

What's in This For You? What's in This For Me?: A Win-Win Perspective of Involving Study Advisory Committee Members in Palliative Care Research

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Abstract

Study advisory committees (SACs) provide critical value to clinical trials by providing unique perspectives that pull from personal and professional experiences related to the trial's healthcare topic. The Emergency Medicine Palliative Care Access (EMPAllA) study had the privilege of convening a 16-person SAC from the project's inception to completion. The study team wanted to understand the impact this project had on the SAC members. In this narrative, we use reflective dialogue

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to share SAC members' lived experiences and the impact the EMPallA study has had on members both personally and professionally. We detail the (1) benefits SAC members, specifically patients, and caregivers, have had through working on this project. (2) The importance of recruiting diverse SAC members with different lived experiences and leveraging their feedback in clinical research. (3) Value of community capacity building to ensure the common vision of the clinical trial is promoted.

Keywords

study advisory committee, palliative care, engagement, stakeholders

Introduction to the Issue

In clinical trials, study advisory committees (SACs) are often formed to provide unique perspectives and ensure that the patient experience remains at the focus of study objectives. To convene meaningful engagement, SACs are often comprised of a diverse group of members (eg, patients, caregivers, payers, clinicians, and policy advocates) from various backgrounds and have either experience participating in research or are familiar with research processes.^{1,2}

SACs provide immeasurable value as they bring forth the perspectives of diverse community members' attitudes and beliefs.³ They serve as a liaison between communities and academic researchers as they improve research by overcoming complex questions of research design and implementation.⁴ In partnership with research teams, SACs are often a sounding board and a critical voice in ensuring patient ethics, safety, and engagement are at the forefront of research design implementation and dissemination decisions.⁵

Research often cites the value SAC members add to individual studies^{6,7} but neglects to explore the breadth of impact that engaging in clinical trials as an SAC member has on individuals on the SAC.⁸

Key Factors for Consideration

The Emergency Medicine Palliative Care Access (EMPallA) study is a Patient-Centered Outcomes Research Institute (PCORI)-funded, pragmatic, two-arm, multisite randomized controlled trial of 1350 older adults (50+ years) with either advanced cancer or end-stage organ failure recruited during an Emergency Department visit, comparing nurse-led telephonic case management to facilitated, outpatient specialty palliative care. Patients and informal caregivers were recruited between March 2018 and July 2022, from 18 Emergency Departments across the United States. The primary outcome was a change in patient quality of life, as measured by a change in Functional Assessment of Cancer Therapy – General (FACT-G) from enrollment to 6 months. Secondary outcomes included healthcare utilization, loneliness, symptom burden and caregiver distress, quality of life, and bereavement. More details on this study protocol have been previously published.⁹ While the EMPallA study enrolled patients living with advanced-stage cancer, end-stage renal disease, congestive heart failure, and chronic obstructive pulmonary disease, the research team sought to convene a diverse group of patients, caregivers, payers, and policy advocates with a range of

experiences to provide a well-rounded perspective on study design, implementation, and dissemination.¹⁰ Details related to how the SAC was formed, meeting frequency, and the methodology for engagement with the EMPallA SAC have been published elsewhere.¹⁰

Throughout the research process, the study team identified not only the impact that members had on the study itself but also the life-long impact of this study that committee participation had on individual SAC members. During one of the routine research study team and SAC member meetings, all SAC members were asked how the EMPallA project has impacted them either personally or professionally. A small cohort of members decided to provide written testimonials. As such, using their own voices and quotes we share EMPallA SAC members' perspectives in participating in a six-year clinical trial.

I joined EMPallA SAC to gain a perspective on palliative care methods and to be a better advocate in the education process. I found the experience much more personal than I had anticipated. I was able to walk my ex-husband through the processes of palliative care because of my involvement on this committee. At the same time, I was able to help the research team thoughtfully develop the study design and intervention components.—SAC Member 1, Community Faculty, Health Educator, Caregiver.

It was because of the challenges of getting palliative care for my mother that I wanted to participate in this particular SAC. It allows us [SAC members] to advocate directly and indirectly for ourselves and people just like us, improves our sense of self-worth, gives us a purpose, and even helps us to communicate better with our own doctors and other medical professionals. At the University of Florida Shands Hospital, I am now a permanent member of the Patient Advisory Board, the Community Hospice and Palliative Care Coalition, and a sponsor of the Putting Families First educational programs.—SAC Member 2, Caregiver, Patient Advocate.

I joined this SAC serving as a liaison between community and academia. I never imagined that my role would change from professional to personal due to silent seizures. I have become a palliative care patient while working on this SAC. Not knowing about palliative care before joining this study, and still trying to accept the life changes with my new diagnosis, I began seeing that there were other people in my shoes and that I was not alone. I can communicate much better with my doctors and even my own daughter,

and I have learned how to accept help without feeling ashamed. I know I am in a better place mentally and emotionally because of the blessing to be on this study.—SAC Member 3, Patient, Community Liaison, Health Educator.

