A PEER NAVIGATOR HEALTH PROMOTION INTERVENTION FOR INDIVIDUALS WITH SPINAL CORD INJURY

Spinal Cord Injury Grand Rounds
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Learner Objectives

- Identify common, potentially preventable secondary conditions that occur after SCI
- Describe application of a community-engaged research approach to the development and pilot testing of a health promotion intervention for individuals with SCI
- Describe the role of a Peer Navigator in the prevention of secondary conditions after SCI
Background
Secondary Conditions

- Conditions that are more common among persons with certain primary impairments (i.e. compromised skin integrity for people with lower extremity paralysis). (Pope & Tarlov, 1991)

- Diseases of the GU system and skin leading cause of rehospitalization post-SCI (NSCISC, 2012)

- Second leading cause death after SCI is septicemia
  - Usually associated with decubitus ulcers, urinary tract or respiratory infections (NSCISC, 2012)
Secondary Conditions

- Secondary conditions associated with SCI are considered highly preventable with appropriate health care maintenance.

- Increasingly shorter acute inpatient rehab stay results in reduced time for education and practice in essential self-management skills. (Dejong et al, 2011)

- Numerous physical and social environmental barriers that inhibit optimal health in the community setting.

- Prevention and management of secondary conditions after SCI is a persistent “uphill battle”. (Guilcher et al, 2013)
Addressing the problem...

- Historically, interventions designed to promote health after SCI focused at the level of the individual with SCI
  - Little emphasis on the context of the environment in which the individual lives
- Very few published rehab intervention studies that include people with disabilities in the research process in a role beyond study participant. (Ehde et al, 2013)
- Research implemented with the goal of improving the lives of persons with SCI must reflect the demands of living in their environment of choice
Action Model to Achieve Healthy People 2020 Goals

Determinants of Health

Planning
- Needs assessment
- Interventions
  - Policies, programs, health communication

Outcomes**
- Monitor and evaluate for:
  - Behavioral outcomes
  - Specific risk factors, disease, and conditions
  - Injuries
  - Well-being and health-related Quality of Life
  - Health equity

Assess effectiveness, Disseminate, Refine

* Cost Effective: Evidence-based, informed; ROI > 1:1; <$50,000 QALY; ** SMART: Specific, measurable, achievable, realistic, time-specific

Healthy People 2020 Disability and Health Objectives
“Community-engaged research” is an approach to conducting research that requires partnership development, cooperation and negotiation, and commitment to addressing local health issues of the community of interest.
Community Engaged Research

- Ideally community input is incorporated in all phases of research.

Research Question ➔ Dissemination of Results

- There can be varying levels of community involvement depending on the goals of the research.
- An important element of the successful translation of research from bench to bedside and community.
Community Engaged Research

- Complements the philosophy of Independent Living as an approach to disability research
  - PWD are the best experts on their needs
  - Self-determination
- Brings people with disabilities to the research table as partners in the research process
Partnership
SCI Peer Navigator Intervention

Problem Identification
Photovoice Study (2008)

- Descriptive qualitative study
  - CEnR approach
  - Photovoice method
    - Applied as a participatory assessment and issue selection tool
What are the environmental barriers and facilitators to community integration in the Charleston community, as perceived by 10-12 individuals with spinal cord injury (SCI)?
Repeated theme of difficulty in identifying and accessing essential resources, such as health care facilities, vocational rehabilitation, and adapted driving training.

Many participants expressed a desire to assist others with SCI in the hopes that they might provide support by sharing knowledge gained through their experiences in navigating the “system”.
Need Assessment Survey (2010)

- Pilot survey of community dwelling individuals with SCI to determine perceived unmet service needs and barriers to receiving services
  - (n=73, 56% response rate)
- Survey development guided by “Survey Steering Committee” including individuals with SCI
Key Need Assessment Survey Results

- Participants reporting secondary conditions in the last year:
  - 60% UTI
  - 42% Pressure Ulcer

- 68% reported needing help getting or managing services after SCI

- “I didn’t know where to get help” most commonly reported barrier to services (35%)

