What are the characteristics of survivors and caregivers attending a stroke camp?

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Background

- Depression, loneliness, and social isolation are common characteristics of stroke survivors and caregivers.

- Limited stroke camps are available in the country and there is limited data on effects of a camp experience on emotional status of survivors and caregivers.
Retreat and Refresh Stroke Camp

• Developed by a stroke caregiver

• Two and a half days of education, recreation and support activities
Objectives

- Determine demographic characteristics of camp participants and effect of stroke camp on survivors/caregivers perceptions of depression, isolation, and loneliness
Study Method

• Descriptive ongoing survey

• Tool developed by investigators, reviewed by a panel of stroke neurology and neuro psychology professionals and reviewed for understandability by an individual with aphasia
22. Which of the following have provided you with long term support? (Select all that apply)
- Spouse/Significant other
- Parent(s)
- Sibling(s)
- Child/Children
- Friend(s)

Other (please specify)

23. What do you think of when you hear the words: depression, isolation, loneliness?

24. How did the experience of camp help you with feelings of depression, isolation, and/or loneliness?
- It did not help me.
- It helped me somewhat.
- It helped me a great deal.
- No Response

25. Please use the space below for any additional comments.
Study Method

• Individuals attending camps in 2009 and 2010 were asked to participate

• Survey data collected, compiled and analyzed to plan future direction for stroke camp educational and support activities and evaluate for future research study
Results

• There were 8 camps in 2009

• 54 survivors and 42 caregivers completed the surveys

• Over half of the campers were new to the camp experience

• Age of campers ranged from 21-91 years
Results

• There were 11 camps for 2010

• 61 survivors and 49 caregivers completed a survey; 66 females, 43 males

• 57 campers were returning to camp

• Age range of participants: 20-91 years
Results 2011

- 18 Camps
- Focus on Caregivers
- 35 have completed survey
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BACKGROUND
Depression, loneliness, and social isolation are common characteristics of stroke survivors and caregivers. Limited stroke camps are available in the country and there is limited data on effects of a camp experience on emotional status of survivors and caregivers. The Retreat and Refresh Stroke Camp was developed by a stroke caregiver and provided two and a half days of education, recreation and support activities in an environment which brings survivors and caregivers together to share experiences. Over the past four years the number of camps has increased due to demand for this type of supportive environment.

OBJECTIVES
Determine demographic characteristics of camp participants and effect of stroke camp on survivors/caregivers perceptions of depression, isolation, and loneliness.

STUDY METHOD
Descriptive ongoing survey. Tool developed by investigators, reviewed by a panel of stroke neurology and neuropsychology professionals and reviewed for understandability by an individual with aphasia. Individuals attending camps in 2009 were asked to participate. Survey data was collected, compiled and analyzed to plan future direction for stroke camp educational and support activities.

RESULTS
Total 8 camps for 2009; 54 survivors, 42 caregivers completed surveys. Age range of participants: caregivers 21-88 years, survivors 21-91. Fifty-five percent of caregivers and 61% survivors were new to camp experience.

About 88% of the caregivers were female, average age 51-65 year old, over 50% care for survivor with stroke in the past 1-3 years. Almost 60% of caregivers attend support group and felt this important; 41% felt camp was important. Over 80% thought family, friends, and significant others most important. Sixty five percent felt camp helped with feelings of depression, isolation, loneliness.

Survivors were 61% male, 43% 51-65 years old. 31% had stroke in past year, 66% were left hemiphere intact. Fifty percent attended a support group, 38% felt support group important, 43% felt camp important. Seventy-seven percent thought camp helped with feelings of depression, isolation, loneliness.

Caregivers/survivor issues included independence, speech, driving job, socializing, confidence, family, friends, future goals, multi-tasking, comprehension, control, physical/emotional companionship, confidence, secure retirement, general independence.

REFERENCES
Results

- Caregiver/survivor losses included independence, speech, driving, job, socializing, family, friends, future goals, multi-tasking, comprehension, control, physical/emotional companionship, confidence, secure retirement, general independence
Conclusions

• Stroke Camp has had a positive impact on both survivors and caregivers.

• Although survivor and caregivers acknowledge the importance of family/friends, both groups felt they had lost these supports.

• 97% think a camp experience will be helpful to others.
Conclusions

- The camp environment with others who share a similar experience may help alleviate feelings of depression, isolation and loneliness in these individuals who have experienced a life changing event.

- 85% of survivors in 2010 indicated camp experience made them feel less alone.
Caregiver: “It was not only the beautifully run camp, but also the interpersonal connections of staff and attendees reaching out to us that made this such a rich experience.”
Caregiver: “Stroke camp is uplifting and refreshing. It is good to hear others stories and see they are going through the same things we are”.
Survivor: “We felt normal for a change and comfortable - very hard to express how great it was”.
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Background
Depression, loneliness, and isolation are common words used by stroke survivors and caregivers. Few stroke camps are available in the country and there is limited data on the effects of a camp experience on emotions of campers. The Retreat and Refresh Stroke Camp was developed by a stroke caregiver and provides days of education, recreation, and support in an environment which brings campers together to share experiences. The goal of this study was to survey campers about the effect of stroke camp on their feelings of depression, isolation, and loneliness.

Study Process
A descriptive ongoing survey was used. The survey was created by investigators, reviewed by a group of stroke neurology and neuropsychology professionals and by a person with aphasia. Campers from 2009 were asked to participate. Survey data was collected and examined for future stroke camp education and support activities.

Campers Losses
Caregiver: “...loss of independence...I must make all the decisions alone...there is no one to talk with...friends, people don’t come around...”
Caregiver: “...the ability to talk with my spouse, the loss of our joint dreams and freedom and flexibility to do so many things, loss of my independence and time to pursue my interests and connect with our grandchildren, children, and friends-freeedom”
Survivor: “Confidence in my life. I feel like I will be judged at my job...and I never cared what people thought”

Results
There were 8 camps in 2009 with 54 survivors and 42 caregivers completing the surveys. Caregivers were 21 to 88 years in age. Survivors were 21-91. Over half of the campers were new to the camp experience.

The majority of caregivers were female, average age 51-65 years old. Over half care for a survivor who has had a stroke in the past 1-3 years. The caregivers thought that camp was important but more than half of them felt support group was more important to them personally. The majority thought family, friends, and significant others were most important. Most felt camp helped with feelings of depression, isolation, and loneliness.

The majority of survivors were male, average age 51-65 years old. A third had had a stroke in the past year, with over half of the strokes occurring in the left hemisphere of the brain. Half of the survivors attend a support group. More than half of the survivors thought that camp was important, but less felt support group was important. The majority thought camp helped with feelings of depression, isolation, and loneliness.

Camper’s losses included independence, speech, driving, job, socializing, confidence, family, friends, goals, multi-tasking, comprehension, control, physical and emotional companionship, confidence, secure retirement, and independence.

Conclusions
Stroke Camp has had a positive impact on both survivors and caregivers. Although campers recognize the importance of family and friends, both groups felt they had lost these supports. Sharing similar experiences with others at camp may help lessen feelings of depression, isolation, and loneliness in these people who have gone through a life changing event.

References
Available upon request.
References