Participating as a palliative care SAC member helped me to develop and offer a support system to assist patients to live as actively as possible until death, as well as integrate the psychological and spiritual aspect of patient care.—SAC Member 4, Community Faculty.

Partnering with the EMPAllA researchers, nurses, and fellow colleagues has given me an opportunity to share my experience as an only child caregiver. I never looked at caring for someone you love as a job, but it does become complicated. Although I didn't recognize caregiving as a job, it is important to realize as a caregiver we must care for ourselves first and then our loved ones. Make sure you see your doctor. Let your family and friends know you need help. Take time for yourself to do these things so you can be a blessing to the ones you love. Researcher, Dr. Grudzen, has opened doors in public health, like this SAC, to help those in need.—SAC Member 5, Caregiver.

I work directly with Latino patients undergoing cancer treatment in clinical trials. I am a breast cancer survivor, who underwent chemotherapy and radiation treatment and that helps me understand fully the difficult moments that patients go through with this disease. I also took care of my father who died of lung cancer and I would have liked to have known that palliative care existed. I do my work with passion and dedication to the community. I am a community promoter on a variety of health topics including cancer care. There is a lack of knowledge in the Latino community when it comes to health topics and therefore a great need for my representation on the SAC to be able to deliver the information to people who need it. Being a member of the EMPAllA SAC has given me more knowledge about palliative care. It is a great need to have these [palliative care] services during difficult times. In our Latino culture we are very attached to our loved ones and palliative treatment is very helpful in these difficult times for both patients and family members. The Latino community is one of the most vulnerable and I sincerely thank this project as it's had a big impact on our Latino patients. It has positively benefited of our community.—SAC Member 6, Latino Community Promoter, Caregiver.

Recommendations

It is clear within clinical research that there is significant value in convening a SAC. However, researchers and clinicians often forget that there are tremendous benefits to our partnering SAC members as well, particularly when researching a sensitive health topic such as palliative care and serious illness.¹ Through our research project, we recognized that there was as much value to the researcher as there was to the patients/

caregivers being recruited and receiving the intervention and individual SAC members convened.

As SACs are often convened to enhance study design, implementation, and dissemination it is critical that research teams identify potential SAC members with a wide range of experiences, both professionally and personally. Since we convened a group of diverse individuals related to the clinical trials subject matter we were able to initiate deep conversations and develop strong connections. This allowed members to expand their horizons and absorb each other's experiences while collaborating across specialties.

Our routine study team meetings served as a venue for SAC members to network with other passionate researchers, community members, clinicians, and advocates, all with the same common goal. Creating a space for SAC members to develop interpersonal relationships beyond routine meetings encouraged personal and community growth and capacity building. People who would have never met otherwise created bonds strong enough to help each other through difficult personal struggles. This type of immeasurable impact cannot be ignored.

Future researchers and study teams collaborating with SACs should continually discuss, assess, and evaluate SAC engagement in an effort to ensure a strong mission (vision and commitment) driven relationship is fostered.

As researchers we need to remember that it shouldn't always be "what's in this for you/us?" (The research study/study team benefits), but also "what's in this for me?" (Benefits to the individual SAC members).

Conclusions

The benefits of having patients, caregivers, and community leaders involved in research are evident, but the impact on each of the individuals involved should continue to be explored. Research studies should continue to integrate SAC members in all stages of the research process. SAC members not only contribute an incredible amount of value to all portions of the research process but also in return are positively impacted in ways that often cannot be quantified, and the ripple effects can be enormous on communities.

Abbreviations

SAC	Study Advisory Committee
EMPAllA	Emergency Medicine Palliative Care Access
PCORI	Patient-Centered Outcomes Research Institute
FACT-G	Functional Assessment of Cancer Therapy – General.

Author Contributions

JBV: writing and editing; DR: writing and editing; RB: review and editing; GC: review and editing; PD: review and editing; RG: review and editing; EH: review and editing; EI: review and editing; CKG: writing and editing; MM: review and editing; MN: writing and editing; NRP: review and editing; WV: review and editing; SW: review and editing; PW: writing and editing; AYB: review and editing; KVA: writing and editing; AMC: writing and editing; RLY: writing and editing MF: writing and

editing; KSG: investigation and reviewing; CRG: conceptualization, investigation, supervision, funding acquisition, writing, review, and editing.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Disclaimer

All statements in this report, including its findings and conclusions, are solely those of the authors and do not necessarily represent the views of the Patient-Centered Outcomes Research Institute (PCORI), its Board of Governors, or the Methodology Committee.


Ethics Approval and Consent to Participate

This study was approved by the New York University School of Medicine Institutional Review Board (study ID s17-01211). Informed consent was collected for all study participants at the time of enrollment. Before March 2020, consent was written only, but during the COVID-19 pandemic, we obtained the ability to consent patients verbally, which was approved by the above Institutional Review Board.

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