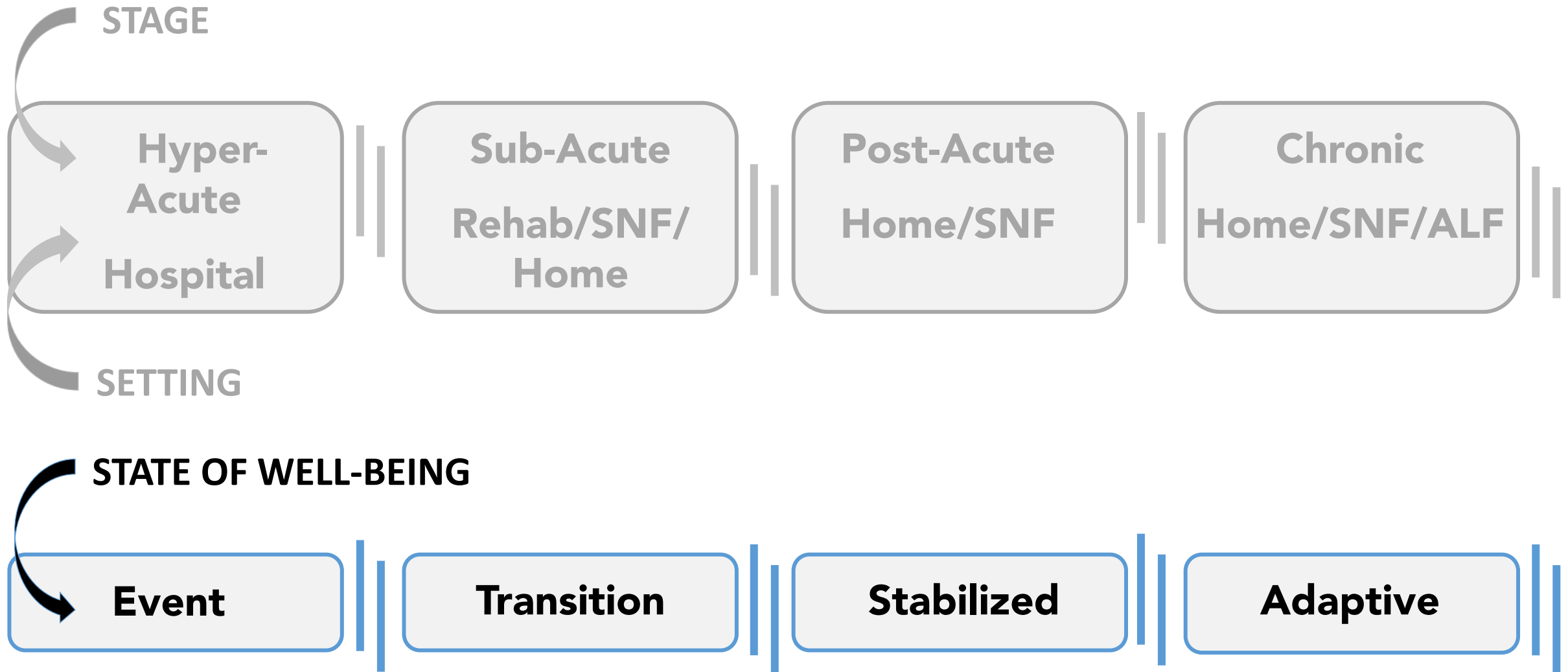
◆ Volunteer

- ◆ Member, AHA/ASA National Advisory Committee
- ◆ Chair, AHA/ASA National Subcommittee on Post-Acute Stroke
- ◆ Member, AHA/ASA Greater Southeast Affiliate Research Committee

The Post-Stroke Journey



The Post-Stroke Journey



The Post-Stroke Experience – A Caregiver



“It’s all overwhelming.”

“How will I manage?”

“How can I remember all this?”

“There are too many decisions.”

“It is so hard right now.”

“I feel all alone.”

“Who can I trust to help me do the right things?”

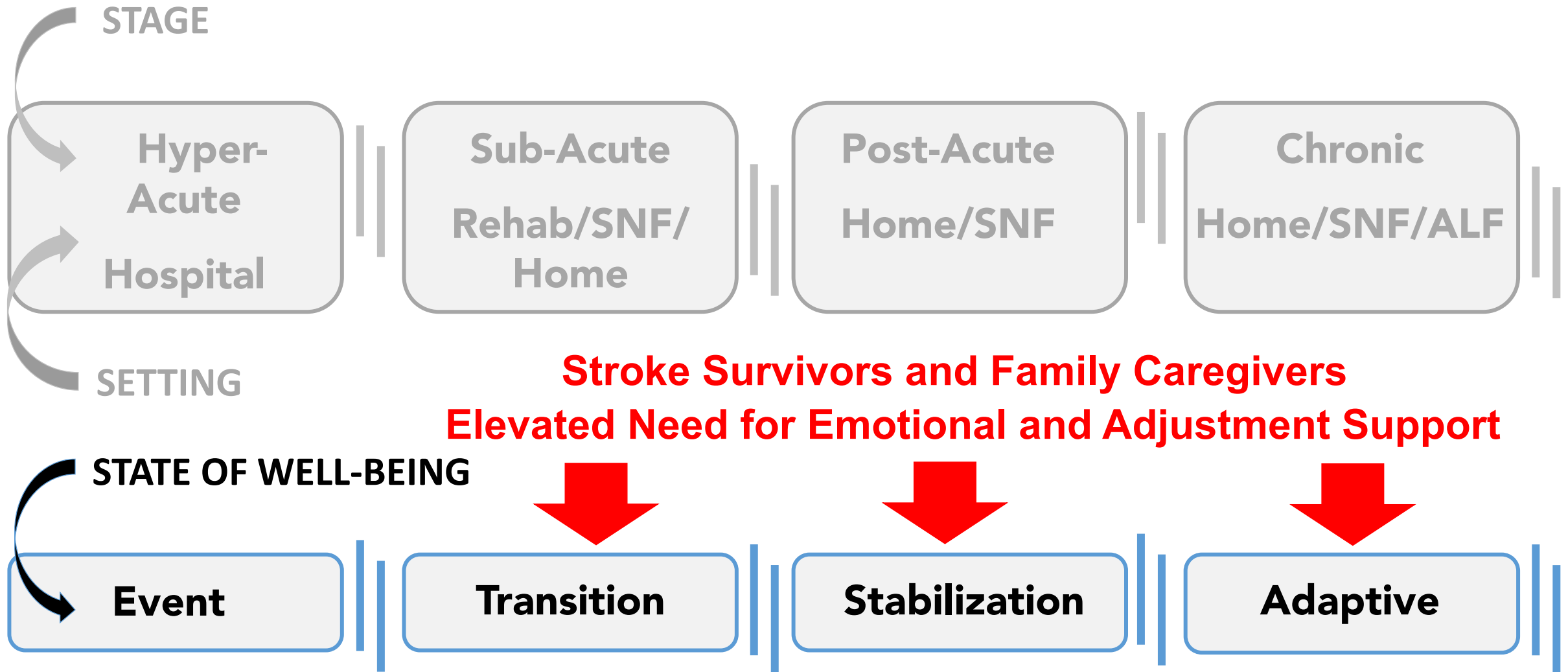
The Post-Stroke Experience – A Patient

“On AUG. 26, 2014 I had a stroke.

