

Palliative Care for People living with Dementia and Their Caregivers: Needs, Challenges, and Ideas to Improve Care

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BACKGROUND

UCSF is working to expand palliative care (PC) for patients living with dementia (PLWD) and their loved ones. We assessed needs and solicited feedback from PC providers and caregivers of patients seen at the UCSF PC service to assess impact and generate ideas to improve care.

METHODS

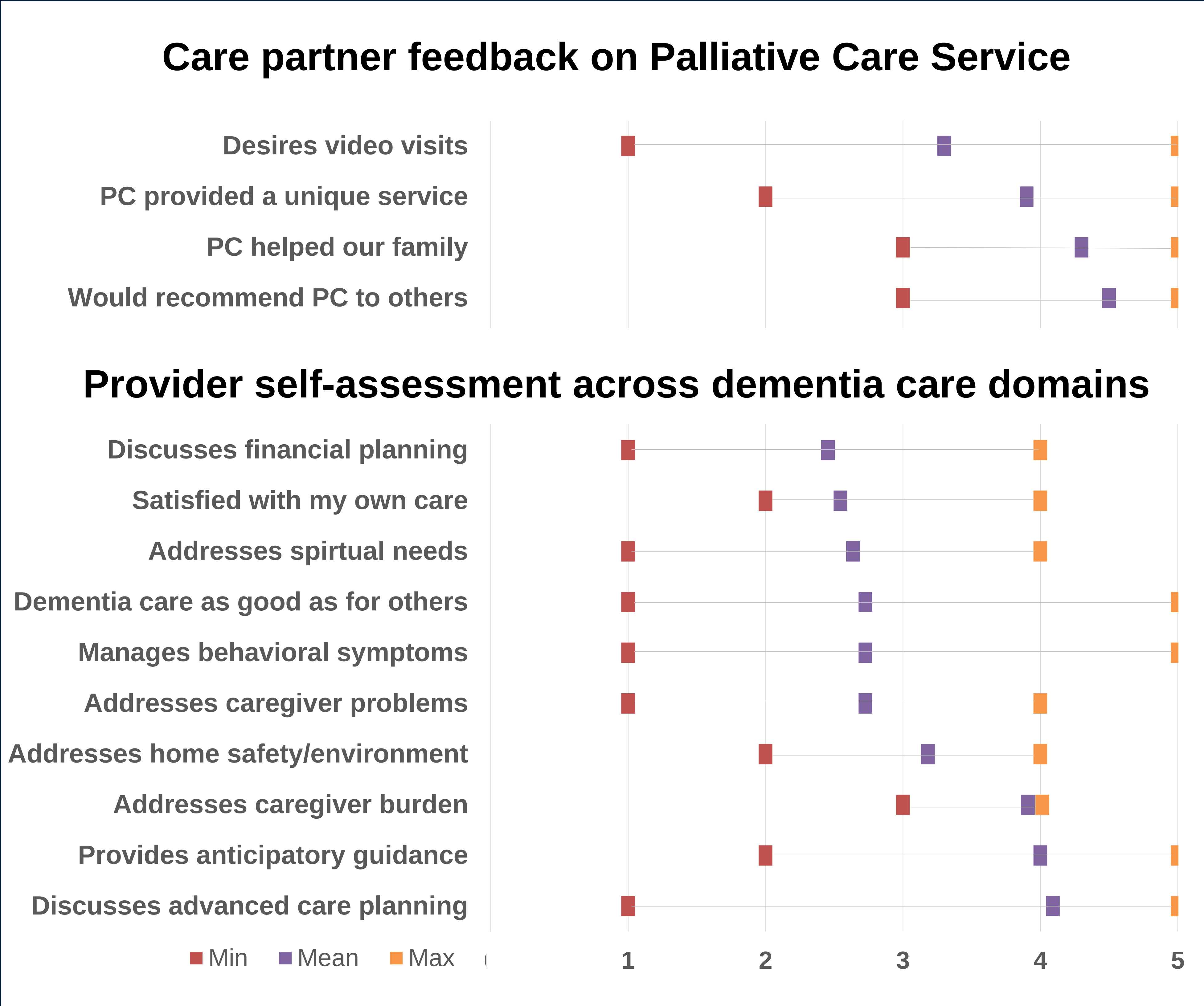
- Semi-structured telephone interviews with (n=10) caregivers of patients seen at UCSF palliative care Mar 22 – Mar 23.
- Needs assessment survey and one-time focus group with 12 PC providers
- Descriptive statistics for fixed responses; thematic analysis for open-ended answers

RESULTS

- Most care partners felt PC helped their family and would recommend to others
- Many felt it would have been better to start PC earlier in the illness course
- Growth areas include better communication around palliative care offerings, scheduling logistics, and shared decision making
- Many providers felt their formal training inadequately prepared them to care for this population
- Most providers felt they would benefit from a formal practice standard for how to approach care of dementia patients

Patient-families living with dementia benefit from palliative care but note ways to improve patient-provider communication and service delivery.

Palliative care providers want more dedicated training for dementia-specific care.



Answer choices were numerically coded from 1-5, descending from 5 = “Strongly agree”, to 1 = “Strongly disagree”



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SELECT PARTICIPANT QUOTES

“They are the kindest, most compassionate, attentive, present group of people... They’ve been an outstanding group and if there’s anybody I trust, it’s them.” – CP

“It might have been easier to maybe have met them a little earlier in our relationship... You know, to say, ‘we are here, you can engage us at this point, or here, or there, wherever you want to engage us. Because ... one day it just slapped both of us in the face, and then we didn’t know what to do.’” – CP

“Would like to have more contact with the doctors... more personal contact... and not at 4:30 in the afternoon.” – CP

“[In discussing transition to facility] they did not give me what I needed. Because their main focus is safety for both of us. So for them, safety was a facility where there was lockdown... my feeling was against all of that,” – CP

“I can just speak to medical training – it’s totally failed us. I don’t have any, any training in how to manage patients with dementia other than how to manage their delirium with Haldol and Seroquel in the hospital, which is actually horrifying” – PC Provider

DISCUSSION

Stakeholder perspectives are important to building a successful care program. This effort highlights several opportunities to improve PC for dementia and better support PC providers caring for PLWD and their loved ones.