Parkinson's Foundation Palliative Care Champion Newsletter

December 2022

Palliative Care Resources

Is there a Place for Spirituality in Neurology?

- This article explores how patients and physicians alike may benefit from increased comfort with the wellness domain of spirituality as it pertains to providing medical care, particularly for people with neurologic conditions. It covers how to have a conversation, including how to start a conversation and what questions to ask, how to incorporate spirituality and chaplain support into clinical care, and how a team approach to spirituality can benefit clinicians. Access the article here.

Spirituality in Serious Illness and Health

- In our coaching calls we continue to have insightful discussions around assessing and supporting the spiritual needs of patients and families. In this recent publication in JAMA, the authors provide clear definitions of spirituality, religiosity, spiritual needs, and spiritual care to help us all understand these concepts better as we work with people with Parkinson's and families. Access it here.

Podcasts

- The Cure for Bullshit podcast interviews patients, doctors, researchers, and skeptics about their practical advice for navigating the healthcare system and avoiding medical scams. In a recent episode, "Authenticity and Curiosity", Dr. Michael Okun discusses his approach to patient advocacy and how to talk to doctors. You can listen to the full podcast here.

- GeriPal is a geriatrics and palliative care podcast for every healthcare professional. The episode, "Transforming the Culture of Dementia Care", features speakers Anne Basting, Ab Desai, Susan Mc Fadden, and Judy Long discussing the importance of viewing individuals with dementia from a lens of resilience, the importance of creative engagement, the role of collaborative care, and what we can do to improve inclusivity for individuals with dementia in our community and health care system. Listen to the full podcast here.

Palliative Care Project Updates

1. **Advance Care Planning (ACP) Town Hall**

   - This December we held our first palliative care town hall on advance care planning. It is a part of a larger town hall series where we will continue to discuss topics related to the 5 pillars of palliative care and best practices for implementation. Some of the topics covered during the December town hall included tips for ACP billing, group clinic models for ACP, tips for having roadmap discussions, how to use EPIC for documenting ACP, and incorporating a team-based approach. If you were not able to attend, or would like to re-visit the talk, you can access the recording here. Passcode: F5#L6BtP

2. **Registration Information for the Palliative Care PD Health @ Home Series**

   - Beginning January 2023, we will be launching our educational series for people with Parkinson's and their families on the 5 pillars of palliative care. This series will be airing throughout 2023 via PD Health @ Home through the Parkinson's Foundation. Using this link, people with Parkinson's and their families can register for entire series, including the first live talk on January 11th, 2023, which will serve as an introduction to palliative care and why it is beneficial. We will follow up with more details as additional talks roll out, including information on how your patients and families can continue to access this important content.

Center Spotlight: Palliative Care COE Implementation

Integrating Spiritual Care at Indiana University

By S. Elizabeth Zauber, MD, Director, Parkinson's Foundation Center of Excellence (COE) at Indiana University

At the Indiana University PD COE, we have added a chaplain to address the spiritual needs of our patients. The chaplain is present in clinic two half-days a week and is funded by our COE grant. We contacted the head of spiritual care who connected us to a chaplain with prior neurology experience in the ALS clinic. Since the PD clinic is set up differently than the ALS clinic, we did need to brainstorm how to best integrate him into clinic flow, and help him understand the needs of people with PD. We began by having him shadow us, and he continues to do that for about half the time he is in clinic. We introduce him as a chaplain and a new member of our team. When the physician completes the visit, he stays in the room and introduces himself to the patient and family. Some patients just want to take his card, others welcome the chance to visit with him. Then he makes notes in the EMR (Electronic Medical Record). If we see a patient on a day, he is not in clinic we send him a message through the EMR and he calls the patient or caregiver the next half day he is scheduled with us. He does ask that patients verbally consent to be contacted, because it can be frightening to receive a call from a chaplain unexpectedly. He also comes to our monthly PD COE team meetings, which helps everyone on the team remember that they can also refer patients and care partners to him as well via EMR message.

