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11-5-2021

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Recommended Citation


Montalbano A, Chadwick S, Miller D, et al. Demographic Characteristics Among Members of Patient Family Advisory Councils at a Pediatric Health System. *J Patient Exp.* 2021;8:23743735211049680. Published 2021 Nov 5. doi:10.1177/23743735211049680

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Demographic Characteristics Among Members of Patient Family Advisory Councils at a Pediatric Health System

Journal of Patient Experience
Volume 8: 1-6
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Article reuse guidelines:
sagepub.com/journals-permissions
DOI: 10.1177/23743735211049680
journals.sagepub.com/home/jpx


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Abstract

Patient Family Advisory Councils (PFACs) are groups of patients, families, and clinical health system leaders collaborating to improve the quality, safety, and experience of care. Best practices encourage PFAC membership to reflect the diversity of the communities served. A cross-sectional survey was conducted from September 2019 to January 2020 collecting demographic characteristics of the members of a pediatric health system's 17 PFACs. Of the 93 respondents (71.5%), notable inequities were racial (4.8% adult PFAC members vs. 17.4% patients were Black) and financial (adult PFAC median annual income was >\$100,000 compared to the community median \$77,589). The governing family advisory board used this information to codesign interventions to achieve the ideal state of inclusive excellence by identifying barriers for participation for the Black community, recruiting and retaining diverse board members, and continuous monitoring to maintain a diverse board representation.

Keywords

diversity, inclusion, recruitment, family advisory board, patient family advisory councils

Introduction

Patient family advisory councils (PFACs) are formal groups of patients, families, and health systems, and clinical leaders who meet regularly to collaboratively improve the quality, safety, and experience of care. Research shows that patients and families who actively engage with their health care teams have better outcomes, often choose less expensive options when participating in shared decision-making, and express greater satisfaction with their health care experiences (1,2). While the evidence is clear that patients and families need to be engaged in their care to achieve better individual outcomes, their voice also needs to be present at the executive level of health care decision-making to impact processes and policies that affect all patients and families. "A learning health care system is anchored on patient needs and perspectives and promotes the inclusion of patients, families, and other caregivers as vital members of the continuously learning care team" (1). The philosophy of patient- and family-centered care guides health care organizations to collaborate with patients and families as they are the experts on the experience of actually receiving care.

Recognizing the need to create an opportunity to learn of the realities of patient experiences, the first PFAC established in our pediatric health system was the Teen Advisory Board in 1999, comprised of patients 13 to 18 years of age. The Family Advisory Board (FAB) was established in 2003 to close the gap in collaborating with caregivers of patients. Recognizing the need to infuse the perspective of non-English speaking populations, El Consejo de Familias Latinas y Hispanas ("Consejo") was formed in 2008. Following the success of these 3 groups, additional PFACs were created to have various membership requirements

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such as a diagnosis (eg, cystic fibrosis), certain demographics (eg, medical complexity), or experiences of care (eg, neonatal intensive care use). Best practice guidelines set out by the Institute for Patient- and Family-Centered Care encourage ongoing recruitment strategies to ensure that PFAC members reflect the diversity of the communities served (3). The governing FAB expressed a concern of perceived homogeneity in volunteer members, but this had never been quantified.

The primary aim of this project was to assess demographic characteristics of patient and family advisory council members compared to the population of patients served at a Midwestern pediatric health system and contextualized using summary demographics of the immediate service area community.

Description

The Patient and Family Engagement (PFE) team who supports the facilitation of all PFACs, including the governing FAB, partnered with researchers in Health Services and Outcome Research to develop a research plan to administer an assessment of the demographic characteristics of PFAC members. In evaluating the current state, critical race theory was used as a framework to identify environmental and predisposing factors that were contributing to the current state, modifying factors that needed to be embraced to reach the aspirational goal, and the interventions needed to achieve inclusive excellence (4) (Figure 1). Three tenets of critical race theory were hypothesized to be contributing to the current state. First and foremost, systemic racism created an institutional bias where inequities result regardless of the good intentions of the individuals within the institution. The institution's policies and actions represented the views, needs, and culture of those who are empowered, creating a centrality of whiteness. The inequities were exacerbated by the cultural mismatch of the empowered racial and ethnic groups providing the feedback to the institution and those of greater racial and ethnic diversity who are using its services. A large portion of those served by the institution are of racial or ethnic minorities, and their social determinants of health may not be met by the institutional policies advocated for by the representatives of the current board.

