Original Article

Patient and family advisory councils (PFAC) feedback as the voice of health care consumers

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Background: Throughout the U.S., healthcare organizations continuously find ways to incorporate patient feedback with efforts to advance the delivery of patient-centered care. Patient and family advisory councils (PFACs) can be used as a strategy to better understand and honor the patient experience and improve care delivery thanks to patient input to obtain patient perspectives. The importance of formal efforts to incorporate the patient perspective is highlighted by the Comprehensive Primary Care Plus (CPC+) program implemented by the Centers for Medicare and Medicaid Services which requires organizations to establish PFACs to receive funding. Site support for PFACs included a patient experience manager who oversaw recruitment and facilitated each clinic's council meetings. Other support personnel consisted of the practice manager, physicians, care coordinators, and advanced practice providers. This study employed a leadership framework to better understand how health care organizations use PFACs to discover and define patient/family advisors perspectives and how they can be related to different styles of leadership used within healthcare settings. Using contemporary leadership styles such as servant leadership, transactional leadership, transformational leadership, and leader-member exchange (LMX) theory, we examined perspectives of PFAC member's associated with leadership and its effect on their experience as a patient/family advisor. This study aimed to understand the patient/family advisor perceptions associated with the impact of PFACs and the decisions surrounding the academic medical center and how health care leaders can support these perceptions with the leadership styles outlined above.

Methods: We conducted a qualitative study of patient/family advisors serving on a PFAC within a Midwestern Academic Medical Center during the time of this study. Using a semi-structured interview guide, we conducted primarily individual in-person interviews. The interview guide addressed issues include the participant's understanding of patient engagement, experiences on the PFAC, what they valued from participation on a PFAC, perceptions of healthcare and impact on health outcomes. This manuscript examines an emergent finding related to the impact of leadership on PFACs and patient/family advisors.

Results: Nineteen participants were interviewed across five PFACs and four main themes were identified and linked to the leadership styles and PFAC involvement: qualities of leaders; seeking a 360 degree view of the patient experience; seeking focused feedback on specific AMC initiatives; and the importance of trust. Advisors appreciated leaders who were open-minded and focused on improving the patient experience. They also discussed ways in which their input reflected a comprehensive view of what patients experience that may not be easily observed by healthcare team members and leaders. In addition, they described how they provided feedback on specific initiatives within the healthcare system. Finally, they valued an environment within the PFAC that felt trusting and comfortable.

Conclusions: As health care continues to grow and improve, patient and family engagement techniques are

continually evolving. This study surrounding the experiences of patient/family advisors and PFACs can be used for further research and to gain a better understanding of this topic. This research presented patient/family advisors experiences, working together on patient family advisory councils with health care leaders, staff, providers, and managers, signaling the distinctive experiences of these participants which merits additional examination. There is further need for a meaningful discussion concerning the distinctive way doctors, providers and patients perceive the importance and meaning of medical encounters and patient and family engagement strategies.

Keywords: Leadership; patient family advisors; advisory council

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Introduction

Across the country, healthcare organizations increasingly seek to incorporate patient feedback into efforts to improve the provision of patient-centered care. Patient and family advisory councils (PFACs) are a common mechanism through which healthcare organizations can gain useful insights into the patient experience of current care provision and solicit patient perspectives about planned initiatives. According to Schlaudecker *et al*. [2019], "a PFAC is a group of patient and family members working together collaboratively with providers and staff to improve health care (1)". The Institute for Patient-and-Family-Centered Care additionally describes PFACS as contributing not only to patient care initiatives but also to research activities in the healthcare setting by providing input and offering patient-centered insights into the patient experience (2). While healthcare systems also utilize patient satisfaction surveys, PFACs offer a mechanism to receive real-time feedback that can be explored through conversation (3). Patient/family advisors' perceptions surrounding patient/family engagement and PFACs present a method to include both health care consumers and professionals to better understand ways to improve the overall patient experience and the relationships between patients, providers, medical staff, managers, and leaders.