Nothing has been the same. It's like my whole world has been turned upside down. After 4 months I still have a lot of weakness on my left side. I'm in a foot brace and walk with a cane. I'm dealing with anger, anxiety, depression, comprehending, expressions and much more. I'm unable to return to work. I find it hard to motivate myself to wanting to do stuff. I'm wondering if things will get better.....”



The Post-Stroke Journey



WHAT WE KNOW

Impact of Social Support in First Stroke

STROKE 1993



One of the Earliest Studies - 1993

- **Purpose:**
 - **Examine impact of social support on recovery**
- **Methodology:**
 - Prospective cohort study
 - Social support measured 1, 3, and 6 months
 - Measured changes in functional status – average Barthel Index of activities of daily living
- **Findings:**
 - **Significant differences across levels of social support**
 - **High levels of support associated with**
 - **Faster recovery**
 - **More extensive recovery**

Social Network, Social Support and Risk of Incident Stroke

STROKE 2014



M. Nagayoshi, S. Everson-Rose, H. Iso, et al. Stroke, 2014; 45: 2868-2873

WHAT WE KNOW

Social Factors and Relationships on Health Outcomes - 2014

- **Purpose:**
 - Examine longitudinal association of a small social network and lack of social support with risk of incident stroke
- **Methodology:**
 - 14,348 participants
 - Network size and perceived social support measured on Visit #2
 - Active social network size assessed - family, friends and neighbors
- **Findings:**
 - Having a small network size was independently associated with increased risk of incident stroke
- **Conclusion:**
 - Health care professionals are encouraged to:
 - Screen for network size in community outreach; discuss importance of social connections
 - Provide information on community resources that enhance one's social network

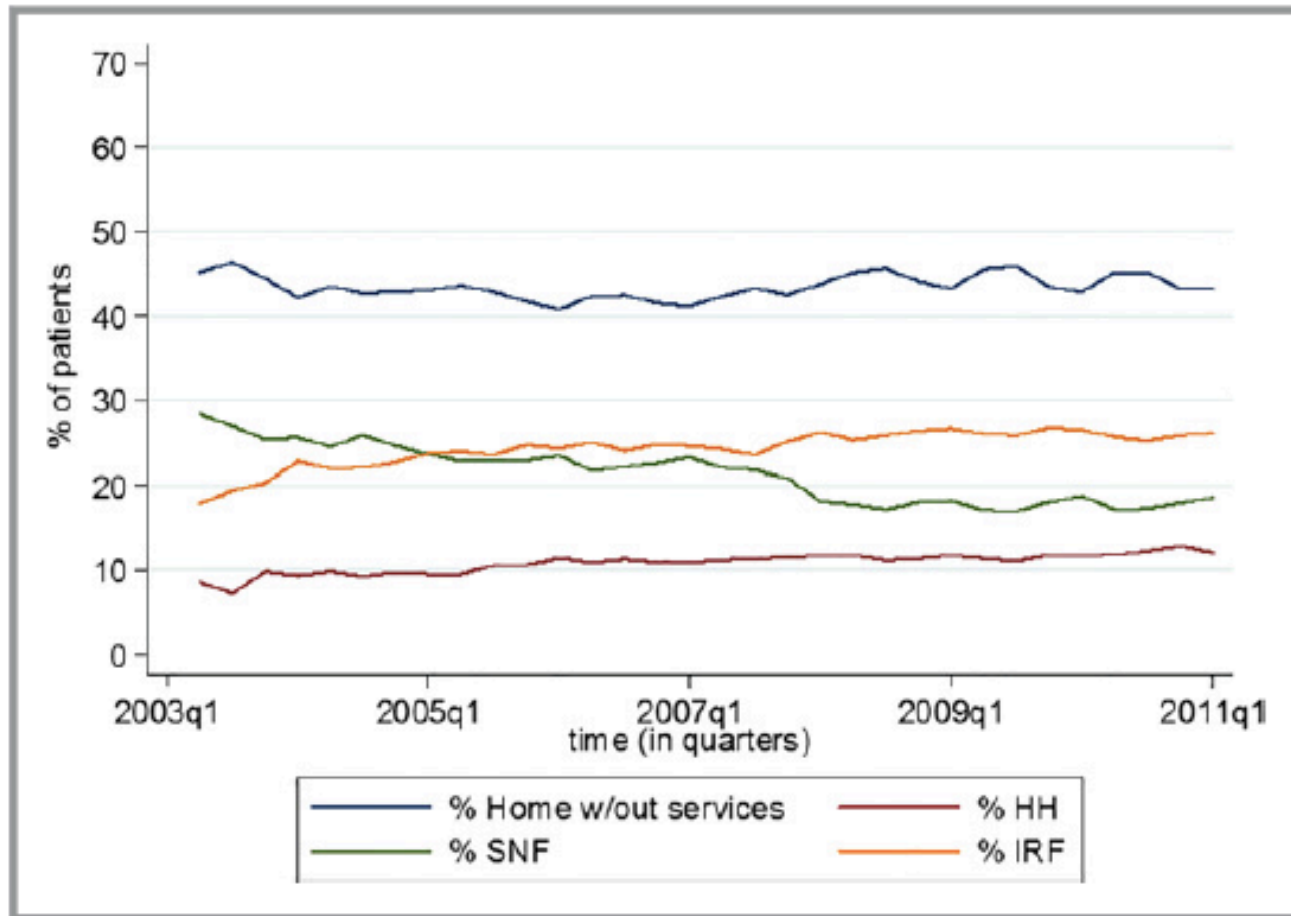


Figure 2. Proportion of patients discharged to postacute care of IRF, SNF, and HH or discharged home. HH indicates home health; IRF, inpatient rehabilitation facility; SNF, skilled nursing facility.

POST-ACUTE SERVICE USE

Recent Trends in Post-Acute Services - 2015

- **Purpose:**
 - Examine use of post-acute services based on age and discharge disposition
- Methodology:
 - 849 patients from 1687 hospitals
 - Get-With-The-Guidelines database
- **Findings:**
 - 4 out of 10 patients were discharged home without services
 - There has been no increase since 2003

