

Abstract

Hospitals have leveraged the voice of their customers through Patient and Family Advisory Councils (FAC) to continually improve the quality of their care and services. FACs have not been widely adopted by hospice providers. Suncoast Hospice recognized the value in capturing the voice of the customer. With our commitment to human centered care, Suncoast Hospice formed a diverse committee of bereaved family members who could provide valuable input towards improving care. Since implementation, our FAC has helped identify emotional touch points of the care experience. This led to changes in clinical staff education regarding best practices before, during, and after a visit. Additionally, the FAC members created a check list of “when to call” to both guide and encourage overwhelmed caregivers on the importance of calling the hospice team for help. The FAC has become an integral part of Suncoast Hospice and has improved our care. We strive to create a culture where we are committed to seeking the unique and diverse perspectives of this committee and changing community.

Introduction

Hospices must constantly adapt to comply with changing regulatory requirements. It is not uncommon for organizations to make significant care delivery changes without consulting customers receiving services. Recognizing the potential risks involved in making changes without feedback from the most important stakeholders, Suncoast Hospice leadership began the process of developing our own version of a FAC. Our intention was to ensure that a patient-centered focus was primary with all major changes to our organization. From staffing models to the content of educational materials provided to family members, we wanted input from those affected most.

Materials

Early on we relied heavily on information from other healthcare entities. Beginning in late 2018, our Quality leaders gathered available guidelines and research on existing councils, such as Planetree International’s “Toolkit for Patient-Family Advisory Councils”, Advisory Board’s “Four Steps to an Effective Experience Advisory Council”, several guides from the Institute for Patient- and Family-Centered Care, and various materials shared with us by active PFACs locally and nationally. Our team also had the valuable experience of attending a local hospital’s FAC meetings.

Methodology

After several months of research, we identified our vision for an Experience Advisory Council. We decided on a Family Advisory Council (as opposed to a Patient **and** Family Advisory Council) due to the barriers involved with including hospice patients in a consistent and meaningful way. Additionally, we made sure to consider how grief and loss may impact a family member’s involvement in a council as we developed our application, charter, bylaws, and other structural materials. Our initial steps included recruiting staff members to assist with the council meetings and processes. In addition to our Quality department facilitator, we included a volunteer coordinator (as our council members are formally considered volunteers), a psychosocial professional to be available for support in difficult or emotional conversations, and

an administrative assistant for general council tasks such as meeting organizing, minute taking, and other administrative tasks.

Following development of our application and staff recruitment, we began the challenging process of recruiting council members that would provide the most effective and meaningful advising as well as represent the diversity of those we serve. Initial recruitment of our first council membership took approximately 3 months and remains ongoing as we continue outreach to underrepresented demographic groups. Interested volunteers completed a paper application as well as an interview. The Charter and Bylaws were completed in fall of 2019, with the first meeting scheduled for November of 2019--nearly 1 year after the decision was made to move forward.

Results

The FAC provided many valuable contributions, even when meetings were disrupted and adjusted due to COVID, including identifying the most significant “emotional touchpoints” of the care experience that were then used to modify our clinical staff education. They assisted with reviewing education and promotional materials and made recommendations to our Patient and Family Guide. They also offered feedback regarding possible web-based videos that would review available Hospice services. As a result, we added a “When to Call” list to our Patient and Family Guides that would direct and encourage overwhelmed caregivers to contact their hospice team in times of need. Our Council was consulted regarding the pros/cons of Tele-health visits with physicians and practitioners. The FAC also provided feedback on revisions to comfort medication educational materials and adjustments to the development of a new Evening/Weekend team staffing model, participated in a focus group for a community needs assessment, and gave guidance on barriers to acceptance of spiritual support. Our current meeting topic is focused on improving service delivery for our support programs (DME, Pharmacy, and Medical Supplies).

Conclusion

Our FAC provides an invaluable resource to our organization, allowing our leadership and staff to receive feedback directly from those who best understand the care impact. We get feedback in real time, not months later as with the CAHPS survey. This allows us to be proactive about our quality of care. Access to a dedicated group of customers committed and invested in the hospice care experience for their community is key to becoming a world-class care provider.

Recommendations

- Ensuring diversity and representation in the council can be one of the more challenging aspects of recruitment—start early and engage any/all resources available. The larger the pool of applicants, the easier it will be to select members that are both appropriate for the role and representative of your customer population
- Be open to innovation—working in unique healthcare setting such as hospice requires straying from the norm to meet the needs of those we serve. The care we provide isn’t “traditional”; an advisory council likely shouldn’t be either.

Suncoast Hospice Family Advisory Council

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Hospitals have leveraged the voice of their customers through Patient and Family Advisory Councils (FAC) to continually improve the quality of their care and services. FACs have not been widely adopted by hospice providers. Suncoast Hospice recognized the value in capturing the voice of the customer. With our commitment to human centered care, Suncoast Hospice formed a diverse committee of bereaved family members who could provide valuable input towards improving care. Since implementation, our FAC has helped identify emotional touch points of the care experience. This led to changes in clinical staff education regarding best practices before, during, and after a visit. Additionally, the FAC members created a check list of “when to call” to both guide and encourage overwhelmed caregivers on the importance of calling the hospice team for help. The FAC has become an integral part of Suncoast Hospice and has improved our care. We strive to create a culture where we are committed to seeking the unique and diverse perspectives of this committee and our community.

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Materials

- Planetree International’s “Toolkit for Patient - Family Advisory Councils”
- Advisory Board’s “Four Steps to an Effective Experience Advisory Council”
- Institute for Patient - and Family-Centered Care guides
- Local PFAC materials – Charters, Bylaws, Meeting Agendas, Meeting Minutes
- Attend existing local PFAC meetings

Methodology

- Identified need for council Fall 2018
- Outlined vision– decide to comprise council of family members only.
- Developed application, and later developed charter, bylaws, and other structural materials.
- Recruited staff members to assist with the council meetings and processes (Volunteer Coordinator, Psychosocial support, Administrative assistant).
- Recruited council members
- Applicant interviews conducted
- Held first meeting November 2019, continued bimonthly.

Results

Some of the outputs of the council to date:

- Reviewed educational and promotional materials for both staff and patients/families.
- “When to Call” handout created and added to Patient/Family Guide.
- Feedback on services, including Telehealth visits by physicians and practitioners.
- Development of new staffing models
- Participation in focus group regarding community needs assessment
- Advice on barriers to providing spiritual care
- Input on service delivery of support programs.

Leaders continue to consult the FAC for feedback and assistance with improving care and services.

Conclusion

Our FAC provides an invaluable resource to our organization, allowing our leadership and staff to receive feedback directly from those who best understand the care impact. We get feedback in real time, not several months later as with the CAHPS survey. This allows us to be proactive about our quality of care. Access to a dedicated group of customers committed and invested in the hospice care experience for their community is key to becoming a world -class care provider.

Recommendations

- Focus on diversity of members- widespread or intentional outreach may be necessary.
- Be open to innovation – hospice is a unique setting and can require modifying the “standard” to meet our needs.

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