Development and Testing of an Informal PA Training Program (R-8)

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Program in Occupational Therapy

Community Living Summit
Sept. 19-21, 2016
Alexandria, Virginia

Washington University in St. Louis
SCHOOL OF MEDICINE

Occupational Therapy

Research &
Training Center on
Community Living

Project Objectives

1. Design content for an informal PA training program, to assist informal care providers and recipients in improving the recipients' experiences in community living.

2. Develop informal PA training program using an iterative process to test and refine the training.

3. Pilot and determine the effectiveness of the informal PA training program.

The Need

- The number of adults requiring PAS is expected to grow due to an increase in life expectancy, increasing older adult population and number of individuals with disabilities (Centers for Disease Control and Prevention, 2009).

- Current PAS is not fulfilling the expectations of its consumers, as an estimated 3.2 million adults in the United States has one or more unmet need regarding PAS (Kennedy, 2001).

- The lack in met needs from PAS may be related to low hours of allowed PAS, inadequate training, or low numbers of PAS providers (Grossman et al, 2007).

- Unmet or inadequate personal assistance needs are associated with adverse outcomes, such as deterioration in ADL and IADL performance, and can lead to increased risks of institutionalization and greater overall health care costs (Allen & Mor, 1997; LaPlante et al, 2004).

Informal PAS

- In the US, an estimated 34 million unpaid caregivers provide care to someone age 18 and older who is ill or has a disability (AARP, 2008).

- Informal care providers regularly decide what care the individual will receive, yet they receive little to no training and face a considerable amount of stress (Batavia et al, 1991).

- Informal PAs often view the care receivers' success in daily activities or occupations as a sign that they were providing good care (Hasselkus & Murray, 2007).

- Not as limited as paid PA providers because they are not restricted by time and duties
  - May be able to promote community integration because they spend more time with the recipient and are not limited to providing help with activities of daily living inside the home.

Current Knowledge

- Most studies on training Informal PAs focus on increasing caregiver competence and decreasing caregiver burden, but do not address outcomes related to the care recipient (Northouse et al, 2010, Bee et al, 2009).

- Majority of past research focuses on caregivers of people with Alzheimer's Disease/Dementia, as this disease demonstrates many behavioral challenges and stressors to the caregiver (Etters et al, 2008; Butcher et al, 2001)

- Although information and education is important, proper training is needed to teach Informal PAs the hands-on skills involved with daily activities, including, but not limited to: lifting, handling, mobility and transfers, personal care, and communication.

Overview

- Phase I
  - Assembled the draft of the training program
  - Used Moodle to organize the information
  - Reviewed by....
    - *4 Consumers/Recipients (PWD)*
    - *4 Informal PA Providers (IPA)*
- Phase II
  - Modified content of training based on feedback
  - Received IRB approval
  - Recruiting 10 dyads for trial of program
- Phase III
  - Pilot test the training program and assess the impact and effectiveness
  - 40 dyads
  - Individuals newly injured or at risk for institutionalization

Phase I Results- Suggestions for Improvement

- Additional topics to include in the training program
  - (1) Driving adaptations and transportation options, (2) travel accommodations, and (3) safety planning and emergency procedures

- Training delivery method
  - Need to take user's computer literacy into consideration
  - Have alternative delivery methods (e.g., in-person class, handouts or DVD) available

- Organization of the modules and content
  - Divide the content into segments (e.g., type of disability or level of assistance required)

- Where to go for additional help or resources?
  - Message center (e.g., live chat or discussion thread) to get answers to questions

Phase I Results-Rank Order of Module Topics from Most to Least Important

Module Topic (PWD)	Mean	Module Topic (IPA)	Mean
Personal Care	1.75	Personal Care	2
Body Mechanics and Transfers	3	Effective Communication	3.5
Effective Communication	3.75	Health and Wellness	3.5
Physical Disabilities and Conditions	4.5	Physical Disabilities and Conditions	3.75
Health and Wellness	5.5	Body Mechanics and Transfers	5.25
Secondary Conditions	5.5	Secondary Conditions	5.75
Psychological and Emotional Conditions	6.75	Assistive Technology	5.75
Assistive Technology	7	Psychological and Emotional Conditions	7.75
Recognizing Abuse and Neglect	7.25	Recognizing Abuse and Neglect	7.75