Methods

Participants

All 130 members from the 17 PFACs were invited to participate. Some members were involved in more than one PFAC; however, they were only allowed to submit one response.

Design

Researchers, members from the PFE team, and FAB workgroup members collaborated to develop the Demographic PFAC survey in English. The survey was subsequently

translated into Spanish. To promote trust and confidentiality, the survey was introduced by the PFE team, but the actual invitation to participate was then sent to the members via email from a member of the Health Services and Outcome Research Team. For the Spanish-speaking council, Consejo, members were given the time to complete the survey during a scheduled meeting. For those not present, the survey was sent via email in Spanish. The 3 teen councils also completed the survey during a normally scheduled meeting. One month after the survey was emailed to PFAC members, the PFE team sent a reminder via email with the link to the survey asking members to complete the questionnaire if they had not done so already. The email also listed all the PFACs with the percentage of completion for each group.

Survey Measures

Adult council members completed a survey regarding demographic characteristics including age, race, ethnicity, education, preferred language, health insurance type, household income, marital status, number of children, and children's health status (Supplement). A shortened survey that did not include questions about children, household income, or marital status was completed by teen council members. Additional questions about their satisfaction with their contributions as a PFAC member and interest in participating in the research were also collected, but not reported here.

Analysis

Data collection was carried out from September 2019 to January 2020. All responses were collected and managed using REDCap electronic data capture tool (5,6). To preserve council member anonymity, all data collection and analysis were conducted by the research team, and only aggregate data was reported to the PFE team and the PFAC members. All analyses (frequencies and percentages) were completed in March 2020 via IBS SPSS Statistics software (7). Data from patient and family council members were compared to the demographic characteristics of the pediatric health system's patient population (8,9) and surrounding service area (10,11). Only one completed survey per member was included in the analyses to prevent duplicate responses (eg, members of multiple advisory councils). This project was deemed nonhuman subjects research by the institutional review board.

Results

Participants

Seventy-two percent of the 130 council members completed the survey ($n = 93$, 10 teens and 83 adults). The median age for council members was 16 years (interquartile range [IQR] 15, 17) for teens and 41 years (IQR 37, 49) for adults. The demographics of the adult members are displayed in

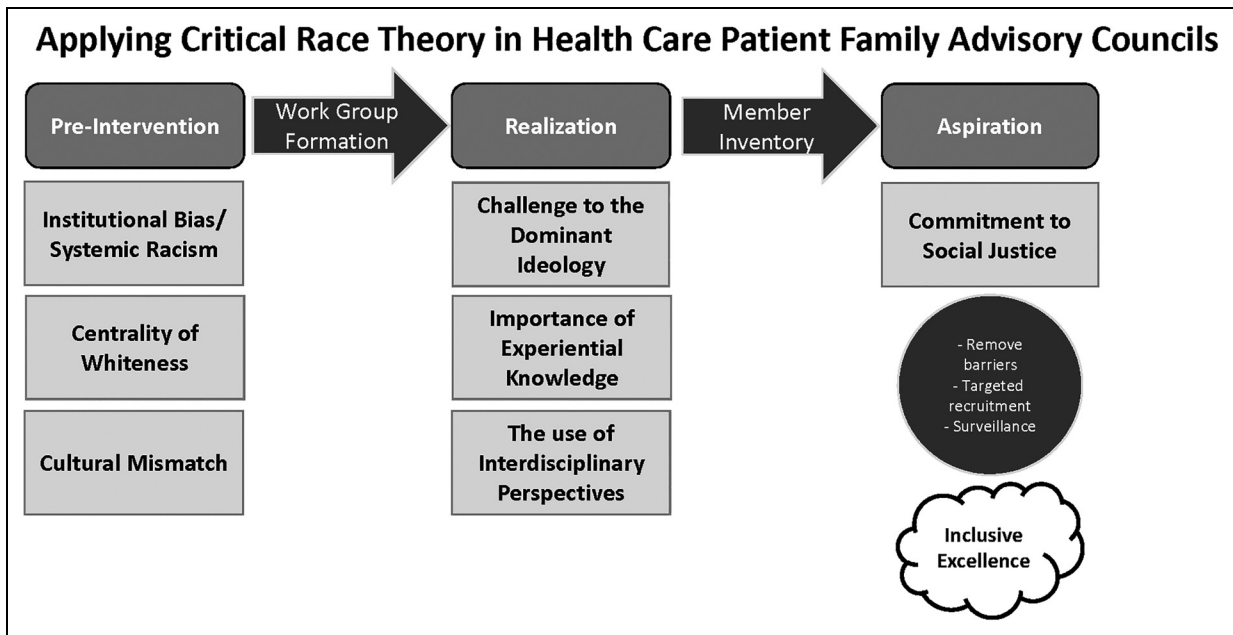


Figure 1. Applying critical race theory in health care patient family advisory councils (PFACs).

