2025 North Carolina Brain Injury Conference

Brain Injury Conference April 14-15th, 2025

Lumina on Wrightsville Beach

> BRAIN INJURY ASSOCIATION OF NORTH CAROLINA

BETTER: A TBI Transitional Care Program

Melissa Kandel, OTR/L, BCPR Brittany Albert, OTR/L, CSRS, CBIS Mayra Soto, OTR/L Tolu Oyesanya, PhD, RN



Learning Objectives



HIGHLIGHT CONTEXT OF TBI OUTLINE BETTER STUDY
PILOT AND OUTCOMES

RECOGNIZE THE ROLE OF TRANSITIONAL CARE FOR TBI REVIEW NEXT STEPS FOR BETTER

Agenda

- Team/Presenter Introductions
- TBI Context
- Pilot of BETTER TBI Transitional Care Intervention
 - Intervention description
 - Methods and findings
 - Lessons learned
- R01: BETTER Randomized Controlled Trial
- Recognizing the Role of Transitional Care Management
- Case Study
- Occupational Justice
- Sample from Brain Injury Coping Skills
- Q&A

Team Introductions



Tolu Oyesanya, PhD, RN Associate Professor Principal Investigator (PI)

Melissa Kandel, OTR/L, BCPR Assistant Manager, Rehabilitation Services Transitional Care Manager

Brittany Albert, OTR/L, CSRS, CBIS Transitional Care Manager

Mayra Soto, OTR/L Transitional Care Manager



Acknowledgments



Investigator Teams

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Study Staff (current and former)

Gabrielle Harris, PhD, MSN, RN Callan Loflin, BA

Melissa Kandel, OTR/L, BCPR Karen Johnson, MOT, OTR/L, CBIS, CAPS, CSRS

Brittany Albert, OTR/L, CSRS, CBIS

Mayra Soto, OTR/L

Anne Pioppo, OTR/L Binnie You, MSN, RN Victoria McReynolds, BS

Brian Anaya, BS

Michelle Huang, BS



Providers & Organizations Assisting with Study

Case management team (across 11 units)

Inpatient speech team (Lindsay Dutko)

Neuro & trauma APPs

Brain Injury Associations



Research Funding

REACH Equity CDA & Vouchers Program Award (Grant #U54 MD012530, PI Johnson)

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NIH R01 (Grant# R01NR020818, PI Oyesanya)



Research Participants

We thank all our research participants who have graciously participated in our studies over the years

Traumatic Brain Injury (TBI) – Definition & Statistics



TBI is defined a bump, blow, or jolt to the head that disrupts the normal functioning of the brain.

2.7 million new TBIs/year

\$76.5 billion cost/year

5.3 million living with disabilities

TBI Severity & Impairments



Racial and Ethnic Disparities in TBI Outcomes

- Compared to non-Hispanic White patients, Latiné and Black patients with TBI and family caregivers have worse outcomes:
 - Higher rates of TBI incidence and hospitalization
 - More severe injuries at the time of discharge
 - Worse physical, mental, and social outcomes
 (6)
 - Higher readmission rates,(7) long-term disability,(8) depression,(9) substance abuse,(10) and unemployment^(8, 11, 12)
 - Higher need for care but less access to resources
 - More reliance on family for support



TBI Transitional Care Research

- Patients with TBI and families struggle after injury
 - Difficulty transitioning home from the hospital
 - Problems navigating health system
 - Desire transitional care support
- Limited TBI transitional care programs available
 - No U.S. transitional care standards for patients with TBI
 - Not effective for racial/ethnic minorities
 - Do not incorporate family
 - Do not focus on quality of life



Transition from Acute Hospital Care to Home



Study Goals

- <u>Ultimate goal</u>: To decrease racial/ethnic disparities in TBI transitional care process
- <u>Specific Aims</u>:
 - Aim 1: Develop and refine TBI transitional care intervention protocol
 - Aim 2: Examine the feasibility, acceptability, and preliminary outcomes of intervention



BETTER: A TBI Transitional Care Intervention



BETTER: A TBI Transitional Care Intervention

BETTER TBI Transitional Care Program Activities

 Assessment of patient / family needs and referral to communitybased resources by phone 2. Patient goal setting and review of goals by phone

(includes updating / establishing primary care physician)

3. Health care coordination by phone

 Availability of transitional care manager to patient / family by phone 5. Training on self- and familymanagement and brain injury coping skills by phone or Zoom

6. Warm hand off / referral to stateaffiliated Brain Injury Association

- Culturally- and linguistically-adapted
 - All materials available in English- and Spanish
- Patient- and family-centered
- Behavioral intervention

Transitional Care Manager



BETTER TBI Program is currently delivered by Occupational Therapy Practitioners (OTP's)



Development of the protocol took into consideration that the BETTER program could be implemented by different types of providers allowing various health professions to be trained to deliver the intervention, depending on resources and prior training experience available.

