

# “A huge, life-changing thing:” A Qualitative Survey of the Priorities and Goals of Young Stroke Survivors

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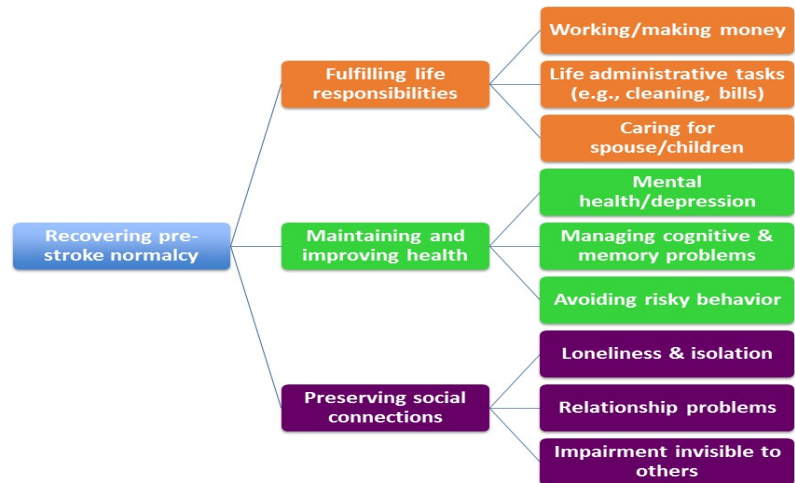


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## Abstract

- We used in-depth, semi-structured interviews with young stroke survivors aged 18-65 years (n=7) to elucidate the specific challenges and priorities of members of this population.
- Data from interviews were analyzed according to grounded theory. Thematically organized interview data offer insight into prioritized aspects of the lives of participants.
- We addressed the following research questions:
  - **What are the primary health, wellness, and functional goals of young survivors of stroke, and what are the barriers to the fulfillment of these goals?**
  - What specific tasks present a problem for younger stroke survivors and how do they manage and cope with these limitations?
  - What metrics do young stroke survivors consider effective measures of their rehabilitative progress?



Grounded theory of challenges and priorities among young stroke survivors

## Introduction

- Between 2006 and 2016, the National Stroke Association reported a staggering forty-four percent increase in the number of adults **under the age of forty-five** who required hospitalization due to stroke [1].
- Despite the increase in the observed incidence of stroke in younger adults over the past decade, post-stroke rehabilitative efforts are still informed primarily by the needs of older adults.
- As stroke has historically been associated with older adults, rehabilitative care for stroke survivors may disproportionately focus on the needs of people in this age group, while the growing cohort of younger stroke survivors may not receive care that is appropriately tailored to their lifestyles and goals.
  - For instance, younger stroke survivors are far more likely to prioritize a return to work, as they are more likely to be in their prime working years [2].

*“I didn’t realize...with the stroke, it’s a huge, life-changing thing, so even if you don’t think you need one, you might need one [a psychiatrist].”* - Interviewee, Age 36

*“Because you present well, people think you’re great. It’s a problem.”* - Interviewee, Age 30

*“Medical care was not well coordinated: One [clinician] would concentrate on my bladder, one would concentrate on my pain, the PT would concentrate on not getting atrophy...but no one was concentrating on the ‘insides’...”* - Interviewee, Age 36

## Methods and Materials

- This qualitative study, guided by the application of grounded theory, entailed conducting in-depth, individual, anonymous, semi-structured interviews with seven young stroke survivors. This study was approved by the Northeastern University IRB and all participants provided written and verbal informed consent.
- Most participants were recruited through a collaboration with the Stroke and Young Adults program at Tufts Medical Center in Boston, MA. Participants were required to meet the following inclusion criteria:
  - be 18-65 years of age,
  - be ambulatory,
  - be at least 4 weeks post-stroke, and
  - be proficient in speaking in English.
- Collected data were analyzed by members of the research team according to the principles of grounded theory. A visualization of these data is represented in the figure above.

## Discussion

- Few participants spoke highly of the medical and rehabilitative care they received. Some explicitly identified a mismatch between their own priorities and those of members of their clinical care teams.
  - Research supports the notion that age-appropriate rehabilitative interventions for younger stroke survivors are lacking [4,5].
- Most participants discussed issues with sleep, stress, or managing daily life tasks, which could be mitigated by assistive technological interventions.
  - Many subjects expressed interest in potential technology-based interventions. Such tools could easily be integrated with the smartphones that many younger adults already use to manage their calendars and communicate with friends and family.

## Conclusions

- Based on our results, we suggest that research in the following areas is urgently needed:
  - What are the differences between the effects of stroke in younger versus older adults (with regard to both the impact on patients, and the priorities of patients)?
  - How can we increase awareness of young stroke to make it easier for young survivors of stroke to navigate their surroundings during recovery?
  - **How can rehabilitative services be tailored to suit the individualized needs of young stroke survivors?**

## Results

- Young stroke survivors were found to place a high emphasis on:
  - **Returning to work** and maintaining financial stability despite fatigue and cognitive issues;
  - The maintenance of health, with particular emphasis on **mental health** and the avoidance of stress and depressive symptoms; and
  - The preservation of **meaningful interpersonal relationships** to safeguard against loneliness.
- Stroke causes highly variable impairments in young adults; accordingly, post-stroke care should be patient-centric and highly personalized.
- Psychological and emotional problems often underpinned even superficially material values; for example, the desire to return to work was often implicitly or explicitly driven by a desire for self-reliance and a sense of purpose rather than straightforward financial need. This is supported by earlier semi-structured interviews, in which a sense of compromised identity accompanied survivors’ post-stroke loss of independence [3].

STROKE CAN HAPPEN AT ANY AGE



National Stroke Association, 2017

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