Formally established in the 1990s and engaged informally for decades before, the development of PFACs became widespread after the Institute of Medicine identified patient-centeredness as one of the six aims of quality health care along with safety, effectiveness, timeliness, efficiency and equity (4). Given this focus, PFACs can help to institutionalize a partnership between hospital leadership, clinicians, patients, and families to improve care delivery. PFAC advisors share their perspectives as patients or family members of patients and provide input on hospital policies and programs; serve as a resource to providers, and promote relationships between staff, patients, and family members (5). PFACs also play an important role in promoting patient- and family-centered care, ensuring that patient needs and values are at the center of the care delivery system. Studies have highlighted the importance of involving patients and families with the engaged care processes within the healthcare industry.

More formal efforts to incorporate the patient perspective were established when the Centers for Medicare and Medicaid services required to primary care practices to establish PFACs as a part of the payment and delivery reform program, Comprehensive Primary Care Plus (CPC+). CPC+ is a primary care–centered five-year initiative started in 2017 which expands the concept of the medical home and seeks to strengthen payment reform (6). One area of focus was patient and family engagement which required primary care practices to establish a PFAC representative of their patient population which would meet on a regular basis to offer suggestions and feedback on practice initiatives. Practices meeting all requirements received additional payment incentives which could be used to support initiatives, such as development of PFACs, to address the programmatic areas. To date, over 3,000 practices have joined the CPC+ program, vastly expanding the number of PFACs across the country (7).

Effective incorporation of PFAC feedback relies on the support and engagement with healthcare organizational leaders (HCO leaders). While not typically a participant in a PFAC, these HCO leaders are critical in establishing, fostering and utilizing the input from PFACs. As they are responsible for managing the demands and limitations

of the organization they serve and meeting the needs of their patients, their approach to utilizing PFAC input may reflect a balancing of all of these goals. For example, early findings from CPC+ studies suggest that PFACs offer useful advice related to practice improvement that also seek to balance the impact of clinic staff (3). Additionally, PFAC member engagement with HCO leaders can increase trust in the feedback process (8). Others have found that clear communication with PFACs about the care delivery structure and healthcare system priorities facilitated more opportunities for quality improvement (9). While PFACs are generally run by a patient experience department member and not HCO leaders, given leaders' ability to implement changes based on PFAC feedback, individual HCO leadership styles are an important factor in how these leaders make decisions that incorporate the patient perspective.

Leadership styles such as servant leadership, transactional leadership, transformational leadership, and leader-member exchange (LMX) influence the ways in which PFACs engaged at the organizational level of health care systems to deliver more patient-centered care. Leaders exhibiting a servant leader style of leadership share power and focus on the helping employees develop to their highest ability (10). The Transactional leadership style is characterized by rewarding performance based on defined goals (11). Leaders who seek to present a vision for the organization and both expect and appreciate high performance (11). Finally, the leaders demonstrating a LMX style of leadership tend to develop high-quality, positive relationships with their employees, inspiring these individuals to engage in behaviors that exhibit trust and respect with each other and within the organization as a whole (12,13). Leaders are not limited to one leadership style and may use different styles of leadership dependent upon the goal or project in which they are engaging (14).

The leadership approaches embodied by HCO leaders help create awareness of patient/family advisors, and demonstrate to their organizations the importance of supportive systems that can share perceptions regarding policies and procedures within the organizational level of patient/family engagement. For example, servant leadership has been viewed by many organizations as a mechanism to help leaders become more ethical, effective, employee and customer focused (15). Transactional and transformational leadership styles may be applied when the organization draws upon patient family advisors to guide improvements within the institution and help shape cultural transformations. The LMX style describes the relationships between the leadership and patient family advisors and hearing the patient's voice.