Supporting Patients & Families: TCM Role

- Meet patient and family 24-72 hours pre-discharge
- Contact patient/family intermittently by phone to obtain updates on recovery and needs
 - First call at 24 hours post-discharge
 - Weekly calls for 4-weeks post-discharge, then again at 6-, 8-, and 12-weeks post-discharge
- Assess patient/family needs (mental, physical, social, cultural) by phone
- Refer patient/family to other services to meet needs by phone
 - Assist patient and family by phone post-discharge to find resources related to housing and food (PRN)
 - Assist patient and family by phone post-discharge to apply for health insurance applications or other insurance related issues (PRN)
- Assist patient/family with care coordination by phone
 - Call patient's primary care doctor to give update about patient's condition
 - Assist patient/family by phone post-discharge to secure transportation to patient's follow-up appointments (PRN)
- Availability to answer patient/family questions about post-discharge concerns



Needs Assessment

Physical needs

Mental/Emotional needs

Community re-integration needs

Social needs

Healthcare needs

Follow-up care needs

Vocational needs

Substance use disorder needs

Cultural needs

Equipment needs

Family caregiver needs

When did we reach out and why? Timeline for Intervention



- Remotely educate patient/family dyads on brain injury coping skills topics
- Weekly, scheduled education sessions
 - Beginning within 1 week of discharge until 4 months post-discharge
 - 20-30 minutes sessions
 - Meetings via Zoom
 - 20 total sessions,
 16 for dyad, 4 for
 caregiver only

Table 1. Brain Injury Coping Skills (BICS) Sessions Delivered in BETTER				
BICS Sessions for Patient/Family Caregiver Dyads				
Session #	BETTER Session Name			
Session 1	Consequences of TBI on Patient			
Session 2	Expectations of Recovery			
Session 3	Family Caregiver Role			
Session 4	Managing Challenging situations, Part 1 (Anger, Impulsivity, Lack of Initiation)			
Session 5	Managing Challenging situations, Part 2 (Intimacy, Fatigue, Sleep, Memory)			
Session 6	Signs and Symptoms of Depression			
Session 7	Other Mental and Emotional Issues (PTSD, Anxiety, Irritability)			
Session 8	5 R's of Stress Management			
Session 9	Relaxation			
Session 10	Reassuring Thinking and Effective Problem-Solving			
Session 11	Communication and Relating Assertively			
Session 12	Medication Management			
Session 13	Goal Setting and Local Resources			
Session 14	Navigating the Health System			
Session 15	Alcohol and Substance Use			
Session 16	Graduation			
BICS Sessions for Family Caregivers Only				
Session #	BETTER Session Name			
Session 1B	Consequences of TBI on Family Caregiver + Supporting Patients with TBI			
Session 9B	Family Caregiver Stress and Coping			
Session 11B	Supporting People with TBI in Everyday Communication			
Session 15B	Supporting Patients with Alcohol and Substance Use Disorder			

Methods & Findings from Pilot Test of BETTER

Transitional Care Managers

- DUHS clinicians who delivered as BETTER (interventionists)
- 2 OTPs for Pilot
- Experience
 - At least 3 years clinical experience with neuro or trauma patients
- Training & oversight
 - Complete 40 hours training on study protocol
 - Reading manual, role playing, discussions, watching videos
 - Engage in weekly supervision to ensure adherence to study protocol

- 4 OTPs for R01
 - Melissa Kandel
 - Mayra Soto (Bilungual)
 - Brittany Albert
 - Anne Pioppo (Bilingual)