The Post-Stroke Journey

- Findings:
 - Younger patients are more likely to be discharged with services

POST-ACUTE SERVICE USE

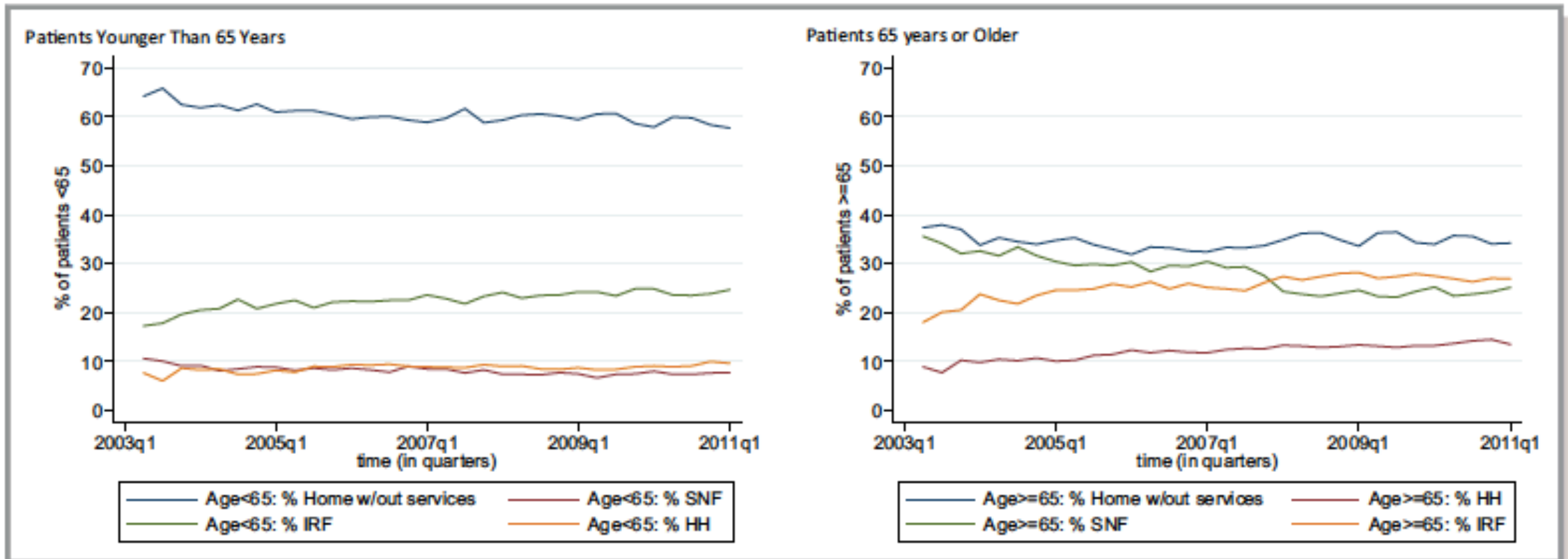
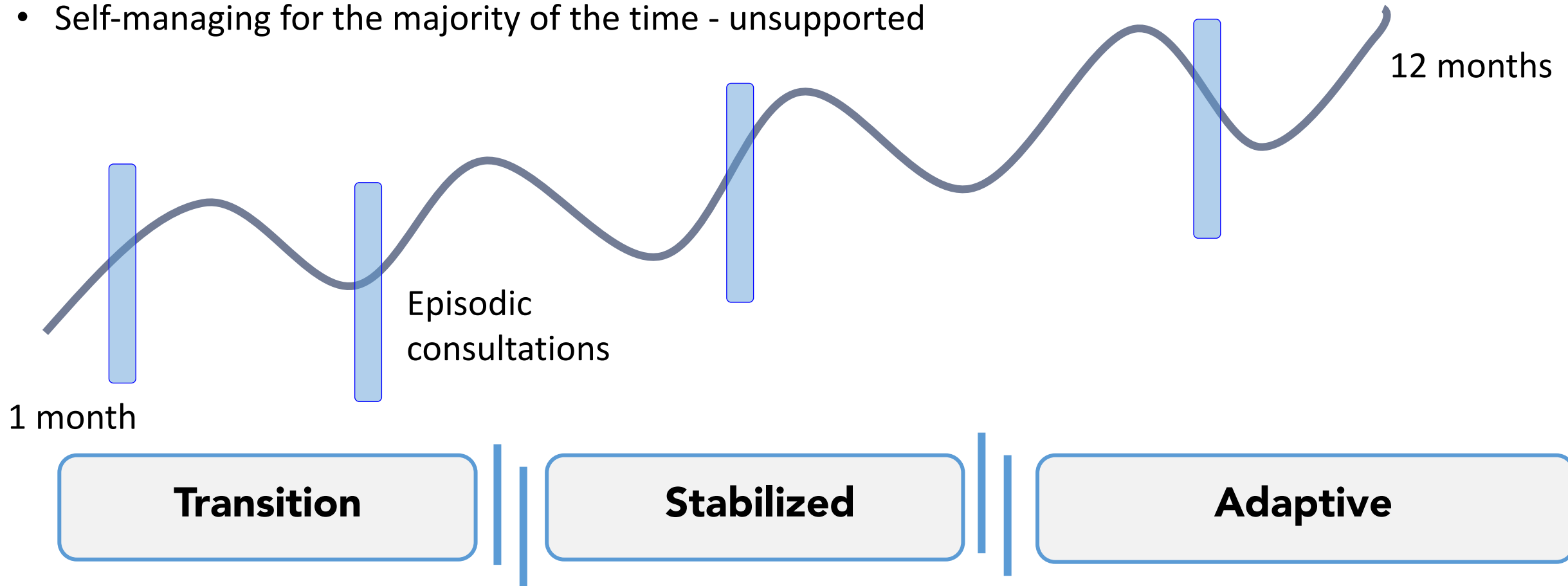


Figure 3. Proportion of patients by age discharged to postacute care. HH indicates home health; IRF, inpatient rehabilitation facility; SNF, skilled nursing facility.

The Post-Stroke Journey

LIVING WITH A LONG TERM CONDITION

- A year in the life of someone with long-term disabilities
- Self-managing for the majority of the time - unsupported



POST-STROKE REHAB

“There are types and degrees of disability resulting from stroke.”

NINDS WEB SITE – POST-STROKE REHAB



Post-Stroke Rehabilitation

- In the US, more than 700,000 people suffer a stroke each year
 - 2/3 survive and require rehabilitation
- 5 Types of disabilities resulting from stroke
 - **Motor control**
 - **Sensory disturbances**
 - **Problems using or understanding language**
 - **Problems with thinking and memory**
 - **Emotional disturbances**
- Goal of rehabilitation
 - **Help survivors become as independent as possible**

The Post-Stroke Journey

Survivor Disabilities

- Motor control
- Sensory disturbances
- Problems using or understanding language
- Problems with thinking and memory
- **Emotional disturbances**

• Goal of rehabilitation

- **Help survivors become as independent as possible**

Caregiver Stressors

- **Emotional disturbances**
- Memory problems
- Problems using arm or hand affected
- Bowel-related difficulties
- Difficulty understanding/expressing in conversation

• Goal of rehabilitation and beyond

- **Help caregivers cope**

WHAT WE KNOW

Perceived Social Support –
Post Stroke Depression
STROKE 2015



Post-stroke depression common occurrence after stroke

- **Purpose:**
 - Examine impact of social support on post-stroke depression
- **Methodology:**
 - Depressed and non-depressed patients
 - Enrolled 1-month post-stroke
 - Depression severity by the PHQ-9
 - Improvement measured at 12 weeks
 - Defined as PHQ-9 < 5 or
 - Decrease by least 50%
 - Social support measured by *Medical Outcomes Study Social Support*
- **Findings:**
 - Positive social interaction was a **significant** contributor to variance in initial post stroke depression
 - Social support **was independently associated** with the presence and severity of post stroke depression
 - Did not find relationship in subsequent depression

WHAT WE KNOW

Intervention Studies for Caregivers of Stroke Survivors

PATIENT EDUCATION COUNSELING 2005



Effective Interventions for Caregivers

- **Purpose:**
 - Evaluate the effectiveness of interventions for caregivers of stroke patients
 - To relate differences to timing after stroke and the content of the intervention
- **Methods:**
 - Literature search
 - 22 studies reviewed
- Interventions distinguished
 - Specialist services (12)
 - (Psycho) education (5)
 - Counseling (4)
 - Social support by peers (1)

