



Design and Needs Assessment of Framework for Group Palliative Care Visits for Atypical Parkinsonism

Julie J. Berk, MS, PA-C ; Judy Knudson, MPAS,PA-C

Statement of the Problem

- ~15% of persons with Parkinson's symptoms have Atypical Parkinsonism (APD)
- APD patients undergo very rapid cognitive and physical disease progression
- Lack of support resources for this disease cohort results in family isolation

Background/Literature Review

Patients treated through group visits have shown decreased emergency department and outpatient utilization; increased quality of life; improved self-efficacy; and higher satisfaction with care. There is evidence that group medical visits can improve clinical, lifestyle and psychosocial outcomes. Group neuro palliative care would facilitate combined palliative care and increased support for families of patients with APD. Our hope would be to foster connection and develop supportive community for APD.



Objectives

1. Design curriculum for five group medical visits for APD patient/caregiver dyads using neuro-palliative care concepts
2. Administer needs assessment phone questionnaire
3. Administer and assess pilot class with caregivers

Methods

- Needs assessment phone interviews conducted on 15 family caregivers in January/February 2018
- Five group visits designed
- Pilot caregiver class 2/17/18 to 12 caregivers
- Setting: APD patients outpatient neurology clinic
- Measurement tool: questionnaires x 2 *questionnaires available on request

Design for 5 Group Neuro-Palliative Visit Modules

- 1) **Theme=INDIVIDUALITY** [Medical Provider]
Goal= Help patients tell their story and reconfirm what is important to them
-Use of personality testing tool/story-telling tool, value awareness
Outcome= Self knowledge, increase in self-efficacy
- 2) **Theme=STAYING SAFE AND STRONG** [Physical Therapist/Occupational Therapist]
Goal= Teach importance of physical health maintenance and safety
-Home safety issues, overview of useful tools for maintaining independence
Outcome= Personal goals set for exercise and review of safety equipment
- 3) **Theme=ADVANCE CARE PLANNING** [ENACT class]
Goal= Understanding need for MDPOA and advance directives
-Consider use of 'Conversation project' or similar
Outcome= Participants complete MDPOA and MOST forms
- 4) **Theme=RESOURCES** [Social Worker]
Goal= Assemble resources and support for family
-Caregiver class, resilience training for patient/family
Outcome= Participants assemble list of personal and professional care resources
- 5) **Theme=PEACE** [Spiritual Care Provider]
Goal= Educate about grief/loss issues and provide tools for coping
-Tools for making peace with loss, Dignity Therapy or similar
Outcome= Participants create plan for legacy project

Findings/Results

15 needs assessments: (9 male; 6 female patients)
mean and median education level of patients=16 years
60% of those surveyed were unwilling to go to 5 group medical visits and 40% were willing
Monthly timeframe preferred
Chief concerns= not able to attend due to care issues, caregivers thought patients would be uncomfortable in group and felt concern for possible unmet needs in group setting
Advantages identified= chance to share ideas and concerns with other families

12 caregivers and 1 patient attended pilot visit:
60% responded to written questionnaire that group visit was helpful and informative

Conclusions

- Participants reluctant to participate in group visits
- Additional barriers: limited clinic space, need to train staff, complex billing and recruitment
- Limitations: small sample, rare disease population, lack of experience in administering group visits



Future Directions

- Plan to repeat caregiver class 2x/year
- Create webinars of visit modules
- Develop on-line support group for APD
- Develop story-telling blog for patients with APD and other neurologic diseases

References

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