Methods for Pilot Testing of BETTER

- **Design:** Prospective, quasi-experimental, single arm, single center pilot study
- Setting: Level I trauma center in Southeastern U.S.
- Sample: N = 15 patient/family dyads; TBI patients (mild-to-severe), aged 18-64 years, who were discharged home from acute hospital care without inpatient rehabilitation and their family caregivers.
- Study timeframe: February-December 2021
- Measures of focus described today:
 - 1) Recruitment, enrollment, and data collection feasibility
 - 2) Intervention acceptability
 - 3) Clinical outcomes of the intervention
 - 4) Patient/family needs
 - Primary outcome = patient QOL (SF-36) @ 16 weeks post-discharge
 - Secondary outcome: caregiver preparation (caregiver preparedness scale)
 - Longitudinally collected data at: 1) 24-72 hours pre-discharge (baseline), 2) 8-weeks post-discharge (intervention midpoint), 3) 16-weeks post-discharge (intervention endpoint), and 4) 24-weeks post-discharge (maintenance)



Recruitment & Enrollment Feasibility



Demographics N = 31

Demographic Characteristics of Participants (N = 31)					
Variables	Patients at Baseline (N=15)	Caregivers at Baseline (N=16)			
Age, mean years (SD)	39.07 (15.15)	43.38 (10.45)			
Sex (female)	5 (33.33%)	14 (87.50%)			
TBI severity					
Mild (GCS score: 13-14)	6 (40.00%)	6 (37.50%)			
Moderate (GCS score: 9-12)	4 (26.67%)	4 (25.00%)			
Severe (GCS score: 3-8)	5 (33.33%)	6 (37.50%)			
Cause of injury					
Car accident	8 (53.33%)	9 (56.25%)			
Fall	1 (6.67%)	1 (6.25%)			
Sports Injury	1 (6.67%)	1 (6.25%)			
GSW	2 (13.33%)	2 (12.50%)			
MV vs. pedestrian	2 (13.33%)	2 (12.50%)			
Other	1 (6.67%)	1 (6.25%)			
Race/Ethnicity					
Black/African American	9 (60.00%)	8 (50.00%)			
White	5 (33.33%)	7 (43.75%)			
American Indian/Alaska Native	1 (6.67%)	1 (6.25%)			
Primary language = English	15 (100%)	16 (100%)			

Demographics N = 31

Variables	Patients at Baseline	Caregivers at Baseline
	(N=15)	(N=16)
Marital Status		
Married	4 (26.67%)	9 (56.25%)
Divorced	2 (13.33%)	1 (6.25%)
Separated	-	2 (12.50%)
Single	9 (60.00%)	4 (25.00%)
Education		
High school diploma/GED	6 (40.00%)	6 (37.50%)
Two-year/Technical College	3 (20.00%)	4 (25.00%)
Bachelor's degree	2 (13.33%)	4 (25.00%)
Other	4 (26.67%)	2 (12.50%)
Annual income prior to injury		
\$0-30,0000	11 (73.33%)	5 (31.25%)
\$30,001-60,000	2 (13.33%)	5 (31.25%)
\$60,001-90,000+	1 (6.67%)	4 (25.00%)
Declined to report	1 (6.67%)	2 (12.50%)
Patient insurance status		
Insured	10 (66.67%)	10 (62.50%)
Uninsured	5 (33.33%)	6 (37.50%)
Relation to patient		
Spouse/significant other	-	7 (43.75%)
Parent	-	6 (37.50%)
Other (sibling, child, friend)	-	3 (18.75%)



Changes in Patients' Quality of Life (QOL) Over Time (SF-36)					
Domains of SF-36 (Patients Only)	Baseline	8 weeks post-	16 weeks post-	Change between	p-value
	(n = 13)	discharge	discharge	baseline and 16	
	Mean (SD)	(n = 11)	(n = 11)	weeks post-	
		Mean (SD)	Mean (SD)	discharge	
Total score (SF-36)	47.97 (24.93)	54.15 (31.44)	68.86 (29.08)	20.89 (26.90)	0.0712
Physical Component Summary (PCS)	30.29 (22.70)	46.53 (24.29)	61.65 (27.41)	31.36 (24.95)	0.0056*
Mental Component Summary (MCS)	65.65 (36.22)	61.76 (42.81)	76.07 (32.68)	10.42 (34.66)	0.4710

Changes in Caregivers' Preparedness of Caregiving					
Preparedness for Caregiving Scale	Baseline	8 weeks post-	16 weeks post-	Change between	p-value
(Caregivers Only)	(n = 16)	discharge	discharge	baseline and 16	
	Mean (SD)	(n = 15)	(n = 13)	weeks post-	
		Mean (SD)	Mean (SD)	discharge	
Total score	25.75 (8.02)	25.63 (6.59)	25.38 (9.68)	-0.37 (8.80)	0.9123



