



**SLI - Wellness Center**

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# **Transitional Life Experiences of the Long-term Brain Injury Survivor: A Qualitative Study to Understand Survivors' Perspectives**

Sindi Samayoa, MS, CRC,  
Senior Director of Quality Management, Advocates, Inc.

Laura Lorenz, PhD, MEd, CBIS,  
Senior Research Associate & Lecturer, Brandeis University

Therese O'Neil-Pirozzi, ScD, CCC-SLP,  
Professor, Northeastern University

Michelle Demore-Taber, ScD, CBIS,  
Director of Brain Injury Services, Advocates, Inc.



## Objectives

By the end of this workshop, participants will be able to:

- Identify 3 themes of survivor experiences with transitions
- Identify 3 strategies to facilitate transitions
- Apply 3 strategies to their organizations



## **Workshop Outline**

- 1. Study Background and Purpose – Why did we do this study?**
- 2. Results – What did we learn?**
- 3. Discussion and Implications – How will we apply our learning?**

*Each part includes a hands-on exercise*



## **Background: SLI/Advocates**

- SLI Homes (Woburn, 1997; North Reading 2001; Lexington, 2008).
- SLI property manager; Advocates service provider.
- 39 brain injury survivors live in 3 homes.
- About 1/3 of individuals transitioned from long term care settings.
- Importance of transitions as a natural part of life.



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## Background: SLI Wellness Center

- Initiated in 2008
- An interdisciplinary collaboration
- Encompasses two main components:
  - **Rehabilitation:** Exercise, support groups, internships with university students, volunteers, and Advocates Brain Injury Community and Day services
  - **Research:** 3 pilot studies to date, others in the works

*Today: Our pilot study, of lived experience with transitions*



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## **Background: SLI Wellness Center**

Our mission is to close the community integration gap between adults with brain injury and their communities. SLI Wellness Center partners with individual and group communities to create evidence-supported, person-centered, opportunities for physical, cognitive, and social fitness of the community at large.



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## **Brainstorming Session**

**What does “transition” mean to you?**



## Research Purposes

- **Understand the transitional life experiences** of long term brain injury survivors, who have been living with an acquired brain injury for at least two years
- **Give voice to the long-term brain injury survivor** related to their experience moving to a community-based, independent living model of housing
- Identify ways to **improve the transition process**

*Brandeis University IRB approved the study*





## Research Methods - 1

### **Task 1: Reviewed published stories and identified transition-related themes:**

- Feeling invested in the process
- Transitioning to more/less structure (restrictions)
- Finding a balance between privacy and independence with supports
- Defining a new purpose in life
- Practicing hobbies and interests
- Experiencing faith, fulfillment and acceptance related to disability



## Research Methods - 2

### Task 2: Recruitment and Informed Consent

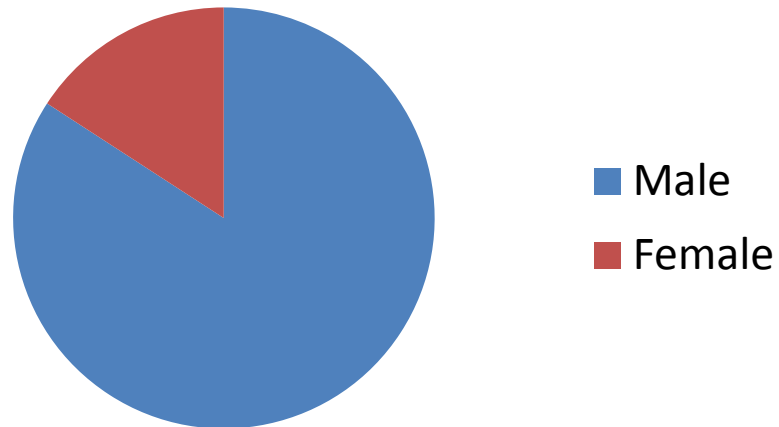
- We introduced the study during regularly scheduled SLI managers meetings
- Recruitment flyers were posted as well as placed in individual's mailboxes
- Managers and nursing staff helped in getting individuals and their guardians to sign consent forms prior to the interviews



