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Lauren N. Brinkman
Cincinnati Children's Hospital Medical Center, lauren.brinkman@cchmc.org

Myra S. Saeed
Cincinnati Children's Hospital Medical Center, msaeed1014@gmail.com

Andrew F. Beck
Cincinnati Children's Hospital Medical Center, andrew.beck1@cchmc.org

Michael C. Ponti-Zins
Cincinnati Children's Hospital Medical Center, Michael.Ponti-Zins@cchmc.org

Ndidi I. Unaka
Cincinnati Children's Hospital Medical Center, Ndidi.Unaka@cchmc.org

See next page for additional authors

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Cover Page Footnote

We would like to thank the thousands of families and patients who took the time to give us feedback on their care and experiences, without which this study would not be possible. This article is associated with the Policy & Measurement lens of The Beryl Institute Experience Framework (https://www.theberylinstitute.org/ExperienceFramework). You can access other resources related to this lens including additional PXJ articles here: http://bit.ly/PX_PolicyMeasure

Authors

Lauren N. Brinkman, Myra S. Saeed, Andrew F. Beck, Michael C. Ponti-Zins, Ndidi I. Unaka, Mary C. Burkhardt, Jareen Meinzen-Derr, and Samuel P. Hanke

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Research

Sociodemographic characteristics and patient and family experience survey response biases

Lauren N. Brinkman, *Cincinnati Children's Hospital Medical Center, lauren.brinkman@cchmc.org*
Myra S. Saeed, *Cincinnati Children's Hospital Medical Center, myra.saeed@cchmc.org*
Andrew F. Beck, *Cincinnati Children's Hospital Medical Center, andrew.beck1@cchmc.org*
Michael C. Ponti-Zins, *Cincinnati Children's Hospital Medical Center, Michael.Ponti-Zins@cchmc.org*
Ndidi I. Unaka, *Cincinnati Children's Hospital Medical Center, Ndidi.Unaka@cchmc.org*
Mary C. Burkhardt, *Cincinnati Children's Hospital Medical Center, Mary.Burkhardt@cchmc.org*
Jareen Meinzen-Derr, *Cincinnati Children's Hospital Medical Center & Univ. of Cincinnati, jareen.meinzen-derr@cchmc.org*
Samuel P. Hanke, *Cincinnati Children's Hospital Medical Center, Samuel.Hanke@cchmc.org*

Abstract

Enhancing Patient and Family Experience (PFE) is vital to the delivery of quality healthcare services. Sociodemographic differences affect health outcomes and experiences, but research is limited on biases in PFE survey methodology. We sought to assess survey participation rates across sociodemographic characteristics. This retrospective study analyzed a health system's ambulatory PFE survey data, collected January 1 – July 31, 2019. Outcomes of interest were rates of survey response, completion, and comments. Predictors included respondent-reported race, ethnicity, language, and measure of social deprivation attached to a respondent's home address. Addresses were geocoded to census tracts. The tract's degree of socioeconomic deprivation was defined using the Deprivation Index (DPI). Associations between outcomes and predictors were assessed using the Chi square test. 77,627 unique patient encounters were analyzed. Patients were predominantly White (76%); 5% were Hispanic; and 1% were Spanish-speaking. The overall response, completion, and comment rates were 20.1%, 17.6%, and 4.1%, respectively. There were significant differences across assessed sociodemographic characteristics in response, completion, and comment rates. White patients were most likely to respond, complete, and leave a comment. Spanish-speaking respondents and those living in the most deprived areas were more likely to respond and complete the survey, but less likely to comment than English-speaking respondents and those living in less deprived areas, respectively. PFE survey participation differs across a range of sociodemographic characteristics, potentially introducing noteworthy biases. Health systems should minimize differences in how they collect feedback and account for potential biases when responding to experience data.

Keywords

Measurement, patient experience, pediatrics, survey response bias, social determinants of health

Introduction

Patient and Family Experience (PFE) surveys are used by healthcare organizations to assess perceptions of healthcare delivery and quality within their systems. However, survey participation biases may affect survey results and should be considered during interpretation. For instance, patients' and families' response rates vary based on their perceptions of a provider or experience. Additionally, while a single patient may score a provider or experience similarly across multiple questions, ratings may differ considerably from patient to patient, or family to family.[1] Furthermore, social and economic inequities influence health outcomes.[2, 3] Emerging evidence suggests these differences may impact patient experience.[4] Patient specific characteristics, such as health status,[4] English proficiency,[5] age, education level,[4,6] race, and employment status[6] affect a patient's ability to participate in their healthcare[5,6] and likely influence how different patients (or family member respondents) report on their experience.[4]

The varied characteristics and experiences of patients and families are important for healthcare systems to understand fully in order to implement systemic changes and drive improvement. Still, most work assessing potential PFE survey participation biases has been conducted among adults. In a study of adults, Tyser et al. found differences in survey participation based on ages from 18 and up, sex, insurance type, and orthopedic care visit types.[7] A similar study, conducted in a pediatric subspecialty division, found response biases stemming from demographic differences in race, and insurance status as well.[8]

There is a paucity of research into the impact of sociodemographic characteristics on patient experience within pediatrics.[9] Since survey participation differences can affect the generalizability and usefulness of PFE surveys results,[1] such differences are critical to understand participation biases. Such data is lacking especially in the context of pediatric healthcare, leaving a gap in the understanding of potential participation biases in PFE data sets. Thus, we sought to enumerate response, completion, and comment rates to our PFE survey across key sociodemographic characteristics.

