Introduction

• As of 2020, there are 6.1 million informal caregivers in the United States providing care to adults between the ages of 18 and 49
• Additionally, individuals diagnosed with Intellectual or Developmental disabilities are living longer, increasing the length of time that caregivers are providing care, with many caring for their children into late adulthood
• Long-term caregiving has significant effects on the caregiver’s physical and psychological health and well-being impacting overall quality of life
• The Exceptional Foundation is a non-profit organization that provides social and recreational services to adults and children with disabilities
• This study aims to (1) identify the needs of caregivers of adults with disabilities and (2) develop a program that addresses these needs to promote caregiver well-being for future implementation at The Exceptional Foundation

Methods

Review of Current Literature:
• Databases searched: CINAHL, ERIC, and Scopus
• Concepts searched: caregiving broadly, caregivers of adults with disabilities and caregiver burden
• Search Terms: (caregiver OR informal caregiver OR family caregiver OR care) AND (adults AND disabilities) AND (caregiver burden OR caregiver stress OR caregiver strain OR caregiver burnout)
• Search filters: English language and published between 2013 and November 2023
• Hand search of references of selected articles was carried out
• 33 articles were selected based on relevance to the present study

Data Analysis:
• Once selected, each article was analyzed for relevant findings, concepts, constructs, and variables.
• NVivo, a qualitative analysis software, was used to categorize or “code” the articles to identify recurring constructs
• Constructs that appeared in more than six articles or 20% were included in the development of this program

Results

- Findings:
  - Six constructs were identified that appear in more than six articles or 20%:
    1. Caregiver burden – 33 articles (94%)
    2. Psychological well-being or mental health – 26 articles (79%)
    3. General health – 18 articles (56%)
    4. Stress – 14 articles (42%)
    5. Coping – 12 articles (36%)
    6. Self-care – 17 articles (52%)

- Program design:
  - Two primary sessions were developed to address these needs:
    1. Session 1: Caregiver burden
    2. Session 2: Stress Management

Discussion

- Stakeholder feedback:
  - The program curriculum (shown in the table below) includes education on the topics of caregiver burden and the importance of wellness promotion, self-care, and stress management/coping strategies.
  - Activities and facilitated discussion are used to support participants in making changes that promote their physical and psychological health and wellness.

- Discussion continued:
  - Limitations:
    - Researcher was unable to collect formal data, so no information was gathered from the caregivers at The Exceptional Foundation
    - Due to the time constraints of the semester, the student was unable to pilot the program at The Exceptional Foundation

Conclusion

- Conclusion:
  - Despite the challenges in informal caregiving, it is essential for healthcare professionals to understand the impact of this role and the needs of this population
  - Coping affects caregivers’ physical and psychological health and leads to overall decreased quality of life
  - Further research is imperative to determine the most effective interventions for supporting caregivers and combat the negative effects of caregiving

References


Acknowledgement & Contact information

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