While these leadership styles have been studied in multiple business domains, including individually in healthcare, their relationship to the functions of a PFAC has not been explored (16,17). To fill this gap, as part of a larger study of the experience of advisors serving on PFACs, we examined the perspectives of patient/family advisors members of advisory councils at an Academic Medical Center in the Midwestern United States to understand their perceptions related to the impact of PFACs on decisions made at the AMC and frame these perceptions within the leadership styles described above. We present the following article in accordance with the MDAR reporting checklist (available at https://jhmhp.amegroups.com/article/view/10.21037/jhmhp-20-112/rc).

Methods

Participants were selected from all patient advisors serving on any PFAC across a Midwestern AMC at the time of the study. The AMC operates a Patient Family Experience Advisor Program which includes five different patient/family advisory councils throughout the medical center focused on maternal and child health, cancer, behavioral health, and vulnerable populations as well as one PFAC addressing issues relevant to the entire AMC. Recruitment was facilitated by e-mail from the program director explaining the purpose, criteria, and the benefits and risks associated with the study. Advisors serving on any council were invited to participate. Participants were asked to email their responses or call with their intention to join within five calendar days. The first 20 people who responded were invited to join the study. The semi-structured interview guide addressed issues such as: definitions of patient family engagement, what has been most meaningful to patient's and families, perceptions of health care, and impact on health outcomes. While the impact of leadership style was not a explicitly included as an interview question, this theme emerged from advisors. Interviews were conducted primarily individually and in-person with a few participants choosing to be interviewed as a pair, and continued until saturation of themes was reached (18). Typically, interviews lasted approximately 45 minutes and were audio recorded and transcribed verbatim. The study was conducted in accordance with the Declaration of Helsinki (as revised in 2013). The study was approved by institutional review board of the Ohio State University (No.: 2016E0756) and informed consent was taken from all the patients.

Table 1 Demographics of the participants

Variable	Participants	Medical center PFAC
Female (%)	74	72
Age (average)	61.5 years old	62.2 years old
Race (%)		
White	95	95
Black	5	2
Other	0	2
Average years on PFAC	3.2	3.5
Average # of PFACs	1.3	1.1

PFAC, patient and family advisory council.

Data analysis

The research team developed a preliminary coding dictionary based on the interview guide. The team jointly reviewed two transcripts and compared coding, and revised the preliminary coding dictionary, following the method outlined by Constas (19). The coding team met regularly to review codes and add emergent codes as needed. These discussions also allow the coders to identify and resolve coding differences. The remaining transcripts were coded individually. Codes were continuously evaluated and refined during the process (20).

Results

A total of 19 PFAC advisors from multiple councils across the medical center participated in interviews. The demographics of the participant sample are provided in *Table 1*. Most participants were female (74%) and the average age was 61.5 years with a range of 35 to 74 years. With regard to number of years of experiences of the participants, of the 19 patient family advisors, 1 (5%) of participants have participated on the council for less than one year, 4 (21%) have participated for the entire length of the councils, 4 (21%) have participated on two different councils. In comparison, the representative of the interviewee sample was very similar to all PFACs across the med center. There were a total of 57 PFAC members, ages 34–81, 12 (21%) were male and 45 (79%) were female.

Qualitative findings

We identified four primary themes shown in *Table 2* related to leadership styles and PFAC participation: qualities of leaders; seeking a 360 degree view of what patients experience; seeking focused feedback on specific AMC initiatives; and the importance of trust.

Qualities of leaders

Participants identified openness to incorporating feedback from advisors and a genuine focus on improving the healthcare experience for patients. For example, one advisor told us, "*I would think an honest desire to educate us, to let us know what's going on and an openness to hearing our questions our concerns, I think some of them would have stayed there the whole hour if the schedule would have it. I can't think of any that seemed like they were forced to be there or they didn't want to be there or whatever.*" Another advisor described what they valued in a leader in this way, "*…the open line of communication is going on, but secondly, I guess they're always looking for ways to make it better for patients.*"

