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# Quality of Life Matters<sup>®</sup>

Serious illness care news & clinical findings | Issue Q3 2020

## OUTPATIENT PALLIATIVE CARE IMPROVES OUTCOMES FOR PARKINSON'S DISEASE PATIENTS, CAREGIVERS

Patients with Parkinson's disease and related disorders (PDRD) randomized to receive outpatient, integrated palliative care (PC) reported better quality of life (QoL) after six months, lower symptom burden, and higher rates of advance directive (AD) completion compared with controls. Caregiver burden and anxiety were also significantly improved at 12 months, according to a report published in *JAMA Neurology*.

"These results show a comparative advantage to outpatient PC compared with standard care in patients with PDRD for several outcomes of interest to patients,

families, and other stakeholders," write the authors.

The authors note that Parkinson's disease is the 14th leading cause of death in the U.S., and although motor symptoms are traditionally used to describe the condition, nonmotor symptoms such as pain and dementia are common and associated with mortality, diminished quality of life, and caregiver distress. Yet, because PC is still often associated with the end of life, especially for cancer patients, the benefits of early, integrated PC for PDRD has been little studied.

### Focus on Quality of Life

Investigators conducted a randomized clinical trial to evaluate the effect of integrated outpatient PC on patient quality of life (using the Quality of Life in Alzheimer's Disease scale) and caregiver burden (using the Zarit Burden Interview) at six months. Participant selection was based on PC needs rather than on prognosis or definitions of illness advancement.

The team randomized 210 patients with PDRD (men, 64.3%; mean age, 70.1 years) and 175 caregivers (women, 73.1%; mean age, 66.1 years) to receive standard care plus outpatient PC or standard care alone at three academic medical centers in

the U.S. and Canada between 2015 and 2017.

Patient participants had probable Parkinson's disease or another PDRD diagnosis (multiple system atrophy, corticobasal degeneration, progressive supranuclear palsy, or Lewy body dementia) and moderate-to-high PC needs based on the Palliative Care Needs Assessment Tool (PC-NAT) modified for Parkinson's disease.

Patients in the control group received standard care provided by the patient's primary care physician and a neurologist. Those in the PC intervention group were cared for by an interdisciplinary team consisting of a neurologist with informal PC training, a nurse, social worker, and chaplain with Parkinson's disease experience, and a board-certified palliative medicine physician. The PC outpatient visits occurred every three months for one year, with the PC team available for participant contact as needed.

Typical PC visits lasted about 2 to 2.5 hours and addressed nonmotor symptoms, goals of care, anticipatory guidance, difficult emotions, and caregiver support. Palliative medicine specialists, when needed, focused mainly on complex goals-of-care discussions and symptom management.

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SAMPLE

## ◀ OUTPATIENT PALLIATIVE CARE FOR PARKINSON'S PATIENTS (from page 1)

### Overall

- 30% of patients in each group had a clinical diagnosis of dementia.
- Two patients (one from each group) were referred to hospice.
- A palliative medicine physician was directly involved in the care of 46.2% of intervention patients.

### Key findings —

#### Quality of life and caregiver burden

- At six months, patients in the PC intervention group reported better QoL than did those in the standard group (0.66 mean improvement vs 0.84 worsening; treatment effect estimate, 1.87; 95% confidence interval [CI], 0.47 to 3.27;  $P = 0.009$ ).
- At 12 months, however, the difference in the treatment effect estimate was not significant (1.36; 95% CI, -0.01 to 2.73;  $P = 0.05$ ).

- The treatment effect for women at 12 months was greater than that for men (2.91; 95% CI, 0.67 to 5.14;  $P = 0.01$  vs 0.47; 95% CI, -1.22 to 2.16;  $P = 0.09$ ).
- Higher PC needs at baseline were significantly associated with greater benefit from the PC intervention.
- The difference in caregiver burden between the two groups was statistically significant at 12 months (treatment effect estimate, -2.60; 95% CI, -4.58 to -0.61;  $P = 0.01$ ), although not at six months (treatment effect estimate, -1.62; 95% CI, -3.32 to 0.09;  $P = 0.06$ ).

### Secondary findings

- A statistically and clinically significant benefit in motor symptoms (treatment effect estimate, -5.98; 95% CI, -9.54 to -2.43;  $P = 0.001$ ) was found among participants in the PC group.
- Among patients with no advance directive (AD) or healthcare proxy at baseline, those in the PC intervention group were more likely than controls to have completed an advance directive at six months (53% vs 26%).
- Among those with AD paperwork, PC patients were more likely than controls to have filed a state-specific AD with their practitioner (83% vs 37%;  $P < 0.001$ ) and to have filed paperwork for a healthcare proxy (67% vs 33%;  $P < 0.001$ ) at 12 months.