WHAT WE KNOW

Intervention Studies for Caregivers of Stroke Survivors

PATIENT EDUCATION COUNSELING 2005



Effective Interventions for Caregivers

- Timing
 - Most interventions started during or shortly after discharge
 - 3 took place in chronic stages (>6 mos. post-stroke)
- Outcome Measures:
 - QOL, emotional state, burden, family functioning, social activity on a daily basis, coping, satisfaction with care, knowledge, social support
- **Findings:**
 - Of 22 studies, 10 reported positive results on one or more outcome measures
 - **Early discharge to community rehab led to worse state of general health among caregivers even with a problem-solving approach**
 - **Model of care focused on patient and too little on goal-setting for the caregiver**

Intervention Studies for Caregivers of Stroke Survivors

STROKE 2014



WHAT WE KNOW

Evidence for Stroke Family Caregiver and Dyad Interventions

- **AHA/ASA Scientific Statement - 2015**
 - Caregiver stress is the leading cause of stroke survivor institutionalization
- **Purpose**
 - **Provide EB recommendations for implementation and future design of stroke family/caregiver dyad interventions**
- **Methods:**
 - Critical analysis of 17 caregiver intervention studies and 15 caregiver/stroke survivor intervention studies
 - Do family caregiver interventions improve survivor outcomes?
 - Do family caregiver interventions improve caregiver outcomes?
 - What type of interventions are most effective for both?
 - What recommendations can be made for designing and implementing interventions that improve outcomes for both?

Intervention Studies for Caregivers of Stroke Survivors

STROKE 2014



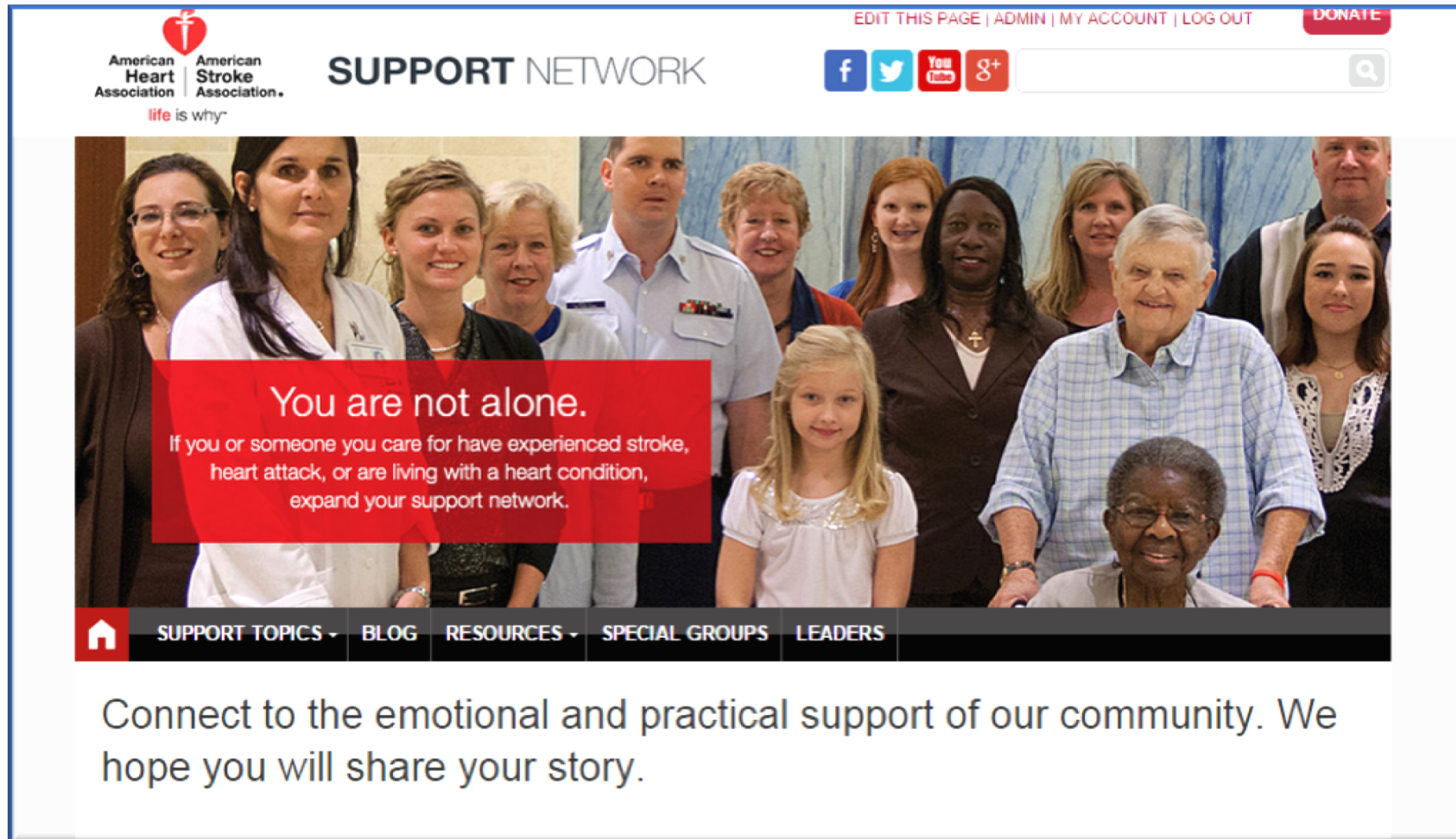
WHAT WE KNOW

Evidence for Stroke Family Caregiver and Dyad Interventions

- Recommendations:
 - More rigorous design with attention to fidelity of delivery and sustainability of outcomes
 - Question whether face-to-face support groups are best
 - High refusal rates and high attrition rates
 - **Consideration to dosage of interventions**
 - **In-person interventions not feasible for busy caregivers**
 - **Develop interventions that are feasible to integrate into clinical practice**
 - **Delivery of interventions via phone and Web may be beneficial approaches**