## Research Methods - 3

Study Sample

N=21

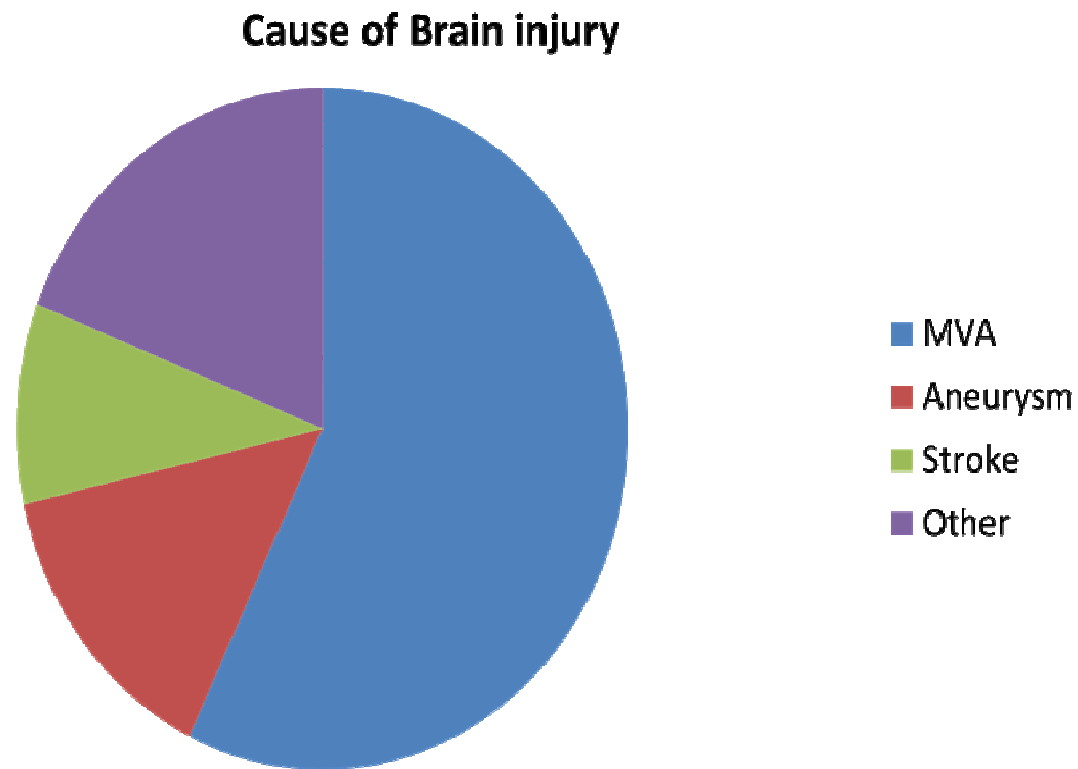


Age Range	Average
28-68 years old	52 years old



## Research Methods – 3 continued

### Study Sample





## Research Methods - 4

### Coding the data

- Two authors coded the data for the six identified themes
- Two Brandeis students counted theme frequencies and coded for a new theme: people



## Research Challenges

- Days of the week and times of the day that the interviews took place
- Recording device, background noise, and difficulties understanding some individuals
- Flow of the interviews in asking open ended questions

Theme	Total	Average	Max
Feeling invested in the process	70	3	14
Transitioning to more/less structure	110	5	<b>18</b>
Finding a balance re privacy and independence	<b>154</b>	7	16
Defining a new purpose in life	113	5	16
Practicing hobbies and interests	60	3	12
Experiencing faith, fulfillment & acceptance re disability	78	4	16

*For each theme, at least one person had no coded segments*



## Investment in Transition Process

### Definition:

- Feeling involved in the transition from a more to less restrictive environment
- Feeling involved in the transition from a less to more restrictive environment





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## Investment in Transition Process

Examples of what people said:

“I make suggestions and offer my 10%.”

“We have a program here.”



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## **Support - Independence**

Definition:

- Balance between supervision and privacy
- Balance between structure and autonomy



## **Support - Independence**

Examples of what people said:

“I get to buy what I want for food and eat what I want. Instead of eating with all of the people, I can eat when I want and by myself.”

“Somebody walked in my room this morning without even knocking, and that gets me.”



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## Purpose in Life

Definition:

- Having a sense of direction
- Having a plan
- Having goals



## **Purpose in Life**

Examples of what people said:

“The typing class and then took computer class...  
I wanted something else to do.”

“Be able to walk one day.”



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## Interests and Hobbies

Definition:

- Doing things that enjoy doing
- Creating
- Socializing with others



## Interests and Hobbies

Examples of what people said:

“I mostly use my computer or I go downtown and just watch the world go by.”

“Let’s get out in the community more. Let’s get us out in the community. Maybe go to museums and stuff like that.”



# People

## Definition:

- “People” encompassed: friends, family, staff, residents, relationships, community, clinicians, and diversity.
- The “people” mentioned (eg friends and relationships) could be existing or hoped for – sometimes both.



Theme	Total	Average	Max
Friends	24	1	7
Family	<b>100</b>	5	14
Relationships	27	1	8
Staff	93	7	<b>20</b>
Residents	59	3	10
Community	31	1	8
Clinicians	37	2	14

*For each theme, at least one person had no coded segments*



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## People – Friends & Family

Examples of what people said:

“I met tons of friends here.”

“My sister heard about this place...So she got a hold of them and we had the interview process and everything.”



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## People – Staff & Residents

Examples of what people said:

“We play games.”

“...everyone else that got a place here was going through the same thing that I was. ...  
And so I mean it just made me feel like I wasn't the only one.”



## Limitations

- Small sample of participants
- Across-participant differences (e.g., cognitive abilities; numbers of previous transitions)
- Objective Accuracy versus Subjective Perception of participant comments



## **Discussion: Key Learning**

- Individuals being transitioned are not always engaged in the process.
- The transition to SLI is only the latest of many transitions, from hospital to nursing home, parents' home, foster family, and SLI.
- Co-morbidities complicate transitions.



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# Implications

Brainstorming exercise:

**What do our findings mean from YOUR  
perspective?**

**How could we make transitions better?**



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## Implications

- Applying the results
- Future research
- Improving quality



## Applying the Results

- Involve the survivor more in the application & evaluation process.
- Review findings with our current residents.
- Determine strategies for making the transition to SLI a transition “home.”





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## Future Research

- Comparisons of each house.
- Monitoring experiences of new resident transitions at each house.



## Improving Quality

- Transition towards Advocates quality management role.
- Use of participants' stories to inform training and program needs.
- Research is aligned with CARF value of person-driven supports.



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## **Panel Discussion – Q & A**

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Michelle Demore-Taber, ScD, CBIS



## Acknowledgments

We express appreciation to the:

- **21 SLI residents** who agreed to participate in our study.
- **Staff** who supported recruitment.
- **Brandeis students** who helped with counting the frequencies of themes and coding for people.
- **Individuals and foundations** that have provided funding for the SLI Wellness Center.



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**Thank you!**

**For more information:**

Peter Noonan, Executive Director

SLI - Supportive Living, Inc.

[pnoonan@supportivelivinginc.org](mailto:pnoonan@supportivelivinginc.org)

[781-937-3199](tel:781-937-3199)