

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

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Objectives:

- design 5 group medical visits for atypical Parkinsonism patient/caregiver dyads
- administer needs assessment phone questionnaire
- administer pilot visit with caregivers

Atypical Parkinson's disease (APD) patients undergo rapid physical and cognitive disease progression which can be overwhelming for patients/caregiver dyads. This cohort of diseases is not well supported by community which may lead dyads to experience isolation. Implementation of neuro palliative care principles have been shown to improve patient experience and there is evidence that group medical visits can improve clinical, lifestyle and psychosocial outcomes. We created 5 group visits that patient/caregivers could attend to serve as healthcare and opportunity for development of bonds to stay connected during disease progression.

Needs assessment phone interviews were conducted on 15 patient caregivers. 9 male and 6 female patients were included with mean and median education level of 16 years. 60% of those surveyed were unwilling to go to 5 group medical visits and 40% were willing. 4 respondents expressed that monthly visits were optimal timeframe. Topics of interest mentioned included how to cope, how to locate resources and how to attend to daily needs. A primary concern was not being able to attend group visits due to care issues. Other concerns expressed were that patient would not feel comfortable in a group and potential for unmet needs. Potential advantages, according to 5 respondents, were to share ideas and concerns with other families. 13 respondents agreed to attend a pilot group visit. 12 caregivers and 1 patient attended a 2 hour group visit. Questionnaires were administered after and 60% were returned answering that group visit was helpful and informative.

We have concluded from this exploration that a single caregiver class would provide easiest access and allow for some implementation of palliative care principles for APD population.

Alternate solution to consider could be online webinars and communities for patients/caregivers.