The Stroke Support Network

www.strokeassociation.org/supportnetwork



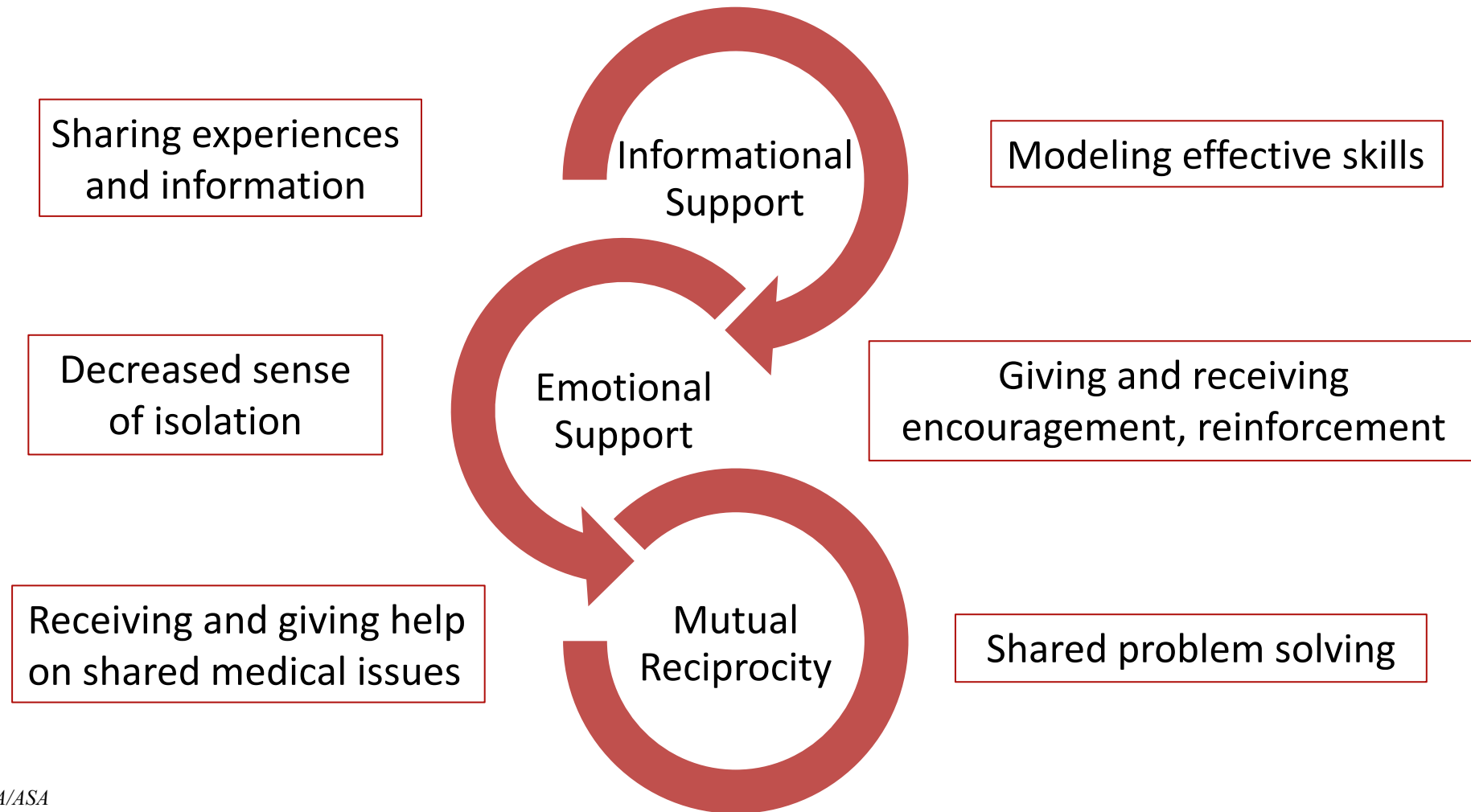
The screenshot shows the website's header with the American Heart Association and American Stroke Association logos, the text "SUPPORT NETWORK", and navigation links: "EDIT THIS PAGE | ADMIN | MY ACCOUNT | LOG OUT" and a "DONATE" button. Social media icons for Facebook, Twitter, YouTube, and Google+ are present, along with a search bar. The main content area features a large photograph of a diverse group of people. A red text box overlaid on the photo reads: "You are not alone. If you or someone you care for have experienced stroke, heart attack, or are living with a heart condition, expand your support network." Below the photo is a navigation bar with a home icon and links for "SUPPORT TOPICS", "BLOG", "RESOURCES", "SPECIAL GROUPS", and "LEADERS".

You are not alone.
If you or someone you care for have experienced stroke, heart attack, or are living with a heart condition, expand your support network.

Connect to the emotional and practical support of our community. We hope you will share your story.