- 73% indicated that they would benefit from working with someone who also has an SCI and has additional training to help locate and access SCI information and resources.
SCI Peer Navigation

- An ecological approach to community-based health promotion after SCI

- Building on evidence from our work & other fields, we developed an intervention using community-based “Peer Navigators” with SCI to proactively mitigate barriers and facilitate access to necessary services and resources

  - Goal to reduce preventable secondary conditions (PU and symptomatic UTI) and rehospitalizations, and improve the community participation of individuals with SCI
SCI Peer Navigation

- Provide tailored health education related to SCI
- Modeling and facilitating problem solving strategies to address participant’s identified needs and barriers related to:
  - implementing recommended self-management behaviors to prevent PU and symptomatic UTI,
  - becoming an empowered healthcare consumer, and
  - achieving preferred level of community participation
Our Survey Steering Committee expanded into a 12-member, self-named “SCI Peer Navigator Task Force”

- Review of other peer mentoring and navigation programs
- Define SCI PN role and responsibilities; develop SCI PN job description
- Adaptation and development of SCI PN Training manual with tailoring to address identified local needs
- Review and selection of educational resources to be used by SCI PNs
- Review and selection of instruments and measures
- Recruitment, selection, and hiring of SCI PNs
SCI Peer Navigators

- SCI Peer Navigators are:
  - people with SCI who have a wealth of knowledge from their personal experiences with SCI
  - ready to share what they have learned with others with SCI
  - able to use their experience to offer firsthand guidance to others on strategies to prevent secondary conditions and stay healthy after SCI

- Required to complete CITI training
  - Administering research intervention & collecting data
Role of SCI Peer Navigator

- Provide information & education about the effects of SCI
- Provide information and demonstrate skills/behaviors to prevent PUs and symptomatic UTIs
- Navigate resources in the community & problems solve barriers
- Help Peers develop self-efficacy through goal setting and achievement
- Provide peer support
SCI Peer Navigator Training

- Chapter 1: The Role of the PN
- Chapter 2: Communication & Relationship Building
- Chapter 3: Spinal Cord Injury 101
- Chapter 4: Maintaining Health: Secondary Conditions & Preventive Care
- Chapter 5: Maintaining Health: Being an Active Health Care Consumer
- Chapter 6: Resources for Navigating Common Barriers
- Chapter 7: Working on the Research Team
- Appendices: SCI Peer Navigator Toolbox
Intervention Components

- Weekly in-person educational session x 4
  - In-person meetings in participants’ home
  - Education
  - Goal setting, barrier identification
  - “Talking Points” document
  - Navigator Checklists
Educational Sessions

1. SCI 101 and Personal Goal Setting
2. Skin Care & Pressure Ulcers Prevention
3. Bladder Care & UTI Prevention
4. Being an Empowered Health Care Consumer
Intervention Components

- Scheduled follow-up contacts of decreasing frequency over remainder of intervention
  - Weekly
  - Bi-monthly
  - Monthly
- Assess progress to goals
- Skin or Bladder issues, or Hospitalization since last contact
- Other concerns
SCI Peer Navigator Intervention

Pilot Testing
(In Progress)
Pilot Testing – Aim 1

- Assess the feasibility of intervention:
  - Evaluate navigator retention and attrition
  - Explicate and pilot eligible participant identification and recruitment processes, and retention and attrition
  - Evaluate intervention acceptability to both navigators and participants using mixed methods
  - Develop and refine intervention protocol manual and standard operating procedures
  - Design and pre-test peer navigator activity monitoring and documentation
Investigate the presence of a preliminary “signal” of efficacy of the intervention as evidenced by:

- Fewer occurrences of secondary conditions (pressure ulcers & symptomatic urinary tract infections) and rehospitalizations, and higher levels of community participation, and satisfaction with life.
- Increased knowledge, perceived outcomes expectations, self efficacy and social support.
Pilot Testing

- **6-month “proof of concept” trial (n=4)**
  - 3-month intervention + 3-month post-intervention follow-up
  - Assess the logistics of the Peer Navigators conducting the intervention in study participants’ homes

