Project Cornerstone: An Upstream Palliative Care Intervention for Rural and African-American Advanced Cancer Family Caregivers

Submitted by: University of Alabama at Birmingham (UAB)

Overview

High levels of burden among rural and/or Black caregivers is associated with distress in patients with advanced cancer. To address the gap in resources specifically designed for Black family members/caregivers of patients living with cancer, the UAB team developed and is currently testing <u>Project Cornerstone</u>. The Cornerstone intervention is led by specially trained lay navigators. It involves a series of weekly phone coaching sessions focused on helping caregivers developing skills in managing stress and providing effective support.

Project Cornerstone begins within 60 days of the patient receiving a diagnosis of advanced cancer and ends six months after the patient dies. The relationship between caregiver and navigator are maintained for that duration to establish a long-term, therapeutic alliance over time and across settings. The basic elements of the program are:

- 1. Lay navigator-led interactions, supported by regular supervision with a palliative care specialist
- 2. Six structured telephone/in-person sessions every 1-2 weeks for 20-60 minutes covering specific topics (e.g., stress management, self-care, and preparing for the future), followed by monthly check-in calls
- 3. A Project Cornerstone Family Support Toolkit that organizes intervention materials and contains educational key point information to complement the coaching sessions
- 4. Regular caregiver distress thermometer screening (used to identify and address any challenging experiences that may make it harder to cope with having cancer)

Impact/Data Outcomes

Early outcomes of the intervention are promising. In a small-scale, pilot randomized trial, the UAB team found that participants were very likely to recommend the program to others (average: 9.4 out of 10). Over 24 weeks of the program, intervention group caregivers were observed to report less anxiety and depression (however, these effectiveness findings are tentative; a fully powered trial is ongoing). Full impact data can be found here: <u>https://pubmed.ncbi.nlm.nih.gov/34874061/</u>

Feasibility

This intervention requires a 50-60 hour training program to ensure high-quality care from the lay navigators, particularly in the areas of coaching, behavioral activation, and palliative care. It also relies on specialty palliative care clinicians to regularly supervise and support the navigator coaches in addressing the complex needs of the caregivers.



Scalability

The initial phase of the project focused on piloting a small-scale, randomized clinical trial (RCT) with 63 family caregivers of rural-dwelling and/or Black patients with advanced cancer. The team is now testing Cornerstone in a larger trial to determine effectiveness and cost. If the program demonstrates benefit, this model of caregiver support could be widely implemented.

Sustainability

The current project is operating in a research setting, which includes grant funding from the National Institute of Nursing Research and the National Cancer Institute. One important consideration in the adaptation of this program to real world settings is how to pay lay navigators. The UAB team will be working on support to demonstrate the business case for this workforce. That said, with the palliative care workforce shortage, the use of lay navigators to support relationship building (while palliative care clinicians continue to manage symptoms) could help ensure a more comprehensive patient-centered experience.

Key Advice

- → High-quality, committed lay navigators are key to the success of the program. Be intentional in the recruitment and retention of your navigators, looking particularly for individuals who have experience, either personally or professionally, with working with individuals and families with cancer or other serious illness.
- → The intervention is geared towards 'meeting people where they are.' Caregivers will have a wide spectrum of different needs that can change over the course of their loved one's cancer. This means being committed to the principle of the program following individuals over the entire arc of the cancer trajectory.

Project Team

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