Table 1. Most adult council members were female (83.9%), reported having an undergraduate degree or higher (78.3%), being married (90.4%), and having a household income of at least \$100,000 annually (56.6%). Most adult council members (91.6%) reported having a child with a special health care need.

Table 1. Demographics of Adult Council Members.

	N = 83 (%)
Age (median, interquartile range)	41 (37, 49)
Gender	
Female	78 (93.9%)
Education	
Some high school or below	4 (4.8)
High school degree or general equivalency diploma	4 (4.8)
Post high school training or some college	10 (12.2)
Undergraduate degree	44 (53.0)
Graduate degree	21 (25.3)
Employment status	
Full-time	39 (46.9)
Part-time	11 (13.4)
Stay at home caregiver	24 (28.9)
Other	9 (10.7)
Marital status	
Married	75 (90.4)
Living with partner	2 (2.4)
Divorced	6 (7.2)
Household income	
<\$50,000	10 (12.0)
\$50,000-\$74,999	14 (16.9)
\$75,000-\$99,999	7 (8.4)
Over \$100,000	47 (56.6)
Prefer not to answer	5 (6.0)

PFAC Member Demographics Compared to the Patient Population

Table 2 compares the demographics of the PFAC representatives with the patient population. The PFAC members were mostly White/Caucasian (70% teen and 84.3% adult) and identified English as their preferred language (100% teen and 91.6% adult). All but one of the 13.3% of adult council members who identified as Hispanic or Latino and the entire 8.4% who indicated Spanish as their preferred language were members of Consejo. Compared to patients of the pediatric health system with 17% identifying as Black/African American and 12% Hispanic/Latino, council members reported less gender, racial, and ethnic diversity. Most PFAC members had private health insurance for their children (80.7%) compared to only 44.2% of the health system’s patient population.

Discussion

The survey of PFAC members provided demographic information allowing targeted recruitment to better reflect the demographics of the patients in our service area. To contextualize our PFAC demographic results, we used data from the Mid-America Regional Council and the 2019 Community Health Assessment for the leading service areas of our institution (10,11). From July 1, 2017, to June 30, 2018, 69.7% of all encounters served families from a 4-county region: Jackson and Clay counties in Missouri and Johnson and Wyandotte counties in Kansas; whereas, 77.2% of our PFAC members were from this region (10). While there is significant variation of the socioeconomic make-up among the populations in these 4 counties, our PFAC respondents

Table 2. Demographics of Survey Respondents Versus Patient Population.

	Patient family advisory council (PFAC) representatives		Patient population (n = 754,506)
	Teen (n = 10)	Adult (n = 83)	
Race			
American Indian/Alaskan Native	0.0%	1.2%	0.3%
Asian	10.0%	0.0%	2.2%
Black/African American	20.0%	4.8%	17.4%
Native Hawaiian/Pacific Islander	0.0%	0.0%	0.3%
White/Caucasian	70.0%	84.3%	58.6%
Other	0.0%	8.4%	2.8%
More than one race	0.0%	0.0%	5.9%
Prefer not to answer	0.0%	1.2%	n/a
Ethnicity			
Latino/Hispanic	0.0%	13.3%	12.6%
Preferred language			
English	100.0%	91.6%	92.0%
Spanish	0.0%	8.4%	6.6%
Somali	0.0%	0.0%	0.4%
Arabic	0.0%	0.0%	0.3%
Burmese	0.0%	0.0%	0.2%
Vietnamese	0.0%	0.0%	0.2%
Child's health insurance type			
Private/commercial	n/a	80.7%	44.2%
Medicaid/medicare	n/a	13.2%	48.6%
Other (self-pay, military, PNTA)	n/a	6.0%	7.2%

had higher undergraduate and graduate degree attainment than even the highest recorded for the community (44% and 21% PFAC compared to Johnson county's 33.6% and 19.3%, respectively) (11). In the Community Health Assessment representing the same 4-county region, 24.8% of respondents were divorced/separated, not reflected in our PFACs with 90.4% of the representatives currently married (10). Another mismatch was median household income when comparing PFAC versus community demographics. Most PFAC respondents (56.6%) reported an income over \$100,000 a year compared to the community median of \$77,589 which is largely augmented by the higher median income found in Johnson County, Kansas (10).