Patient/Family Needs

Table 2. Ranking of Overall Needs During BETTER (N = 15 patient/family caregiver dyads)			
Ranking of needs in descending order (most to least common)	n	%	
Physical needs	13	86.7	
Mental/Emotional needs	11	73.3	
Community re-integration needs	11	73.3	
Social needs	9	60.0	
Healthcare needs	9	60.0	
Follow-up care needs	7	46.7	
Vocational needs	7	46.7	
Family caregiver needs	7	46.7	
Substance use disorder needs	6	40.0	
Cultural needs	4	26.7	
Equipment needs	1	6.7	



Lessons Learned from BETTER Pilot Study

- Recruitment, enrollment, and data collection were feasible
- Intervention was acceptable from patient/family perspective
- Intervention improved patients' physical QOL

- 85 eligible patients (58% of those eligible) were discharged before approached.
 - We had to change our approach with screening the caseload and contacting patients' inpatient providers to obtain information on discharge plans further in advance than initially planned.
- 13 eligible patients (8.9% of those eligible) were not able to be recruited due to language barriers.
 - Initially intended to recruit Spanishspeaking patients at the time of the study
 - Did not have the capacity to do so as significant preparation is needed to translate study materials and locate, hire, and train bilingual interventionists.

Cultural & Linguistic Adaptation Activities





R01: BETTER Randomized Controlled Trial (RCT)

- **Purpose**: Test efficacy of TBI transitional care intervention vs. control with English- and Spanishspeaking adult patients (age 18 or older) with TBI of various races/ethnicities who are discharged directly home from acute hospital care without inpatient rehabilitation and their family caregivers
- Setting: Duke University Hospital
- Sample: N = 436 participants (218 patient family dyads per arm)
- Progress to date:
 - 4 DUHS OTs trained to deliver intervention, including 2 Spanish-speakers
 - Patient recruitment began in February 2024
- Findings will be reported later:

We'll return to present on more findings in a few years! ③ data of

Recruitment Period: 02/08/24-10/18/24

Screened: 560 Ineligible: 372 Eligible: 188 (34% of screened)

Approached: 94 (50% of eligible) Recruited: 61 (62.2% of approached) -Were only consented to the study Declined: 33 (33.7% of approached) TOTAL= 94

Not Approached: 87 Discharged before approached: 81 Language: 4 Staffing: 0

Enrolled: 54 (55% of approached) consented and completed baseline data collection

Design, methods, and baseline characteristics of the Brain Injury Education, Training, and Therapy to Enhance Recovery (BETTER) feasibility study: a transitional care intervention for younger adult patients with traumatic brain injury and caregivers

Tolu O. Oyesanya 🖂 💿, Callan Loflin, HyunBin You, Melissa Kandel, Karen Johnson, Timothy Strauman,

...show all

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Check for updates

The BETTER Traumatic Brain Injury Transitional Care Intervention: A Feasibility Study

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ANALYSIS & PERSPECTIVE

How Subjective and Objective Factors in Research and Practice May Perpetuate Health Disparities amongst Patients with Traumatic Brain Injury

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Metrics

The purpose of this analysis and perspective is to provide recommendations for further examination of subjective factors within TBI research and practice, with the overarching goal of reducing TBI-related disparities. We recommend establishing reliable and valid measures of subjective factors to allow for further examination of the influence of both objective factors and subjective factors in the TBI population.

PAP

CASE STUDY APPLICATION

Case Study- Roberto

- <u>Clinical picture</u>: Roberto is a 21 year-old male living in Durham NC. He is originally from Mexico, uninsured and undocumented. He was in a MVC and was ejected due to being unrestrained. He had a loss of consciousness and head impact and EtOH of .160
- <u>Injuries sustained</u>: fractures of 1st rib, nasal bone, manubrium, whiplash, C5/C6 hyperextension injury, lacerations of R eyelid and nose
- <u>Glascow Coma Scale</u>: GCS on scene was 3 but improved to 13 quickly after admission. He arrived to Duke University Hospital sedated and intubated.
- <u>Procedures</u>: ACDF (anterior cervical discectomy and fusion) of C5/C6, laceration repairs of right eyelid and nose
- Acute Care Therapies: Speech Therapy, Physical Therapy



Introduction Meeting



TCM connected with Roberto and his mother (identified care partner for the study) to perform an introduction meeting and assess immediate health care needs and discharge questions.



