Identifying and Remediating Confidence Gaps in Caregiver Roles: Addressing Patient-Centered Health Care Reform

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Background

The healthcare system is shifting to involve patients and the community more in care. This shift will cause the roles and responsibilities of caregivers to expand. This expansion is positive as it will hopefully lead to better care, but also will put an increased burden on caregivers. Educational programs are essential to helping caregivers prepare for their expanded roles. Before an educational program can be designed, a gap analysis should be performed.

Project Aims

• Perform a gap analysis with the caregivers at three patient/family mental health education programs
• Develop an intervention program specifically for caregivers based on gaps identified gaps
• Evaluate the efficacy of the intervention program
• Identify remaining gaps to be addressed in further programs

Discussion

Caregivers have confidence gaps in caring for themselves and in managing difficult emotions and situations. Caregivers for care recipients with different disorders have similar confidence gaps. The education intervention program was:

• successful in addressing confidence gaps in caring for self and managing difficult emotions
• not effective in immediately alleviating burden—may be a longer term result of intervention programs
• Participants generally felt that the program:
  • met their personal objectives and learning needs
  • presented useful information
• Most participants agreed that they would change the way they cared for themselves or their loved ones after the program
• The increase in confidence caused by this program will help equip caregivers for their new roles in healthcare.
• Future studies should include longer follow-up periods to track long term changes in confidence and burden

Methods

Phase I: Assessment Programs

Procedure

Three separate patient/family education programs were developed as part of series of programs designed to translate the latest research into practical information to help people work more effectively with their doctors. The programs dealt with the topics of schizophrenia, depression/bipolar disorder, and general psychiatric disorders, respectively. The Caregiver Inventory survey 4 was given before and after the program through an online survey tool to measure caregiver’s confidence in caregiving tasks.

Participants

Most caregivers were employed (64.3%), were 51-60 years old (32.2%), had completed college (62.8%), were not the primary wage earner (63.4%), and did not receive federal income assistance (99%). Length of caregiving, care recipient ages and care recipient diagnoses varied as described below.

Phase II: Intervention Program

Procedure

In the intervention phase of the study a program on caregiver burden, “Caring for Yourself While Caring for Others: Mind Body Self-care for Caregivers”, was developed to address gaps elucidated in the three assessment programs. The Caregiver Inventory survey 4 and the Zarit Burden Interview survey 5 were given at the beginning of the program and links to the surveys were emailed to participants two weeks later.

Participants

Caregivers were generally 51-70 (79.3%) years old, were female (84.9%), were employed (47.1%), had completed graduate school (47.1%), were the primary wage earners (52.2%), and did not receive income assistance (80.9%). Care recipients had a variety of diagnoses and were from 1 to over 81 years old. Caregivers in this program were demographically similar to those in the assessment programs, although care recipients had a wider range of ages and diagnoses than in the intervention programs.

Results

Phase I: Assessment Programs

Caregivers in the first three programs felt significantly more confident caring for themselves and managing difficult emotions and situations than in managing medical information and caring for the care recipient.

Phase II: Intervention Program

After attending the intervention program caregivers felt significantly more confident in caring for themselves and in managing difficult emotions and situations than before the program.

While participants did feel less burdened after the intervention program, the results were not significant. The majority of participants felt moderately to severely burdened both before and after the intervention program.

The majority of participants either strongly agreed or agreed that the information presented in the program was useful, met their personal objectives and learning needs, and that they would change how they care for themselves or a loved one.

References