In comparing the racial demographics of PFAC members with the patient population, Black patients were largely underrepresented (17.4% patients vs. 20% teen and 4.8% adult PFAC members). It should be noted that the respondent demographics were of only one caregiver in the patient's household and do not necessarily reflect the racial or ethnic

diversity of their child or other members in the household. While ethnicity and language were fairly well matched, this was largely due to the Spanish-speaking advisory council. There have been previous attempts to encourage a Spanish-speaking representative to join the FAB or other PFACs; however, they have voiced their preference to meet within Consejo and have their feedback provided to the organization by the staff representatives on the Council.

From the few reports available in the literature, there is consensus around the importance of diversity and representation of PFAC members for the communities the organization serves. In a focus group of non-PFAC members from an accountable care organization, participants endorsed that PFAC members should be willing to escalate concerns from the community, and the "who" was central to succeeding in the "what" the PFAC could accomplish (12). The definition of diversity was broad: not just demographic diversity, but also in health status and experience with the health care system. In an opened-ended question about challenges on a survey of New York State hospitals, 40.3% of all survey respondents acknowledged that the PFACs of New York State hospitals were not diverse with regard to socioeconomic status; and almost 25% of those with lower scores for patient and family engagement reported recruitment barriers (13).

There are multiple limitations to this single-institution socioeconomic demographic study. The data does not elucidate demographic differences between survey respondents and nonrespondents. Demographics of all caregivers in the PFAC member household were also not captured on the survey. For the majority of the PFACs, the survey was distributed electronically to overcome sampling only those in attendance at a particular meeting, but this method may have inhibited individuals from responding if they do not frequently use email or have reliable internet access. Teen councils and Consejo were surveyed in person to overcome that limitation. The sensitive nature of the data elements may have prevented some PFAC members from responding. The PFE team attempted to mitigate this response bias by protecting the anonymity of the respondents, using the Health Services and Outcome Research team to collect and manage the data. The specific demographic findings of this particular pediatric health system may not reflect other care systems, and the strategies for PFE may differ from general or adult-only facilities; however, the methods shared here can be replicated by any health system to collect information about their patient and family advisors.

Transparency about the disequilibrium between the racial and socioeconomic demographic composition of our PFAC members and our community was an important opening dialogue to achieving a diverse and representative voice to collaboratively work with hospital leadership to improve the quality, safety, and experience of care. We have presented aggregate results to our governing FAB who used this information within their workgroup to codesign interventions for targeted recruitment and retainment of diverse patient and

family representatives, specifically identifying barriers for participation with our Black community members. The move to virtual meeting platforms mandated during the Covid-19 pandemic may also remove barriers for participation and allow for the recruitment of families outside our immediate service area. The study of our PFAC member demographics was the first concrete step in measuring our inclusiveness of voice, and we are dedicated to the regular evaluation of our PFAC membership.

Conclusions

This project demonstrated the commitment to social justice to reach our aspirational goal of inclusive excellence, but we understand that we still need to remove barriers for those of diverse backgrounds to participate, have targeted recruitment in underserved communities to diversify membership, and continue to survey members to maintain a diverse voice. Critical race theory was used to introduce the concept of how systemic racism impacts PFACs. While unintentional, the cultural mismatch of empowered advisors and the populations served can contribute to institutional bias by influencing policies and procedures that can further alienate underrepresented minorities. Once an understanding of these realities is established, health system leadership can work in collaboration with advisors to administer an assessment to capture the demographic inventory of the current state. Advisor demographics can be compared to the current population of patients served by the organization, as well as the community at large. Objective goals and strategies should be codesigned with the advisory council to reach the aspirational goal of diverse membership focused on social justice and inclusive excellence to improve the quality, safety, and experience for all patients and their families.


Declaration of Conflicting Interests


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


Funding

The authors received no financial support for the research, authorship, and/or publication of this article.

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Supplemental Material

Supplemental material for this article is available online.

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