Training Program- Content

- 11 topics/modules
  1. Personal Care
  2. Health and Wellness
  3. Secondary Conditions
  4. Physical Disabilities and Conditions
  5. Body Mechanics and Transfers
  6. Recognizing Abuse and Neglect
  7. Psychological and Emotional Conditions
  8. Effective Communication
  9. Assistive Technology
  10. Safety and Emergency Planning
  11. Transportation and Travel

Phase II

- Participants 10 dyads
  - Experienced Recipients and Providers
  - Recipients and Providers take Pre Survey
  - Pre Skills/Knowledge Test
  - Attend Condensed Training (1 day instead of 2 day)
  - Post Skills/Knowledge Test
  - Recipients and Providers take Post Survey
    - 4 weeks after attending training
  - Provide feedback on training program and surveys
  - Shown online version for resource/review once at home

Skills and Knowledge Test- Recipients

1. How can you train a new attendant to complete tasks the way you want?
   - ❑ Demonstrate task with old attendant
   - ❑ Give attendant a test
   - ❑ Assume previous experience is enough
   - ❑ Criticize attendant's performance

2. What information should your attendant know about you if he/she needs to call 911?
   - ❑ How many brothers and sisters you have
   - ❑ Location of the nearest firehouse
   - ❑ Basic medical history and disabilities
   - ❑ Location of your car keys

3. How should you resolve issues?
   - ❑ Ignore the issue
   - ❑ Voice your concerns in a calm manner
   - ❑ Let attendant win arguments
   - ❑ Fire attendant

4. Which assistive device can be used as a toilet and a shower chair?
   - ❑ Raised toilet seat
   - ❑ Shower bench
   - ❑ 3-in-1 Commode

Skills and Knowledge Test- Provider

1. How many stages of pressure sores are there?
   ❑ One
   ❑ Two
   ❑ Three
   ❑ Four

2. Pressure sores only develop on a person's back and buttocks.
   ❑ True
   ❑ False

3. If your consumer has weakness on their left side, what part of clothing should be put on first?
   ❑ Right sleeve
   ❑ Left sleeve
   ❑ Both sleeves at the same time
   ❑ None of the above

4. When transferring your consumer, most of their weight should be supported by your:
   ❑ Back
   ❑ Shoulder
   ❑ Legs
   ❑ Wrists

Skills and Knowledge Test- Provider

5. You should always let your consumer have the opportunity to select the clothing he/she wants to wear.
 - ❑ True
 - ❑ False

6. The amount of movement is a joint is called:
 - ❑ Range of Motion
 - ❑ Abduction
 - ❑ Adduction
 - ❑ Internal rotation

7. When performing range of motion exercises, you should always push as hard as you can even when you meet resistance.
 - ❑ True
 - ❑ False

8. When performing bathing with your consumer, you should…
 - ❑ Make sure surfaces are not slippery
 - ❑ Check the water temperature
 - ❑ Make sure all skin areas are dry before applying clothing
 - ❑ All of the above

Recipient Pre and Post Survey

- CORE Survey
  - Demographics- Age, race, gender, income, education , benefits received, etc.
  - Health Status-Secondary conditions, ER & physician visits, use of healthcare resources, choice, satisfaction
  - PA Use-Quality, attributes, satisfaction, number of injuries
- PARTS
  - Dressing, Bathing, Bowel Care, Bladder Care, Meal Prep, Transfers and Exercise
  - Time, control over technique, satisfaction, safety
- SPARC
  - Homes, Grocery Stores, Restaurants, Doctor's Offices
  - Frequency attended, personal assistant use, location visited

Recipient Pre and Post Survey

- Social connectivity and relationships
  - Contact grid
  - Level of honesty, ability to resolve conflict, satisfaction
  - Communication
- Hope Scale
- General Self-Efficacy Scale
- Perceived Stress Scale

Provider Pre and Post Survey

- CORE Survey
  - Demographics, tasks completed, difficulty performing tasks, injuries, knowledge of secondary conditions

- Exemplary Care Scale

- Relationship and Communication

- Hope Scale

- General Self Efficacy Scale

- Perceived Stress Scale

- Caregiver Self-Assessment Questionnaire

Phase III- Participants

- 40 dyads
  - Wait-list control group
  - <u>Recipients</u>-individuals over age 18, who live in a community setting (or have a desire to live in a community setting), have a newly acquired or progressing mobility or sensory disability and individuals at risk for institutionalization
  - <u>Providers</u>- individuals over age 18 with a willingness to provide unpaid assistance to one of the recipients