“Other effects favoring the PC intervention included symptom burden, health-related QoL, grief, caregiver anxiety, the peace subscale of caregiver spiritual well-being, and both patient and caregiver global impressions of change,” add the authors concerning the clinical trial’s secondary findings.

“This model reflects current practice [of integrated PC] and highlights a need to develop hybrid models of PC that build on the strengths of both disease and PC specialists and that efficiently use our limited pool of palliative medicine experts,” write the authors.

“As a new application of PC, a need exists to optimize the intervention, particularly for caregivers, and to develop models appropriate for implementation in non-academic settings and among diverse populations.” The authors express the hope that “the study’s results provide a starting point for future studies integrating PC into standard care for patients with PDRD and other chronic illnesses.”

Source: “Comparison of Integrated Outpatient Palliative Care with Standard Care in Patients with Parkinson’s Disease and Related Disorders: A Randomized Clinical Trial,” *JAMA Neurology*; Epub ahead of print, February 10, 2020; DOI: 10.1001/jamaneurol.2019.4992. Kluger BM, Kutner JS, et al; University of Colorado, Denver; University of Alberta, Edmonton, Canada; and University of Colorado, Aurora.

### OUTCOME MEASURES USED IN THE ABOVE STUDY INCLUDE:

- **Quality of life (QoL):** *Quality of Life in Alzheimer’s Disease (QoL-AD) scale*. Scoring ranges from 13–52 (13 indicating poor and 52 indicating excellent).
- **Caregiver burden:** *Zarit Burden Interview (ZBI-12)*. Scoring ranges from 0–48 (0–10 indicates no to mild caregiver burden; 11–20, mild to moderate caregiver burden; 21–48, high caregiver burden).
- **Symptom burden:** *Edmonton Symptom Assessment Scale, Revised for Parkinson’s Disease*. Range of 0–140 (0, no symptom burden; 140, high symptom burden).
- **Health-related QoL:** *Parkinson’s Disease Questionnaire*. Range of 0–10 (lower scores indicate better QoL; higher scores indicate worse).
- **Patient and caregiver mood:** *Hospital Anxiety and Depression Scale*. Range 0–21 (0 indicating little to no likelihood of depression or anxiety and 21 indicating high likelihood of depression or anxiety).
- **Patient and caregiver grief:** *Prolonged Grief Disorder (PGD) Questionnaire*. Score range 0–44 (0 indicating minimum symptoms of PGD and 44 indicating maximum symptoms of same).

# BEREAVED FAMILIES PRAISE COMPASSIONATE CARE, REGRET LACK OF HOSPICE INFORMATION AND LATE REFERRALS

Recently bereaved family members of cancer patients reported valuing clinical care that showed empathy and concern for their loved ones and themselves as caregivers, along with honest, straightforward information during the illness concerning treatment options and prognosis. They expressed disappointment over lack of end-of-life (EOL) information and timely hospice referral.

“The findings from this qualitative study demonstrate that bereaved individuals can provide important insights into how clinicians can improve the care of patients at the EOL and the care of bereaved family members,” write the authors of a report published in the *Journal of Palliative Medicine*.

The study’s insights highlight “two areas that could benefit from quality improvement efforts: 1) communication skills that focus on enhancing compassionate connection, including conveying empathy and providing reassurance and guidance to patients and their families and 2) communication skills that focus on delivering information about prognosis and the EOL period in an honest and direct way,” the authors write.

Investigators analyzed mail-in survey responses of 140 family members (female, 67%; aged ≥ 60 years, 66%; bereaved spouse or partner, 81%) whose loved ones had died in 2013 and who were listed in the bereavement program database of the Dana-Farber Cancer Institute, Boston. Participants were asked to describe which aspects of care provided by the decedent’s clinical team had or had not helped to ease their grieving process.

## Compassionate care

- Family members said the clinical team made the patient’s experience comfortable, spent time with and demonstrated that they cared about the patient.
- The patient was treated as a whole person within the clinician-patient relationship.
- The caregiver’s role was recognized for its importance in the patient’s care, and the caregiver’s needs were acknowledged. “They listened to me when I made suggestions,” reported one participant.
- A multidisciplinary team approach was provided.

## Competent care

- Participants reported that the clinical team was professional, responsive, and courteous.
- The team more than met the family’s care expectations, often going “above and beyond.”
- The team helped with treatment logistics.

## Bereavement outreach

- A condolence letter or call was received from the oncologist and/or team. “The follow-up from the MDs and their office was wonderful,” wrote a participant.
- Supportive literature on grieving was supplied or access to a support group was facilitated.