Seeking 360 degree view of the patient experience

Advisors described ways in which their input on PFACs offered leaders a more holistic view of the patient experience. One advisor described it this way, "*From a patient and family viewpoint, it's trying to see the umbrella of how patients interact with the hospital and where you can be of assistance to either guide them through or help assist them, it's kind of your role to make their experience here as good as we can make it.*" Another advisor highlighted the how advisors use the information provided to them at PFAC meetings to give their input, "*they really actually provide you with access to a lot more information, um, that enables you to maybe think differently about the experiences that you may have or experiences that others may have.*"

Providing focused feedback on specific initiatives

Advisors discussed ways in which they could offer feedback that was focused on specific hospital initiatives and the importance of receiving follow-up information to understand how their feedback was implemented in such programs. For example, one advisor related their experience on wayfinding signage, "*…when the [hospital] first opened, they had us tour it and pick out signage issues, because we didn't really know our way around, or just signage concerns we had.*" Related to the importance of follow-up information, one advisor described their view this way, "*There's been a huge shift for checking a better emphasis on the patent centered outlook, patient family outlook, and having worked on the councils for as*

Table 2 Leadership style and PFAC participation

Theme	Example quote
Qualities of leader	*"…the administration continuously to improve and they see this as a captive audience that could give them valuable perspective. And I think we're treated that way, with updates we receive and feedback, the opportunity to give feedback."*
	"You have to be able to move and adjust and improve and that I have heard from many leaders here and there willing to listen and they're willing to adapt."
	"I think to have the willingness to be open to, no, I think they have to admit, first of all, that they have to improve. In order to hear what people have to say, or to come to that level of acceptance, that, you know, hey we've got, even if you're good, even if you're good, to be better."
	"I think compassion and empathy. Like, you have to be a compassionate leader, not just of your people, but of the people that you're serving."
	"You have to be able to move and adjust and improve and that I have heard from many leaders here and there willing to listen and they're willing to adapt."
	"I think to have the willingness to be open to, no, I think they have to admit, first of all, that they have to improve. In order to hear what people have to say, or to come to that level of acceptance, that, you know, hey we've got, even if you're good, even if you're good, to be better."
360 degree view of patient	*"…they're just absolutely instrumental in the little teeny things that might otherwise shut down your day. For example, okay, a lot of patients come in here and they bring a cell phone with them that is fully charged, but they don't anticipate being here all day. So when they're on the phone calling everybody, and by the end of the day, they're running out of juice, one of the smallest things that I brought up in there, that I, that I saw just in the area I work in is charging cords. It's an easy, simple fix, but that is not something that, like, medical staff, when they're going about their daily work and trying to save lives, necessarily."*
	"It's commendable that people are stepping up and trying to address that because that is really difficult to quantify and I think that's kind of the idea behind advisory councils, depending on your personal experience, where the gaps, what could we have done better."
	"We tell them our experiences as patients ok and something they might not have been aware of. Like, Like I will frequently talk about sometimes I say sometimes when we are patients at the hospital, ok well we may be you know doing perfect and something like that and our experience is totally different I can't even remember my name. So you sometimes need to know where I'm coming from as a patient, so you know, they'll sit there and you can see them say oh, ok."
	"…they're just absolutely instrumental in the little teeny things that might otherwise shut down your day. For example, okay, a lot of patients come in here and they bring a cell phone with them that is fully charged, but they don't anticipate being here all day. So when they're on the phone calling everybody, and by the end of the day, they're running out of juice, one of the smallest things that I brought up in there, that I, that I saw just in the area I work in is charging cords. It's an easy, simple fix, but that is not something that, like, medical staff, when they're going about their daily work and trying to save lives, necessarily."
	"I like about the group is that it's eclectic; you know people on there have had different experiences. One might be a breast cancer survivor, one might be a bone marrow transplant, all kind of different perspectives and that's one of things that I value about that group. Cause no matter what issue comes, they're going to get lots of different feedback, across the board perspectives."
Focused feedback	*"Just sitting on a council, you know there's a lot of brainstorming and how we can make this better or what we can do to improve upon something however by the time it gets down through all the layers to really implement something it just takes a very long time that you know the point really is the one on one interaction with the patient and the family and you know the councils are great for advice however to actually implement they have to prioritize and things get very complicated with policies and procedures, logistics."*