We have added a question about spiritual concerns to our intake questionnaire, which may also trigger us to connect patients to the chaplain. This question and the chaplain's presence in clinic lets patients and families know that we are willing to talk to them about all of the ways that PD impacts them, and that we aim to support them on multiple levels. Not everyone on our team was initially receptive to adding a chaplain. Many equated spiritual care with religion and felt uncomfortable discussing religion with patients. However, once they learned more about the role of spiritual care and saw the impact on patients and care partners, they began to work with the chaplain as well. As a team, we have noticed that having an additional trained listener can relieve some of the stress on the social worker and nurses. We are hopeful that the health system will see the benefits of outpatient spiritual care and begin to fund positions like this. Currently the only positions funded by the health system are inpatient. We have connected with a team interested in spiritual care research and hope to contribute to research in this area.

If your center is interested in sharing a success story regarding palliative care implementation at your center, please contact Jinnia Nusrat at jnusrat@parkinson.org.

Screening for and Addressing Challenging Emotions and Spiritual Wellbeing

By Dr. Benzi Kluger, MD and The Palliative Care Project Team

The issue of how to screen for and address the pillar of spiritual wellbeing and challenging emotions has been difficult compared to many of the other pillars. To make this process easier and clearer, we decided to tie this pillar to our current state of evidence in Parkinson's disease (PD) and best practices for other serious illnesses.

First, there is evidence that people living with PD (PWP) experience grief.[1] Grief is a sense of loss, and can include the loss of identity, roles, enjoyable activities, and abilities as well as grieving for losses to come with disease progression and lost dreams (anticipatory grief). Grief is distinct from depression and tends to respond better to supportive counseling than antidepressant medications.[2] In fact, one of the core skills in supporting people with grief is to help them to recognize and name their losses and to validate their experience as normal rather than pathologize their sadness as a medical/psychiatric issue.

Second, there is evidence that PWP experience demoralization (loss of hope and meaning)[3] at a higher rate than many other chronic illnesses.[4] While demoralization may be a feature of depression, it may also exist independently and reflect the existential and spiritual challenges of living with an incurable, progressive and frequently terminal illness.[5] As with grief, demoralization that is not tied to depression tends to respond better to supportive counseling than medications.

Third, there is consistent evidence, including in PD, that the majority of people living with serious illness have a desire to be seen and known by their providers as people, including their spiritual selves, and use prayer or other religious/spiritual practices in coping with their illness.[6, 7]

To this end we recommend the following questions (or similar) be considered in addition to traditional screening questions for anxiety and depression in your scales or templates:

1. Do you struggle with the loss of meaning or joy in your life? (From King et al.[8] review and currently in our recommended PC screening scale)
2. Do you feel your life is unfulfilling, empty, or meaningless because of changes or losses related to your Parkinson's disease? (adapted from Prolonged Grief Questionnaire)[9]
3. When thinking about your life and your future, do you feel hopeless or full of regrets? (adapted from The Demoralization Scale)[10]

We would also suggest asking the following question or something similar when first meeting a patient or with significant changes in health status.

4. Do you currently have what you would describe as religious or spiritual struggles? (From King et al.[8] review and currently in our recommended PC screening scale)
5. Anything we should know about your beliefs: spiritual or religious that would help us take better care of you? (adapted from the FICA method of taking a spiritual history)[11]

Lastly, we would suggest considering enquiring into these issues using a positive framework. Using questions such as "*What do you currently enjoy or look forward to?"* or "*Where do you find meaning and joy in your life?".* {Kluger, 2020 #762} By positively framing questions you gain the opportunity to learn more about your patient's strengths and hobbies while still screening for grief and demoralization (e.g., if patient answers "I *used* to enjoy…" or "Not much" you may want to explore grief and demoralization more).

In our work with COE, we've found many providers address these issues with questions that fit their style and personality such as: "*How is your heart doing?" or "How are you shining light these days?". Finding questions that work for you and feel authentic are great so long as they give you the opportunity to connect and explore these issues.*

Many times the issues that are raised may be addressed by simply naming the emotion (e.g., "it sounds like you are dealing with some normal sadness and loss"), validating their experience (e.g., "I can only imagine how tough it must be for someone as independent as you have been in your life to have to deal with this.") and suggesting they explore it with family, counselors or faith community. If the issues raised are particularly troublesome, intense, or the PWP lacks a support system, a referral to a counselor or chaplain may be needed.

References can be found here. Passcode: SmSk8U8h