## Honest facts

- Information about diagnoses, treatment, prognosis, and the imminence of death was delivered in a straightforward, honest manner. “Our family had time to prepare because the team was upfront and frank with us and my husband,” reported a participant. “We knew what needed to be done and what would happen.”

## Hospice

- The team provided information about the dying process and the timing of death, and eased the way to receiving hospice care in a timely manner. “The doctor spent a long time with us, telling us it was time for hospice,” reported a participant. It was “really helpful to have hospice step in.”

Research shows that “the provision of palliative care and hospice services is associated with improved family satisfaction, improved family-reported quality of EOL care, and better bereavement outcomes,” the authors note.

Because bereavement care is basically a preventive model requiring early intervention, “developing ways to improve bereavement outcomes for family members before and after the death of the patient is essential,” they add.

Among the actions that bereaved families reported wishing their clinical team had taken, but did not, that would have made it easier to deal with their loss were: providing more information, and accurate information, regarding the course of the illness; suggesting hospice sooner; and maintaining contact after the transition. “It felt strange to suddenly sever the connection we had to the doctor for 17 years and deal only with hospice,” wrote one respondent. “It would have been nice to get a phone call now and then.”

## Care aspects unhelpful to bereaved families

- Impersonal contact and communication style
- Lack of contact, including lack of caregiver support
- Lack of contact post-death
- Too many changing doctors

(Continued on page 7)

## DISCUSSING MEDICATION USE WITH DEMENTIA PATIENTS, CLINICIANS PROMOTE SHARED DECISION-MAKING

Primary care physicians and their teams addressed the complexities and challenges of deprescribing medications with cognitively impaired older adults and their companions by using a whole-person approach to developing a framework for eliciting preferences, explaining trade-offs, emphasizing quality of life, reassuring that care will continue, and maneuvering around conflict, according to a report published in the *Journal of General Internal Medicine*.

“To our knowledge, this is the first study to use audio-recordings of actual conversations between clinicians and older adults with cognitive impairment and their companions to describe the current state of communication about medication use,” write the authors.

People living with dementia — an estimated 11 million Americans — take an average of five to ten medications, of which only one or two are prescribed for dementia, note the authors. The remainder of the medications are for coexisting, non-dementia illnesses, with a likely one-third of patients taking potentially inappropriate medications.

“For clinicians, achieving optimal medication use for older adults with cognitive impairment is challenging,” write the authors. These patients often have a high burden of comorbidities, but “given the prolonged and variable course of cognitive impairment, determining whether a medication to prevent or treat a coexisting condition is likely to result in benefits or harms during the person’s remaining lifespan is complex.”

Investigators analyzed the content of audio-recorded encounters of primary care clinicians with patient-companion dyads from the SAME Page Study, a randomized controlled trial to examine the effects of an agenda-setting checklist on communication among older adults with cognitive impairment. The trial did not intervene with the clinicians or suggest optimal prescribing/deprescribing.

The clinical visits, which occurred between August 2016 and August 2017 at three clinics in Baltimore, MD, included 93 older adults with dementia (mean age, 79.7 years; female, 51.6%; nonwhite, 41.9%) and their relatives or unpaid companions. Participating clinicians (n = 14) were physicians (family medicine training, 42.8%; specialty training in geriatrics, 42.9%) as well as nurse practitioners or physician assistants.

Intervention patients and companions completed a checklist to establish a shared agenda, then at two-week follow-up also completed a questionnaire on medication adherence and clinician communication. Clinical visits lasted a mean 25.2 minutes.

### Overall

- At baseline, 49.5% of patients had a diagnosis of dementia, cognitive impairment, or symptoms of cognitive impairment in their electronic health record.
- Patients’ mean Mini-Mental State Examination score (administered at the enrollment visit) was 21.6 on a scale of 0–30, on which lower scores indicate higher severity of dementia.
- Nearly one-quarter (23.7%) of patients were taking  $\geq 10$  prescription medications.
- The quality of the medication communication with the clinician was rated as “excellent” by 52% of patients and 63% of companions.

A variety of approaches were used by clinicians to ensure patients understood and were involved in decisions about medication use. The study report includes tables with language used by clinicians in addressing various issues. Analysis of the clinical conversations identified clinician strategies clustered into three major categories.