Table 2 (*continued*)

Table 2 (*continued*)

Theme	Example quote
	"…it could be just a simple thing and we have to be able to be broad mined and open minded enough to understand all of the logistics and the layers but have to happen above to implement something that might make it better for patients and their families."
	"I really like the fact that they bring real life situations, real life people into us, to look for feedback."
	"They wanted to hear from the people who are actually getting stuck with procedures or having things happen and they want to know what these are so they can make positive changes. It's with the realization, yet again, it's a big organization, but they are not sticking their heads in the sand, they really are open and they are listening, they want improvement, they do want improvement."
	"I especially like the fact that they'll invite people who are in the process of reaching a goal and want input from us as part of reaching that goal it's not just here's what we did we hope you like it."
	"Just sitting on a council, you know there's a lot of brainstorming and how we can make this better or what we can do to improve upon something however by the time it gets down through all the layers to really implement something it just takes a very long time that you know the point really is the one on one interaction with the patient and the family and you know the councils are great for advice however to actually implement they have to prioritize and things get very complicated with policies and procedures, logistics."
	"We've seen with the follow up at our meetings that there is definite changes. Even the doctors who are more successful with their patients because of the feedback we have given them."
Trust	*"…you're building these relationships, like, you immediately already have something that, I think, is, is greatly in common, and that's having to do with something when you're very vulnerable. And that kind of binds a lot of people together immediately."*
	"So we all learned to you know to listen to each other, right we've all learned to listen to each other."
	"… the council members have to listen as well because this is a to me this is a collaborative effort were building on each other's ideas and the idea that comes up pit of 3 peoples statements is better than the previous 3 individuals."
	"…you're building these relationships, like, you immediately already have something that, I think, is, is greatly in common, and that's having to do with something when you're very vulnerable. And that kind of binds a lot of people together immediately."
	"I think what I find so impressive is the level of hospital leadership that is involved in the council. And the obvious desire to put everything through the lens of the patient."

PFAC, patient and family advisory council.

long as I have, it's even nicer to see here are some issues, and we get a response back from the university and they say because of your input we have taken it to this council. And this council has said this is what we are going to change. And this is how we've changed it. So it's very empowering."

The importance of trust in a PFAC environment

Several advisors described the importance of developing trust and how leadership can create an open environment to allow advisors to feel comfortable giving honest feedback. As one advisor stated, "*I think when you have really, really good leadership, at some point, because of what you do, you get credibility. And the credibility is what goes a long, long way to shaping the culture.*" This trusting environment allowed everyone to feel empowered to comment, as evidenced by one advisor's comments, "*They are listening to us they ask our opinions about where the entrances should be, how they should be marked where the volunteers should be where the gift shop should be. They are asking our opinion and there is nobody in that room that won't give it. And that's amazing to me. No one in the room to me is hanging back.*"

Discussion

To create change, health care leaders must be able to successfully lead patients, individuals and families within

health care organizations, and various stakeholders (21). As efforts across the healthcare system have focused on changes that increase patient-centered care, PFACs have become a critical tool through which the patient/family advisors' voices can be incorporated into healthcare leaders' efforts to provide more patient-centric care. While leadership style was not an explicit question in our interviews, advisors in our study discussed several ways in which AMC leadership has taken the feedback on initiatives including a quiet at night initiative which included new policies for closing doors on some of the hospital floors and units, turning reducing fire alarm sounds, quieting machines in the rooms, having the nursing team congregate around their computers instead of the hallways, and regular checks on equipment for squeaky wheels. In addition, our advisors discussed PFAC suggestions incorporated into the development of new buildings designs including virtual tours with the development team to make suggestions or improvements to building designs.