Identified Needs at this time Included:

Need for financial assistance to cover hospital costs (TCM assisted client in filling out forms, explaining information to client to ensure understanding)

Rental assistance while out of work (Helping the client to call El Centro Hispano and aided him in explaining his needs)

Establishment of a PCP that took uninsured individuals (Enrollment in Lincoln Community Medical Center, Project Access)

Weekly BETTER Sessions





TCM met with client and his mother weekly via zoom or phone



Answering or triaging post discharge care questions



Assess needs ongoing each week



Brain Injury Coping Skills Sessions





Ongoing communication throughout the week

Graduation from BETTER

BRAIN INJURY

ASSOCI

like

Warm Handoff transitioning client to DukeWELL program

Warm Handoff to BIANC

Tailored resources for local support groups and resources for any ongoing needs

Review of Brain Injury Coping Skills Sessions

Encouraging client to continue to self advocate and utilize provided resources



BRAIN INJURY COPING SKILLS



MANAGING CHALLENGING SITUATIONS: WISE MIND

Wise Mind

Wise Mind means being able to use your emotions and your reasoning ability to help you come up with the best decision or course of action.

EMOTIONAL MIND Thinking with emotions

WISE MIND

A perfect combination of using logic and emotions to make decisions REASONABLE MIND

Using only logic to make decisions



How to use Wise Mind:

(1) Is this in my best interest?

(2) What will be the consequences of me doing this?

3 Is this in line with my values?

(4) Will this help me meet my goals?

Make it individual. Come up with your own questions

General Tips for Caregivers

- Cue them, DON'T criticize them.
- Help them, DON'T 'hammer' them.
- Try using empathy with them and be willing to validate their feelings
- Try not to speak in a condescending voice. Remember to speak respectfully and calmly.
- Be willing to model good behaviors
- Be willing to encourage them to seek treatment, if needed
- Encourage them to use Wise Mind, and be willing to use it yourself.
- Remember to take time for yourself.

RELAXATION



Brain Injury Coping Skills Session sneak peek: Relaxation

Benefits of Relaxation

Reduce anxiety
Prevent stress from accumulating
Improve concentration and memory
Reduce insomnia and fatigue
Prevent physical health conditions from occurring or worsening
Increase self-confidence and reduce blame
Increase sense of control

Relaxation Strategies

•Reading a book •Taking a bath or shower •Meeting friends for dinner Knitting or cross-stitching Exercising (walks, biking, swimming, etc.) •Journaling •Deep breathing Photography •Gardening •Talking to a good friend

Deep Breathing

• How Does it Work?

- Each breath increases our oxygen.
- Chest breathing is shallow, irregular, and rapid. When insufficient air reaches the lungs, blood isn't properly oxygenated. This leads to an increase in heart rate and muscle tension. This often happens when the stress response turns on.
- Abdominal breathing or diaphragmatic breathing is more natural. This is the way we breathed when we were newborns. This allows your breathing to be less constricted. You get more oxygen to your brain and blood cells and this helps your body work more efficiently.



Deep Breathing Continued



How to Deep Breathe



1 Just try to breathe normally and naturally but pay special attention to your abdomen.



(2) Some people like to visualize a balloon inside the belly.



③ Take slow breaths. Try breathing in through your nose and out your mouth.



(4) Count to 4, hold a couple seconds, exhale for 4. Practice twice daily in a quiet room with no distractions.



5 **Take TEN:** Do it for 10 minutes each session or use a 10-second strategy when you really need to stop and breathe.



(6) Do not practice in tough situations when you are first learning. Get good at it first.

Mindful Moment

Take a few long breaths and relax, then take a scan of your inner body and then take a scan of your inner body and then your environment.

Inner body

• How does your body feel?

Examples

• I am sitting, I am lying down, I am hungry, tired, tense, relaxed, my ears are burning, my shoulders feel relaxed, I am not experiencing any pain right now, etc.

What is happening in the environment?

• Focus on sounds, smell, touch, or experiences.

Examples

• The air is blowing, there are two people in the room, people are eating, the temperature is comfortable, etc.



Next Steps

Completion of the R01 BETTER RCT at DUH

Writing grants to expand RCT to other sites

If deemed effective:

- larger scale, multi-site dissemination and implementation studies to translate BETTER into practice
- Adapt intervention to patients with other neurologic conditions

Thank you!

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