- **9-month pilot randomized trial (n=20)**
  - 6-month intervention + 3-month post-intervention follow-up
  - Adds a non-navigated control group that receives bi-monthly mailed educational materials with follow-up phone calls


**Setting & Sample**

- Multisite study – Charleston & Columbia, SC
  - 1 Navigator in each location

- Sample:
  - >18 years old
  - Chronic paralysis due to acute onset spinal cord injury
  - Level and severity of paralysis require locomotion with a wheelchair
  - Living in the community in a wheelchair accessible home
  - Does not use a ventilator
  - No current undiagnosed Stage III or IV pressure ulcer
Assessments

- Demographic data, SCI and health history at baseline
- Skin Exam & Temperature check at baseline, intervention end, & follow up
  - Measurement and photographs of any existing wounds
- UTI, PU, and hospitalization history at baseline, intervention end, & follow up
- Skin care and bladder management practices at baseline, intervention end, & follow up
- Interview for participant feedback at intervention end
- Ongoing feedback from Navigators
Assessments - Instruments

- Pressure Ulcer (PU) knowledge quiz
- Urinary Tract Infection (UTI) knowledge quiz
- Moorong Self Efficacy Scale (MSES) (Middleton et al, 2003; Miller, 2009)
- Perceived Efficacy in Patient-Physician Interactions (PEPPI) scale (Maly et al, 1998)
- Medical Outcomes Study – Social Support Survey (MOS-SSS) (Sherbourne et al, 1991)
- Reintegration to Normal Living (RNL) Index (Wood-Dauphinee et al 1988; Hitzig et al, 2012)
- Satisfaction with Life Scale (SWLS) (Diener et al, 1985)
Current Status

- Proof of Concept Trial complete
- Pilot Trial ongoing
  - Currently enrolling through March for the Pilot Trial in both sites
Preliminary Findings

- **Proof of Concept Trial**
  - *N*=4
    - 3 male, 1 female; all African American
    - 2 Para, 2 Quad; all Incomplete injuries
    - **Annual personal/family income**
      - $<10,000 n=1
      - $10-15,000 n=2
      - $15-20,000 n=1
    - **Education level**
      - $<High school n=2
      - GED n=2
  - **No participant attrition**
Preliminary Findings

- Positive effect on knowledge of pressure ulcer prevention
  - Pressure Ulcer Knowledge Quiz mean score
    - Baseline: 8.25/12
    - Intervention End: 10.25/12
    - Follow up: 11/12
  - No change in knowledge of UTI prevention

- Improvement of pressure ulcers present at baseline

- Increased participation in productive and preferred community activities
Participant Feedback

- “Being able to know about my resources. And, so, that led into other areas that I didn't know about, like, being able to volunteer. Ya'll giving me homework, and stuff like that... And, it helped me go ahead and get active, like right then, that I didn't have to wait.”

- “This really, actually, been more of a support than I've ever really had.”
“You know, the pressure ulcers, the pictures. Pictures tell a whole lot right there, in color. So, I learned that from ya'll. You know and it helps out a lot. Being able to tell a doctor, you know, ‘This is what's going on.'”
Participant Feedback

- “It helped me take care of myself more better. You know, it did a lot for me. Just like I said, when ya'll asked me to do it, I was wanting to do it because it made me more active, because I didn't really have nothing to do.”

- “I notice, I take more notice in my skin. You know, in my health altogether. I learned, in fact, just little releases, you know, keep the pressure off it, that's the best thing.”
Challenges & Lessons Learned

- Good Peer Navigators are busy people
- Balancing Peer Navigator workload vs. time available
- Matching Peer Navigator with Peer
- Income & Disability Benefits
- Documentation of Peer Navigator interactions
- Recruitment
  - Reaching the folks that need the most help
- Optimal time post-injury for navigation?
Next steps...

- Move to statewide implementation
- Identification and training of more and diverse navigators
- Integration of technology to improve reach
- Adding additional education modules and tailoring based on individual needs
- Ideas from you...
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References


