



Hospice and Parkinson's Disease: Interdisciplinary Work Group

"If you loved me, you'd give me a glass of water"

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Introduction

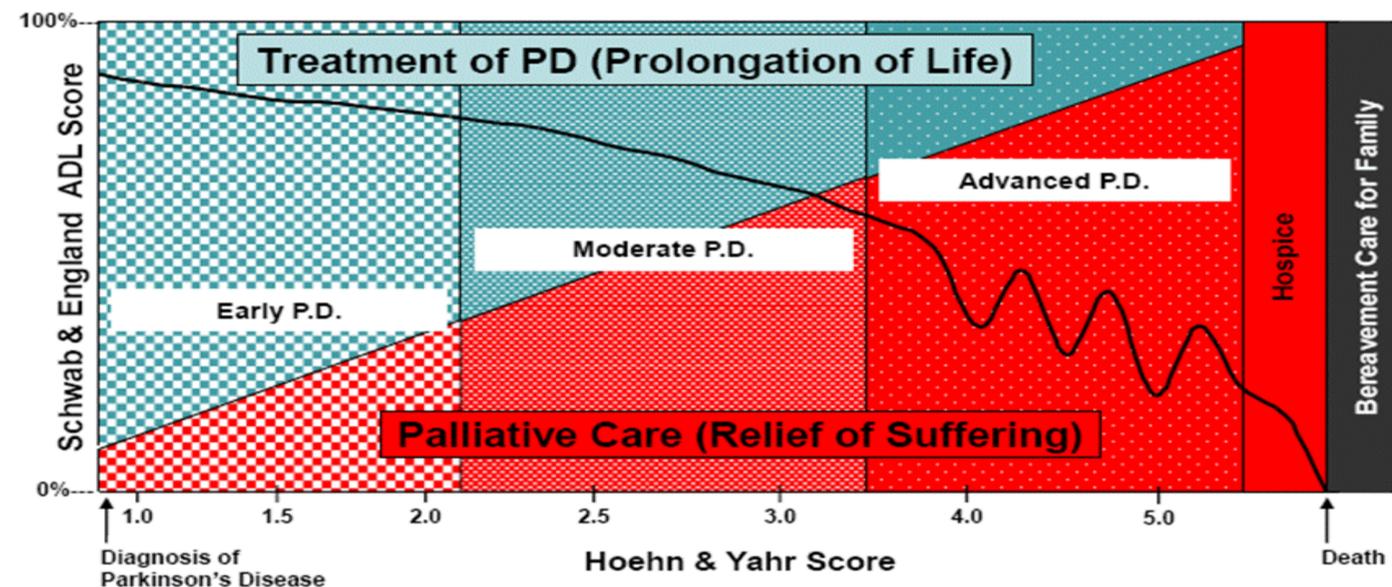
"If you loved me, you'd give me a glass of water"

These words reflect the theme of the last days of life for Mr. G as he transitioned into home hospice for end of life care with Parkinson's disease (PD). A year after his death, his wife would repeat these words to illustrate the importance of hydration, despite the risk of aspiration in end stage Parkinson's disease. "I don't want another family to experience what I went through" (Mrs.G).

There is a dearth of information to guide health care providers in managing PD patients and their family members at end of life. Thus a compelling need exist to translate knowledge from the hospice/palliative care field to the care of patients with movement disorders.

Through a generous grant from Mrs. G., an interdisciplinary roundtable was conducted at Penn Home Care and Wissahickon Hospice to discuss end of life care for patients with PD, with a focus on hydration and aspiration at end of life.

Parkinson's Disease: Model of Care



Future Directions

- Continued collaboration between Penn PD & MDC and Penn Home Care and Wissahickon Hospice to identify needs of families / PD patients at end of life.
- Identify national hospice/palliative care organizations to partner in developing guidelines for the care of PD patients and families in hospice.
- Develop educational opportunities for hospice health care providers to discuss needs for patients with PD in a family centered approach to end of life care.

Work Group Goals

- Short Term: To start a dialogue among clinicians regarding distressing symptoms at end of life in patients with PD and related disorders, stressing patient and family centered approach to care
- Long Term: To establish clinical practice guidelines for end of life care in PD and related disorders, utilizing a patient/family centered approach to care

Discussion

- Dehydration at end of life can be distressing for the patient and family members caring for PD patients in home care hospice.
- Comfort measures should be the overwhelming guiding principle in caring for PD patients at end of life.
- Family members / caregivers are the center of hospice/palliative care services.

