Bringing Value to Research: Engaging Patients and Caregivers in Palliative Care Research

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Patient and Caregiver Engagement

From the PCORI Methodology Standards:
Engage people representing the population of interest. (These) stakeholders...are expected to participate in the research, which may include:

- designing the study,
- selecting measures,
- enhancing subject recruitment,
- interpreting findings, and/or
- disseminating study findings.
A Compelling Reason to Include

“I can’t even imagine anyone thinking about creating a new and innovative system of care, with the goal of patient-centered medicine, and NOT including the patients. It’s ludicrous to me and definitely not congruent with what we are trying to do.”
--Patient
Study Advisory Committee
Recruitment

- Purposive sample of volunteers: 3 patients, 6 caregivers
  - 2 men; 7 women
  - 7 White; 1 Black, 1 Asian
  - Experience with cancer, dementia, CHF
- Identified via personal and professional connections and disease-specific organizations (e.g., local chapter of the American Heart Association).
- Also includes (informally) research team members with direct experience managing serious illness: 1 patient, 3 family caregivers
Task #1

• Are our interventions the right ones according to patients and caregivers?
  – Home! Home! Home!

• If our intervention was successful, how would we know?
  – What outcomes are important for patients and caregivers?
Specific Study Aims

Determine if:

#1 – HBPC improves patient physical and psychological wellbeing. Pain, symptoms, anxiety, depression, hope.

#2 - HBPC results in increased survival time.

#3 - HBPC reduces emergency room and hospital episodes.

#4 - HBPC improves communication between patients and health care providers.

#5 – Caregivers of patients receiving HBPC and those receiving EUC have differences in depression, anxiety, burden, post-death distress.
Engagement Strategies

Quarterly meetings of the Study Advisory Committee (SAC): 47 members representing patients, caregivers, providers, payers, advocates, research team
  – First hour: study business meeting
  – Second hour: Featured presentation by guest speaker drawn from SAC

Google discussion group: Started in April. To date: 34 SAC members, 14 topics posted, 108 total posts
The First GG POST

“I am having trouble coming up with a clear definition of palliative care…”

She cites a few textbook definitions of palliative care, including CAPC’s.

“I can follow the idea of relieving symptoms...and I can follow the idea of teamwork...but what I can't follow is what a patient or caregiver should expect when conditions are not textbook.”

-- Caregiver
A First GG Response

“As a terminally ill cancer patient, I'll share my experience with our hospital's palliative care.”

She recounts her experiences, then concludes:

“So, in my experience, palliative care has nothing to do with end of life issues (which I'm hoping are still off in the distance for me!) and has been solely about supporting me through my treatment.”

-- Patient
Ask the Experts

- Launched “Ask the Experts” consultations in July for participating healthcare partners.
- First question: How do patients and caregivers want to be approached for palliative care?”
Patients and Caregivers Respond

• **I would like hear** of it as a supportive service in addition to what is provided by the physician and his/her staff...

• **I don't want to hear** that: a. it is for end of life care; b. it means less access to the physician and his/her staff; c. there is not much which the physician can do from here on.

• **I need to hear** that my physician will be part of this team...and that...in the event of an emergency, I can call someone on the team 24/7 for guidance.

• **I need to know** the qualifications and experience of the people on this team...

-- Caregiver
Education as an Engagement Strategy

• Ad hoc teleconference presentations that address topics of special interest

• First: Definition of palliative care. The guest speaker was a CAPC consultant who discussed “reframing palliative care.”
A Stakeholder’s Response

“I think that people can be trusted to understand ‘palliative care’ if they are informed gently, thoroughly, with time to think over the definition of PC -- (I am still looking for a bumper sticker to supplement the "pain management" definition of PC).”

-- Caregiver
Final Engagement Strategies

• One-on-one telephone conversations
• One-on-one outreach by email

• These strategies are sometimes employed in response to two challenges that arise when involving patients and caregivers in research.
Stakeholders May Be Hesitant to Participate

“Thanks for allowing me to express my thoughts on palliative care. A lot of times in general, you don't hear it from a male perspective. Sharing my experiences gave me insights to understand it better & share it with our group”

-- Caregiver
Stakeholders May Be Emotional

“I just remembered the day we were in the emergency room, that the person came around reviewing what his wishes were and he asked to rescind his DNR, I looked up at him and asked why, his response was, “I have something to live for…..you.” As a point of truth and honesty, which is something you will always find with me, I’m trying to write this balling my eyes out, because this coming Thursday, will be a year since he passed away. That day in the ED was about 4 and a half years ago.”

-- Caregiver
A Dilemma

“In a recent group I participated in, there was a caregiver representative among researchers, executive leaders, leaders in the field, etc. I don’t think she was used to her highest potential and it saddened me. However, I also found it very difficult to include her in conversations, as she could not apply her personal grief and story about the loss of her husband to the change she wanted to see in the world.”

-- Research Team Member
Planning Contributions

• Helped identify patient and caregiver SAC recruits
• Identified meaningful outcome measures
• Reviewed drafts of proposal
Implementation Contributions

• “Ask the Experts” email consultations
• Role-playing patient and caregiver assessment with RA
• Sharing their experiences, insights, and recommendations regarding preferred practices. This feedback is being used to create educational materials for palliative care providers.
• Reviewing outreach and reporting materials.
• Contributing feedback for this presentation.
The Last Word...

The things I like about the experience as a stakeholder for the palliative care study is learning about challenges other caregivers are dealing with their loved ones. Also with healthcare staff trying to figure out how to address their patients’ needs in a more empathetic and supportive manner...I'm learning so much about it so I can share it with others going through similar experiences I've gone through in the past 2 years. I'm glad to be a part of this study.”

-- Caregiver
Conclusion

• Study aims identified by patient and caregiver stakeholders help to ensure interventions are well aligned with patient/caregiver needs
• Partnering with patients and caregivers provides an increased perspective of patient-centered care
• These partnerships also may improve sustainability of palliative care models
Questions?