While advisors in our study appreciated the opportunity to provide this type input, they also discussed the impact of healthcare organization leaders on both the extent to which their input was utilized and how such results were relayed back to them. In this context, the leadership styles described above provide a useful framework to understand how HCO leaders utilize PFAC feedback. For example, transformative leadership styles can make use of this input to create shifts in the paradigm consisting of collaboration between health care professionals and consumers, creating and supporting exchanging ideas while setting expectations and clarifying needs (22). In this situation, advisors may feel they contributing to creating change not only for others but for themselves as well and the reward of volunteering may generate a feeling of contributing to the organization, creating loyalty and commitment to the organization. Transformational leadership style which understands the advisors needs, stimulates and inspires the advisors level of satisfaction with their services may help to foster these feelings of connection and commitment in advisors. In this way, leaders who seek a 360 degree view of the patient, as described in our findings, may improve the connection within PFACs. In contrast, when advisors provide more focused input for specific healthcare system initiatives, transactional leadership may be more applicable because of its focus on short term goals, policies, and procedures. In this situation, advisors in our study, for example, discussed the transactional nature of their work within a healthcare organization and stressed the importance of closing the loop with advisors and allowing them to realize the impact of their advice.

Trastek *et al*. discuss ways in which a servant leadership approach may be best equipped to help improve the overall patient experience (20). By considering the needs of patients and family members, servant leaders can help to create changes in the organization and in the patient-provider relationship. LMX style can be used when medical leaders and patient family advisors are working together. The model of LMX suggests that leaders do not use the same styles or set of behaviors consistently with all employees (22). Many followers work within organizations where everyday directions and employee evaluations come from different leaders and the various quality of those relationships affect job satisfaction and employee turnover (23). In both of these styles, trust is a critical component. Advisors in our study noted the importance of a trusting relationship in creating a space in which they felt free to express their views and that their views would be taken seriously.

Finally, as is the case in many PFACs across the country, we identified a lack of diversity among our respondents as well as in PFACs across the AMC (24). This is a critical issue that HCO leaders are well positioned to address, regardless of their leadership style. Patients who are geographically isolated in remote or rural places, sexual-and gender-diverse populations, racial and ethnic minorities, low-income and low-literacy populations, and older adults may be less likely to serve on PFACs (25). Exclusion of these groups from PFACs may create priorities that may not be designed, implemented, or disseminated in a way that includes their perspectives (25). Further, research may not be generalizable to these diverse groups and detailed findings that are applicable to these groups may be missed (26). Finally, a focus on diversity helps to ensure that selection of PFAC members is less susceptible to the preferences of leaders. Increasing diversity and representativeness of PFACs is critical to any discussion of leadership efforts to ensure that all voices are heard in our efforts to increase the patient-centeredness of care (3). While servant leader, leader member exchange and transformational approaches place a strong focus on connection and relationships which may foster a PFAC environment in which all members feel comfortable speaking up, transaction styles that address particular initiatives and allow PFAC members to observe the results of their work can increase members' trust that HCO leaders want to address their concerns. We view increasing diversity among PFACs as a critical issue and should be considered the responsibility of all leaders.

Limitations

This study is limited in that the data only represents the patient/family advisors perspectives from one Academic Medical Center. Other healthcare systems may have different structures for PFACs and have different experiences. However, other PFACs in the AMC have been functioning for over 10 years and therefore reflect a strong commitment from medical center leaders and a well-established relationship on which participants in our study could offer their perspectives.

Conclusions

As health care continues to develop, patient and family engagement techniques continue to evolve, this study of the experiences of patient/family advisors and patient family advisory councils which can be utilized for further research and understanding of this topic. This research presented the experiences of patient/family advisors, working on patient family advisory councils with health care professionals, providers, managers, and leaders and signals the unique experiences of these individuals which warrant additional investigation. In addition to researching the individual experiences of patient/family advisors and their perceptions with patient family advisory councils and medical staff, incorporating best practices from the patient and family perspective might inform health care organizations on ways to improve the overall patient experience with patient/family advisors and patient family advisory councils. There is a further need for a meaningful discussion concerning the distinctive ways doctors, providers and patients perceive the importance and meaning of medical encounters and patient and family engagement strategies.

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