

Transitional life experiences of the long term brain injury survivor: A qualitative study to understand survivors' perspectives

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Abstract

Objectives: To give voice to long-term acquired brain injury (ABI) survivor experiences moving to a fully-integrated, independent living model of housing with support services.

Design: Qualitative research design

Setting: Three community-based supported living residences in eastern Massachusetts.

Participants: 21 residents who were at least two years-post acquired brain injury (17 male, 4 female; 28-68 years of age)

Interventions: Investigators reviewed published stories about supportive living residents and identified six transition themes before interviewing the 21 consented participants using an unstructured interview guide. Interviews were 20 to 60 minutes long, audio-recorded, and transcribed. Two investigators independently coded the transcripts based on the six identified themes. Based on initial coding, a seventh theme was identified: people. Two research assistants counted code frequency and coded across themes. Medical records were abstracted for injury-related information.

Main Outcome Measures: Seven transition themes

Results: The 21 transcripts had 585 coded segments, a mean of 29 per person. Themes addressed most frequently: "People" (373 coded segments), "Finding a balance between privacy and independence" (154), "Defining a new purpose in life" (113), and "Transitioning to more or less structure" (110). Themes addressed least frequently: "Experiencing faith, fulfillment & acceptance re disability" (78 coded segments), "Feeling invested in the process" (70), and "Practicing hobbies and interests" (60).

Conclusions: Individuals being transitioned are not always engaged in the process (family members do most of the work); the most recent transition may be the latest of many; and co-morbidities complicate the transition process. Study limitations and implications of findings will be discussed.

Background

Supportive Living Inc (SLI) provides independent living for 39 brain injury survivors in three homes. SLI is the property manager, and Advocates Inc. is the service provider. About 1/3rd of residents transitioned from long-term care settings.

Objectives

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

Findings & Discussion

Table 1A. Transition themes: Frequency, average, and maximum

Theme	Total	Ave.	Max
Feeling invested in the process	70	3	14
Transitioning to more/less structure	110	5	18
Finding a balance re privacy and independence	154	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
Total	585	4.5	15

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

Table 1B. Sample transition excerpts

Theme	Positive Comment	Negative Comment
Finding a balance between privacy and independence	<i>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.</i>	<i>Somebody walked in my room this morning without even knocking, and that gets me.</i>

Table 2A. People themes: Frequency, average, and maximum

Theme	Total	Ave.	Max
Friends	20	1	7
Family	100	5	14
Relationships	27	1	8
Staff	93	7	20
Residents	59	3	10
Community	31	1	8
Clinicians	37	2	14
Total	367	2.9	11.5

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

Table 2B. Sample people excerpts

Theme	Positive Comment	Negative Comment
Staff	<i>Once you get to know them, they get to know you. And when they get to know you, it gets a lot easier.</i>	<i>They always do everything for you. I don't like that.</i>

Limitations

- Small sample size
- Across participant differences (e.g., cognitive abilities, numbers of previous transitions)
- Self-report data: Objective accuracy versus subjective perceptions of participant comments

Application of Findings

Food preparation: Nutrition and healthy cooking are now training topics for staff members and offered in a 2-hour cooking class once or twice a month at Advocates, Inc. main offices. Mobile trainings offered on site are being explored.

Admissions process: Inappropriate candidates have been removed from the applicant waiting list, making it easier for staff to use. Staff are being more deliberate about getting applicant input during the review process. Potential candidates and family members are now required to visit the program. Applicants are now encouraged to have a meal at the house, to become acquainted with residents, staff, and house protocols before they move in.

Name tags: A pilot effort for staff to use name tags is underway, to help residents with short-term memory issues recognize staff and remember their names.

Quality of life: To track application of study results and potential impact over time, the SLI Wellness Center is incorporating a quality of life scale into ongoing programmatic monitoring and evaluation and research studies.

The SLI Wellness Center for Brain Injury Rehabilitation and Research partners with individuals, groups, and communities to create evidence-supported, person-centered opportunities for physical, cognitive, and social fitness. The center's mission is to unite adults with brain injury and their communities, with wellness benefits for all.

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