Phase III- Details

- Attend a face to face training
  - Modifications will be made based on the Phase II feedback
- During one of the training sessions, participants will be trained to administer the Community Health Environment Checklist (CHEC)
  - A tool designed to assess community buildings to determine their usability for individuals with mobility, vision or hearing impairments.
  - CHECs can be scored and the results can be displayed on a Google map to inform individuals of businesses that are usable and able to be visited.
  - This activity will be used to increase community participation by informing individuals of the usability of community sites.
- Complete Pre Survey, Skills and Knowledge test and 3 month follow up surveys
  - Modifications will be made based on the Phase II feedback

Phase III-Hypotheses

1. Informal PA recipients attending the education sessions will demonstrate improved health status, increased exercise participation, increased social contacts, higher reported exposure to environmental facilitators in the community, improved satisfaction with PA providers and increased frequency of participation, improved quality of participation in the community and increased level of comfort directing informal care providers.
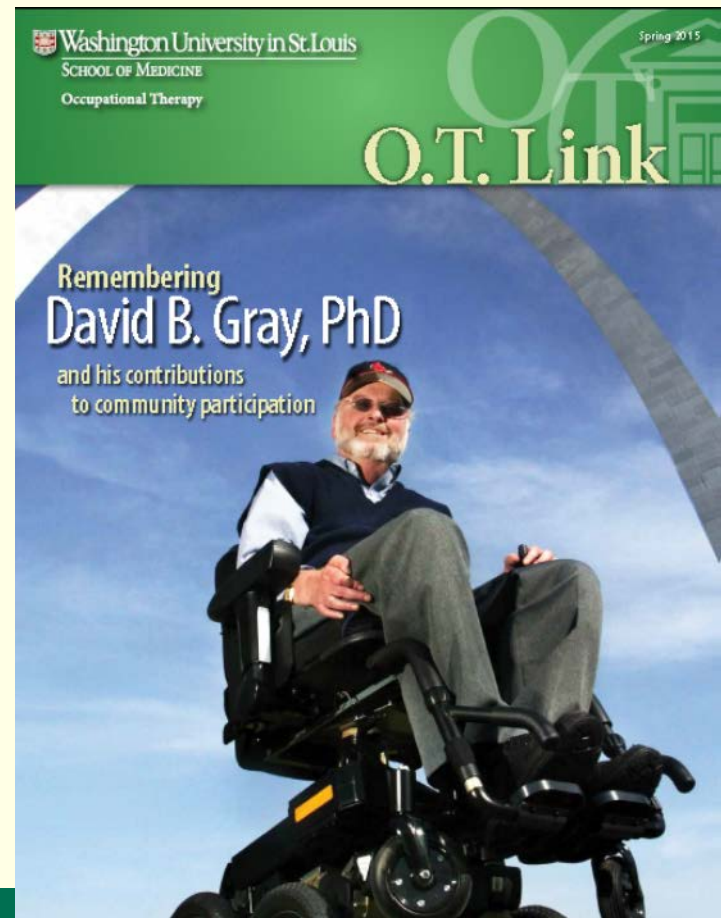
2. Informal PA providers attending the education sessions will improve their approach to preparing recipients for community activities, report less difficulty with completing tasks, have fewer injuries and report less stress and an increased level of comfort during assistance activities than individual providers who do not attend the training intervention.

Future Implications and Directions

- Tool to be used by rehabilitation facilities or ILCs to assist with training family members and friends to provide informal PA

- Consideration of adoption by Community Practice at Washington University to provide billable OT service
  - Policy changes?

- Provide service in-context and determine the effects
  - Policy changes?

Challenges

- Conducting research with rigorous IRB
  - Every change to content has to be resubmitted for approval
  - Delays progress
- Loss of Dr. Gray

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Spring 2015

O.T. Link

Remembering
David B. Gray, PhD
and his contributions
to community participation

Online Training Program Content

- http://dacprolab.com/login/index.php
  - User Name: user1
  - Password: PASUser1

Acknowledgements

- Suzi Skaggs, MSOT/S
- Irene Hsu, OTD/S
- Sarah Zaas, MSOT/S
- Jessy Garcia, OTD/S

Contact Information

- Jessica Dashner, OTD OTR/L
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