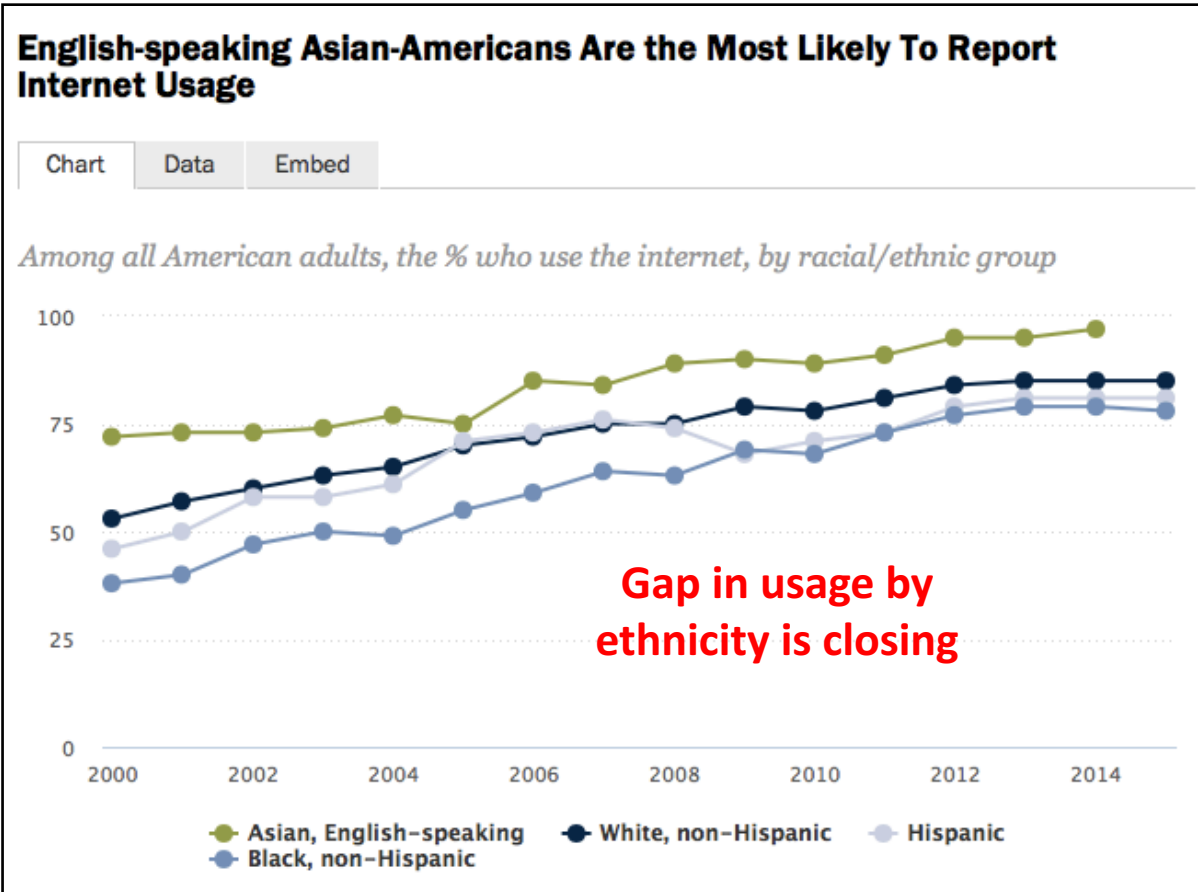
The Post-Stroke Journey

www.strokeassociation.org/supportnetwork

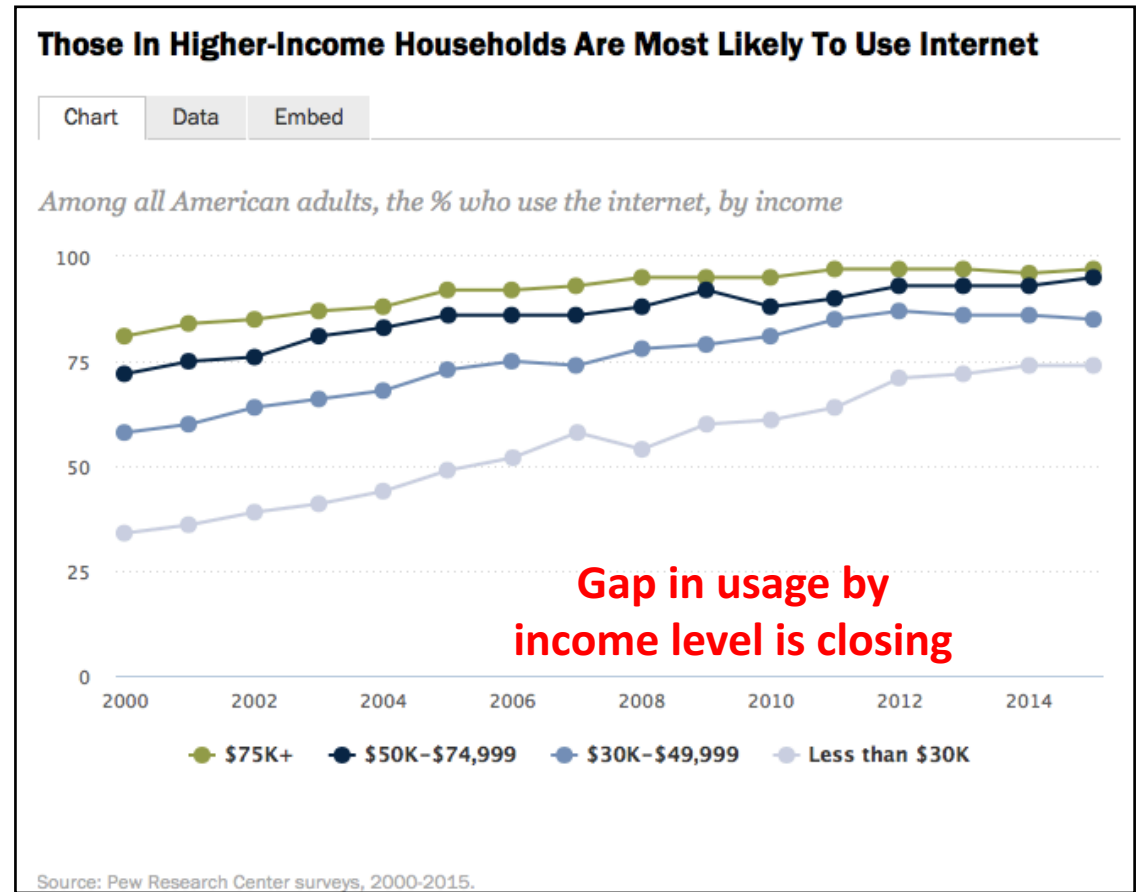


The Post-Stroke Journey

Internet Usage



WHAT WE KNOW

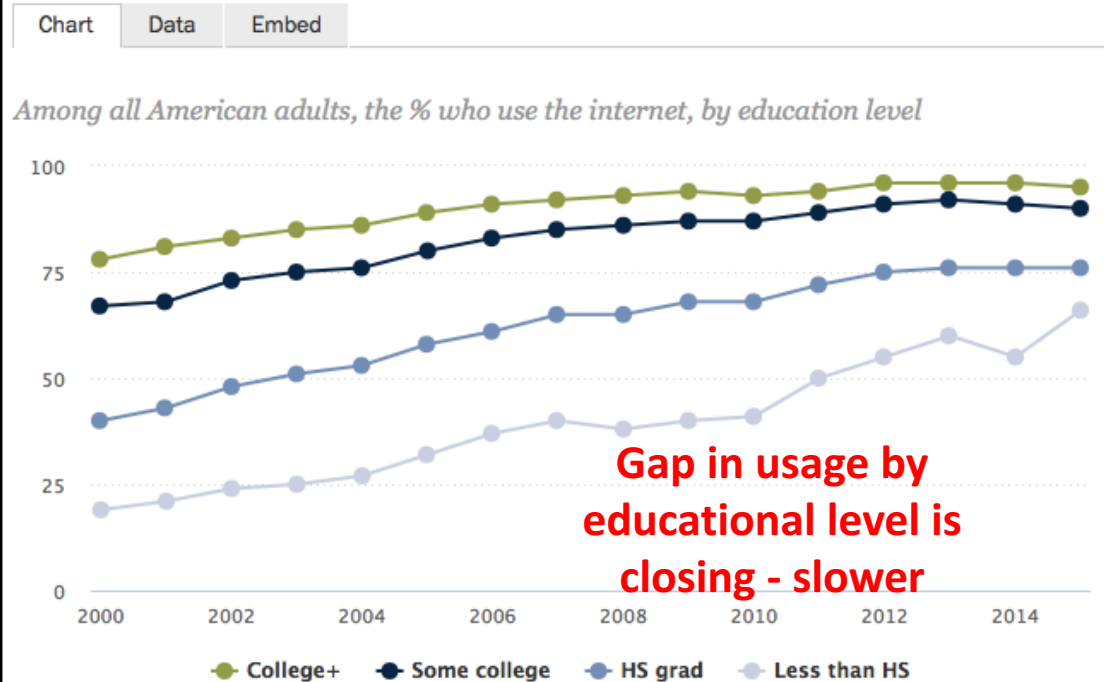


The Post-Stroke Journey

Internet Usage

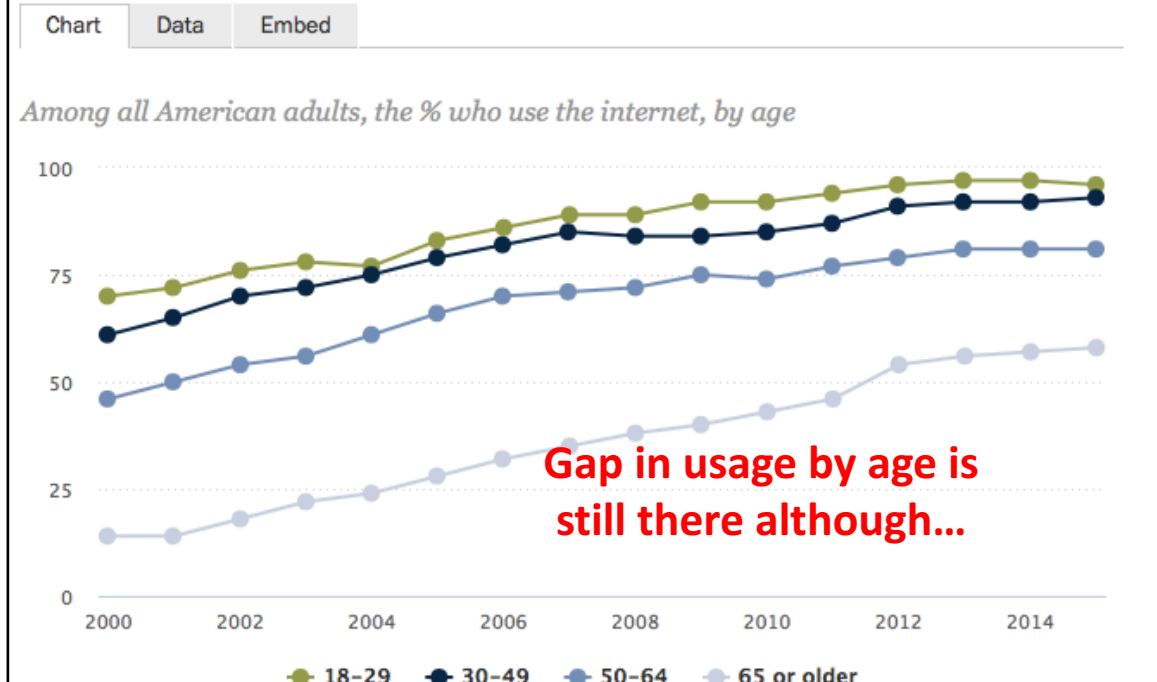
WHAT WE KNOW

While Less-Educated Adults Are Catching Up, Their Internet Adoption Rates Are Still Below Those of College Graduates



Pew Research Center Surveys, 2000-2015.