### Major themes of clinician discussions

#### **1. Introducing patients and caregivers to key principles of optimal prescribing.** Clinicians:

- Presented scaling back the intensity of medications and other interventions as a routine part of care;
- Explained that the balance of benefits and harms and a person’s needs often change with aging and cognitive impairment;
- Prioritized function and quality of life over disease-focused treatment, especially for those with more severe comorbidities or poorer cognitive status;
- Introduced the concept of diminishing returns;
- Explained that symptoms cannot always be “fixed” by medications, which can carry significant risks;
- Acknowledged the uncertainty of the medical evidence with regard to older patients with dementia and comorbid conditions and thus the preference-sensitive nature of decision-making.

#### **2. Fostering shared decision-making.** Clinicians:

- Elicited the patient/caregiver perspective to encourage their involvement;
- Provided reassurance that stopping a medication is not withdrawal of appropriate care and that their care will be ongoing;
- Reassured the patient/caregiver that any deprescribing will be closely monitored.

(Continued on page 7)

# EARLY INPATIENT PALLIATIVE CARE FOUND TO REDUCE BOTH 30-DAY READMISSIONS AND INPATIENT MORTALITY

Adult patients with serious illness who received a palliative care consultation (PCC) following admission to an acute care facility were significantly less likely than comparable patients receiving usual care to be readmitted within 30 days. They were also less likely to die in the hospital, but only if the PCC was initiated within the first six days of hospitalization, according to a report in the *Journal of Palliative Medicine*.

“[C]onsultation within the first six hospital days has the greatest impact,” write the authors. “Early PCC should be encouraged for eligible patients,” because palliative care, which aims to improve the quality of life for both patients and families, “is vital to ensuring the provision of high-quality, cost-effective care for patients with serious illness.”

In the U.S., PCC is available in about 75% of hospitals with more than 50 beds and approximately 90% of those with more than 500 beds, the authors note. However, although previous research has demonstrated PCC-related reductions in 30-day readmissions and inpatient mortality, no large-scale studies have focused on hospital-based PCC alone. “To our knowledge, this is the largest study to date.”

Investigators conducted a retrospective, observational study comparing 30-day unplanned readmissions and inpatient mortality among patients receiving inpatient PCC (n = 6043) to all other acute care patients receiving usual care (n = 43,463) in one of eight hospitals in a single healthcare system based in the southeastern U.S. in 2015.

## Patient characteristics:

- Mean patient age was 69.0 years in the PCC group, 67.6 years in the usual care group.
- The proportion of patients of white race was 69.0% and 72.1% in the PCC and usual care groups, respectively.
- Primary diagnoses most commonly included circulatory system (18.8%, PCC; 33.6%, usual care), infectious and parasitic (18.5%, PCC; 9.7%, usual care), and respiratory (16.3%, PCC; 16.5%, usual care) disease.
- Comorbidities included congestive heart failure (35.5%, PCC; 25.7%, usual care) and cancer (32.5%, PCC; 17.4%, usual care).

The PCC treatment group was stratified into three subgroups by the timing of consult: within 0 to 2 hospital days (early), 3 to 6 days (middle), and 7 to 30 days (late). The researchers evaluated the observed outcomes of care relative to expected outcomes as a leveraged O/E ratio. In additional analysis, they removed effect of usual care from the impact of PCC in order to avoid overestimating the impact of PCC on readmissions and mortality.

## Key findings, overall

- The 30-day readmission O/E ratio was 17.7% lower among PCC patients compared with the usual care group.
- After removing the impact of usual care from the impact of PCC, the readmission reduction was 16.0%.
- Inpatient mortality O/E ratio among PCC patients was 19.5% lower than among usual-care patients.
- After removal of the impact of usual care, the inpatient mortality reduction attributable to PCC was 14.4%.

## Early consults (0 to 2 days)

- 30-day readmission O/E ratio was 15.6% lower among PCC patients (n = 2706) compared with usual care patients. After removal of the impact of usual care from the impact of PCC, 30-day readmission was 14.1% lower.
- The inpatient mortality O/E ratio was 26.3% lower among PCC patients (n = 3248). After removal of the usual-care impact, it was 19.4% lower.

## Middle consults (3 to 6 days)

- 30-day readmission O/E ratio was 21.2% lower among PCC patients (n = 1517) and 19.2% lower after removal of the usual-care impact.
- Inpatient mortality O/E ratio was 25.9% lower among PCC patients (n = 1823) and 19.1% lower after removal of the usual-care impact.

## Late consults (7 to 30 days)

- 30-day readmission O/E ratio was 18.1% lower among PCC patients (n = 627) and 16.4% lower after removal of the impact of usual care.
- However, inpatient mortality O/E ratio was 16.3% greater among PCC patients (n = 867) compared with the usual care group and 12% greater after removal of the usual-care impact from the impact of PCC.