Young Adults Are Most Likely to Use The Internet, but Seniors Show Faster Adoption Rates



Source: Pew Research Center surveys, 2000-2015.

The Post-Stroke Journey

Who is more helpful when you need...	Professional sources like doctors and nurses	Fellow patients, friends, and family	Both equally
Times when professionals matter most			
An accurate medical diagnosis	91%	5%	2%
Information about prescription drugs	85	9	3
Information about alternative treatments	63	24	5
A recommendation for a doctor or specialist	62	27	6
A recommendation for a hospital or other medical facility	62	27	6
Times when non-professionals matter most			
Emotional support in dealing with a health issue	30	59	5
A quick remedy for an everyday health issue	41	51	4
Times when the two groups are equally helpful			
Practical advice for coping with day-to-day health situations	43	46	6

WHAT WE KNOW

Internet Research related to health and health care

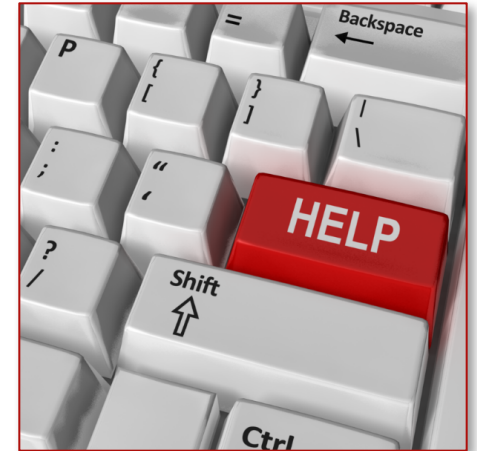
59% find fellow patients, friends and family more helpful when they need emotional support in dealing with a health issue.

Source: Pew Research Center's Internet & American Life Project, August 9-September 13, 2010 Survey. N=3001 adults and the margin of error is +/- 3 percentage points for the full sample.

The Stroke Support Network

AHA/ASA Market Research Survey 2010

- Needs Assessment
 - Objectives:
 - **Provide direction for development of new materials, resources, and tools**
 - Measure post-stroke conditions/effects
 - Understand information needs (per effect)
 - Measure resource use; and **preferred means of receiving information and support**
 - Measure credibility of ASA vis-à-vis other medical information resources



AHA/ASA Market Research Survey 2010

- Printed survey mailed to:
- 14,000* random subscribers
 - Soft launch to measure response rate
 - Followed by full launch (2 phases)
 - July – September 2010
 - No reminders
 - \$5 Amazon.com incentive
- 9.1% response rate



AHA/ASA Market Research Survey 2010

- Findings
 - **The majority of caregivers report experiencing (or the survivor they care for are experiencing):**
 - Some physical effects (99%)
 - Related health conditions (87%)
 - **Emotional effects (90%)**
 - Most notable post-stroke effects, by half or more of respondents include:
 - Physical: fatigue, paralysis/weakness, memory problems, spasticity symptoms, aphasia, and spatial neglect
 - Health: high blood pressure, high cholesterol
 - **Emotional: frustration, depression, mood swings, anger**
 - **Post-stroke effects are generally more often reported by caregivers;** and by those reporting spasticity symptoms



AHA/ASA Market Research Survey 2010

- Needs Assessment
 - **The majority agree it is at least “somewhat important” to connect with others; 3-in-10 survivors consider it “very” important**
 - In-person connections are preferred
 - community settings, support groups
 - **Nearly 2-in-5 and especially survivors, prefer connecting online**
 - **primarily email or discussion boards**
 - Online options appears valid and viable, and more apt to generate returns from survivors themselves
 - Online respondents and more frequent Internet users are likelier to use social networking sites
 - Print vs. online findings generally consistent; but online provided more complete data (fewer “no answer”)




AHA/ASA Market Research Survey 2010



- Findings
- **Although not a primary resource, the Internet nevertheless represents a viable option for a strong minority of survivors and caregivers**
 - **Over 50% of survivors and caregivers *do* access the Internet**
 - Most, especially survivors, are at least weekly Internet users
 - **33% and 25% of survivors and caregivers (respectively) are weekly+ visitors to social networking sites**
 - While there is still a general preference for print over online information receipt, **25% favor an online option**
 - **email or discussion boards preferred over one-on-one instant messaging**
- Use of mobile devices is fairly limited at this time (14%) and thus not a viable outlet



The Stroke Support Network

www.strokeassociation.org/supportnetwork

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 **DEBBIE HILL** 

SUPPORT NETWORK

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COMPLETE YOUR PROFILE


To edit fields, click the arrow  to open each section and click "save" after making your changes.


PERSONAL INFO DISCLAIMER

Please note that the questions in the Personal Information section are for American Heart Association / American Stroke Association uses only and will not be displayed on your public profile. Although these sections are optional, providing your responses will allow us to better tailor the community to your specific needs. Thank you!

EDIT PROFILE

Basic Information 

Reason for Joining 

Subscribe 

I'd like a free subscription to your Stroke Connection digital magazine
 Yes

I'd like a free subscription to your Heart Insight digital magazine
 Yes

[Save](#)

Registration is easy

The Stroke Support Network

Ischemic

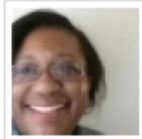
RECENT CONVERSATIONS

Recent Topics

Popular Topics

My Topics

START A CONVERSATION



jbout posted **Brother suffered stroke July 2015** 6 Replies

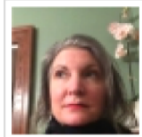
in *Ischemic* on Jan 9 at 12:18pm

Hi:

My brother suffered a stroke July 2015 - and just turned 60 years old in August. He lived by himself in VA and was may have been incapacitated for a couple of days before he was found. It was a major stroke that left him paralyzed on the left...

[View Topic](#)

[Reply](#)



Colonygal posted **Had a stroke just on January 25,2016** 2 Replies

in *Ischemic* on Feb 7 at 4:17pm

I have Broka's aphasia. Hard time finding my words slurred words and my hands are weak. it takes me a long time to do things. i fear that although I am doing quite well I wont be myself again.

[View Topic](#)

[Reply](#)



ConnValley posted **problems of spasticity** 2 Replies

in *Ischemic* on Feb 4 at 5:23am

In March 2013, while staying at the hospital for evaluation over high levels of sugar and blood pressure, I succumbed to a stroke. I went in on a Mon. then by Wed. I suffered weakness on right side. After three CT scans, a small clot was disco...

[View Topic](#)

[Reply](#)

SEARCH THIS CONVERSATION

Search

FEATURED POLL



Have you or someone you are caring for suffered from depression after their stroke?

78% Yes 22% No

Experiencing depression after a stroke is common and you are not alone.

Learn about the signs and way to treat depression.

FEATURED BLOG POSTS

Support Network Blog

James Young, II – Out Of The Darkness And Into The Light

James ignored classic heart failure symptoms, but once faced with a frightening prognosis, he made major changes to turn his health around. Not everyone will experience the level of transformation he has, but we know even small steps can make a big difference in how healthy looks on you. Tell us: Share what healthy looks and feels like to you as you live with heart disease and stroke. Someone once said, "It is only in our darkest hours that we may discover the true strength ..."



Interesting "conversations" to join

The Stroke Support Network



DONATE

VOLUNTEER

WARNING SIGNS



DEBBIE HILL



SUPPORT NETWORK



HOME

HEART ▾

STROKE ▾

CHRONIC CONDITIONS ▾

COMMUNITIES ▾

RESOURCES ▾


VOLUNTEER ▾

BLOG

STORIES OF SURVIVAL




Caregivers Of Survivors With Aphasia

 Public Access

Relevant "communities" to join



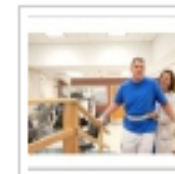
Survivors With Aphasia

 Public Access



Young Women Stroke Survivor Group

 Public Access



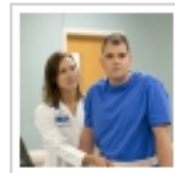
Post - Stroke Tips

 Public Access



Support Group Leader Best Practices

 Public Access



Survivors Under 50

 Public Access

The Stroke Support Network



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SUPPORT NETWORK

Stories of encouragement and hope!

HOME

HEART ▾

STROKE ▾

CHRONIC CONDITIONS ▾

COMMUNITIES ▾

RESOURCES ▾

VOLUNTEER ▾

BLOG

STORIES OF SURVIVAL

Stories of SURVIVAL

READ THEIR STORIES OF ENCOURAGEMENT



STORIES OF SURVIVAL

Subscribe to this blog



MOST RECENT COMMENTS

Stories of Survival

HOW YOU CAN HELP

Intervention Studies for Caregivers of Stroke Survivors

Survivors

STROKE 2014



Recommendations for family caregiver education and support across inpatient, outpatient and chronic care settings based on clinical practice guidelines and evidence-based research.

- Caregivers serve as integral part of the interdisciplinary team
- Assessment of caregiver needs and concerns
- Follow-up contacts and referrals
- Counseling focused on problem-solving and social support
- Provide stroke-related information
- Attention to emotional and physical health of caregiver

HOW YOU CAN HELP



AHA/ASA Patient Support Network

- Screen for patient and caregiver active network size
- Connect patients and family to the Support Network while in the hospital
- Encourage use of the Network in 7-day follow-up phone call
- Be familiar with site registration
- Connect with your local AHA/ASA office for promotional materials
- Register for Support Network and experience it for yourself
- Join and participate in “conversations”



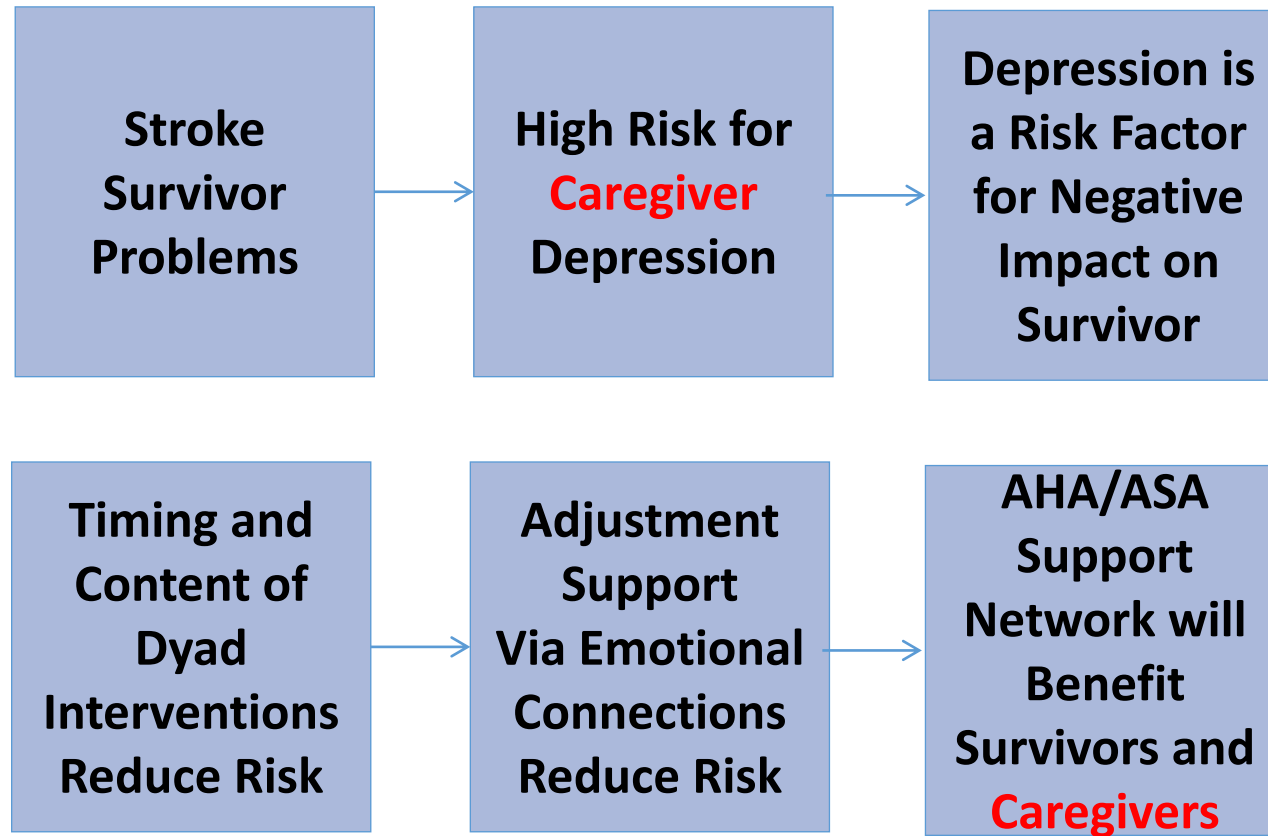
DISCUSSION

Georgia Stroke Professional Alliance – May 17, 2016

- Short-stays are not long enough for caregivers
- Plans for respite care is required in transitions of care for CSCs
- Should have a 48-72 hour follow-up plan and a long-term follow-up plan
 - Meet patient and establish the relationship to schedule follow-up phone call; helps get the correct contact information
- Stroke coordinators should follow patients to their home periodically
- Connect patients and family to the Support Network while in the hospital
- Model hospice who does a great job addressing caregiver needs
- AHA Stroke Peer Visitor program – survivors, caregivers tell their story
- Community outreach: Stroke Survivor Reunion (like NICU, babies

The Post-Stroke Journey

TAKE AWAYS





American Heart Association | American Stroke Association®

life is why™

Coming Next

Online
Self- Management
Tool



American Heart Association | American Stroke Association®

life is why™

DEBBIE HILL, FAHA

DEBBIE@LOMBARDIHILL.COM

407-222-6106

WWW.LOMBARDIHILL.COM

Thank You