“The impact [of PCC] on readmissions remained positive among all timing groups studied, whereas the impact on mortality was positive only in patients consulted within the first six days of their hospitalization,” write the authors, who argue for initiation of palliative care in patients with serious illness well before consideration of hospice may be appropriate.

Source: “Timing of Palliative Care Consultation and the Impact on Thirty-Day Readmissions and Inpatient Mortality,” *Journal of Palliative Medicine*; April 2019; 22(4):393–399. Barkley JE, McCall A, Maslow AL, Skudlarska BA, Chen X; Continuing Care Services; Quality Division; Information and Analytics Services; and Adult Acute Division, Atrium Health, Charlotte, North Carolina.

## ◀ BEREAVED FAMILIES PRAISE COMPASSIONATE CARE (from page 4)

- Lack of information about the patient's prognosis and the reason for the death itself. "I was never told how serious her condition was," reported a participant.
- Regret about an invasive treatment proposed and initiated close to death

"Taken together, our findings suggest that the actions by the clinical team that were considered helpful by these bereaved family members included those actions that promoted human connection, reassurance, and guidance during a very difficult time," write the authors. "Such a connection cannot be minimized, especially in an oncology setting where patients have often been receiving treatment for years and the clinical team is considered to be a 'second family.'"

The authors suggest that perhaps members of the interdisciplinary team, such as social workers and chaplains — as well as palliative care clinicians — could coach oncologists and other physicians in ways to enhance their whole-person approach to communication with patients and families about serious illness, "highlighting compassion and empathy, and the need for accurate information about prognosis, EOL, and the dying process."

Source: "Insights from Bereaved Family Members about End-of-Life Care and Bereavement," *Journal of Palliative Medicine*; Epub ahead of print, February 10, 2020; DOI: 10.1089/jpm.0467. Dana-Farber Cancer Institute; Phyllis F. Cantor Center for Research in Nursing and Patient Care Services, Dana-Farber Cancer Institute; Department of Psychiatry, Boston Children's Hospital and Brigham and Women's Hospital, and Harvard Medical School, all in Boston.

## ◀ DISCUSSING MEDICATION USE WITH DEMENTIA PATIENTS (from page 5)

**3. Addressing and working around barriers.** Clinicians worked to implement the principles of optimal prescribing in the face of challenges such as: behavioral and psychological symptoms of dementia; patient/caregiver expectations; discordance between clinician recommendations and patient/caregiver preferences, or between the patient and caregiver; and balancing disease-based guidelines against quality of life, treatment burden, and side effects.

The authors suggest that future research focus on the

development and testing of interventions that promote optimal prescribing for the growing population of older adults with dementia, and that efforts be made to create deprescribing conversation guides for clinicians.

Source: "How Clinicians Discuss Medications During Primary Care Encounters Among Older Adults with Cognitive Impairment," *Journal of General Internal Medicine*; January 2020; 35(1): 237–246. Green AR, Wolff J, Boyd CM, et al; Division of Geriatric Medicine and Gerontology, Department of Medicine; and Department of Health Policy and Management, Johns Hopkins University School of Medicine, Baltimore.

(THIS CONTENT IS NOT PART OF THE CME ACTIVITY)

### COVID-19 RESOURCES FOR PHYSICIANS

The American Academy of Hospice and Palliative Medicine ([www.aahpm.org](http://www.aahpm.org)) has gathered together a collection of links to websites of professional and palliative-care-related organizations offering guidance and tools to help physicians keep informed and connected as they respond to COVID-19. The sites include:

- **AAFP (American Academy of Family Physicians)** offers daily updates and preparation resources to support physicians' practices and patients in response to COVID-19. [www.aafp.org](http://www.aafp.org)
- **AMA (American Medical Association) Resource Center** provides updates on COVID-19, as well as a downloadable physicians' guide. <https://www.ama-assn.org>
- **CAPC (Center to Advance Palliative Care)** has made its toolkit of COVID-19 response resources—including scripts with specific phrases for communicating with patients and families—open to the public. <https://www.capc.org/toolkits/covid-19-response-resources/>
- **NHPCO (National Hospice and Palliative Care Organization)** maintains a webpage of COVID-19 resources and information, with an option for receiving updates by email. [www.nhpc.org](http://www.nhpc.org)
- **Twitter #pallivoid**; experts and other practitioners share valuable tips, tools, and personal insights regarding the care of COVID-19 patients and their families.
- **VitalTalk**, the training course in serious-illness communication skills, has streamlined its tips into a COVID-Ready Communication Playbook, available for download in English and seven other languages. [www.vitaltalk.org/guides/covid-19-communication-skills/](http://www.vitaltalk.org/guides/covid-19-communication-skills/)

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