Patients and Methods

PFE Survey Methodology

This retrospective study took place at Cincinnati Children's Hospital Medical Center (CCHMC) using data collected between January 1, 2019 and July 31, 2019. CCHMC is a large, urban, free-standing, academic, acute care, children's hospital. For patients contributing more than one visit during the study period, one visit was selected at random. This study analyzed 77,627 encounters from ambulatory medical and surgical specialty divisions where surveys where administered. The study was reviewed and deemed exempt by the CCHMC Institutional Review Board.

PFE surveys are administered following clinical encounters using the NRC Health Real-Time survey platform.[10] Families are automatically contacted within 24-48 hours of an ambulatory visit requesting completion of the PFE survey. This outreach is initially via email, using an email address provided at the time of clinical encounter. If no response is received within 24 hours of the email, a second outreach via an interactive voice response (IVR) phone call is attempted. If there is still no response following an additional 24 hours, a second email is sent. If there is no email on file, or the email is a CCHMC institutional email, all three outreach attempts are made via an IVR phone call. Families have up to 14 days to respond and complete the survey before being identified as a survey non-responder.

Survey Exclusion/Inclusion Methodology

Several exclusion criteria exist as part of the NRC Real-Time platform based on demographic, diagnostic, and prior utilization factors. To minimize survey fatigue, no survey is attempted if a patient received a survey from any other clinical encounter within three days of the ambulatory encounter or from the same ambulatory division within the previous 30 days. The survey is only administered in English or Spanish based on a patient's self-reported primary language. Additional exclusions exist for encounters connected to an international address, those with incomplete or erroneous contact information, and patients in custody of the state or county (<1% of encounters). Finally, to prevent accidental disclosure and to protect patient privacy, patients evaluated for a set of "sensitive diagnoses" chosen *a priori* (e.g., pregnancy, suspected or verified abuse, and visits related to sexually transmitted infections) were excluded.

PFE Survey Elements

Each survey consisted of 14 questions that assess common PFE priorities, including access to care, communication with the care team, continuity and coordination of care, information and education, respect, environment of care, and overall rating of experience. Responses to the questions were anchored to either a three-point or four-point scale, or a 10-point Likert scale for the overall rating of the provider question. Questions and response options are in Figure 1. After these questions, respondents have the option of leaving a free response comment.

Outcomes and Sociodemographic Variables

The outcomes of interest were PFE survey response, completion, and comment rates. A survey response was defined as answering at least one of the Likert-based questions. Completion was defined as answering all the Likert-based multiple response questions on the survey. Commenting was defined as inclusion of any free-text comment.

The patient level sociodemographic variables included were race, ethnicity, primary language, and socioeconomic deprivation. These sociodemographic characteristics were extracted from the electronic medical record. Race was categorized as White, Black or African American, Multiracial, other, or unknown. Other consisted of Asian, Hispanic, and other. Ethnicity was categorized as Hispanic or non-Hispanic, while language was segmented into English, Spanish, or Other/Unknown. Race, ethnicity, and preferred language are self-reported by patients and families during the clinical encounter and entered into the electronic health record. Patients can self-identify as both Hispanic race and Hispanic ethnicity.

Socioeconomic deprivation was estimated using the Deprivation Index (DPI) measured at the census tract level. This measure is used to approximate respondent socioeconomic status and characterize the context in which they live. The DPI is calculated from variables present within the U.S. Census American Community Survey (ACS) such as poverty, educational attainment, and access to health insurance.[11] For this analysis, we grouped respondents into quartiles by their DPI scores with higher DPI indicating higher deprivation. The DPI was obtained by extracting the patient street address from the electronic health record at the time of the encounter which was then geocoded and connected to the corresponding census tract geography. Once the census tract was identified, it was then linked to the DPI value.

Figure 1. PFE Survey Questions and Response Options

Question Text & Order	Question Response Options
Did this provider explain things about your child's health in a way that was easy to understand?	Yes definitely, Yes somewhat, No
Did this provider listen carefully to you?	
Did you talk with this provider about any questions or concerns you had about your child's health?	Yes, No
Did this provider give you easy to understand information about these health questions or concerns?	Yes definitely, Yes somewhat, No
Did this provider seem to know the important information about your child's medical history?	
Did this provider show respect for what you had to say?	
Did this provider spend enough time with your child?	
Rotate 1 of 3:	
For this visit, were you able to get an appointment as soon as you needed?	
Did clerks and receptionists treat you with courtesy and respect?	
During your visit, did your child see this provider within 20 minutes of the appointment time? (wait time includes time spent in the waiting room and exam room)	
Would you recommend this provider's office to your family and friends?	
Using any number from 0 to 10, where 0 is the worst provider possible and 10 is the best provider possible, what number would you use to rate this provider?	Experience 0-10
Using any number from 0 to 10, where 0 is the worst facility possible and 10 is the best facility possible, what number would you use to rate this facility?	Rating 0-10
Magnet Questions (Rotate 2 of 8)*:	
Did nurses treat you with courtesy and respect?	Yes, definitely; Yes, mostly; Yes, somewhat; No
Did nurses listen carefully to you?	
Did nurses explain things in a way you could understand?	
Did you have confidence and trust in the nurses treating you	
Did the staff do everything they could to help you with your pain?	
Did you have enough input or say in your care?	
Were you comfortable talking with nurses about your worries or concerns?	
Was there good communication between the different doctors and nurses?	
Is there anyone you would like to recognize or anything you would like to say about your experience?	Open Question

* Magnet questions are for nursing Magnet Recognition. There are eight options, and two are randomly assigned per survey.

Statistical Analysis

Descriptive statistics enumerated distributions of key variables. We then assessed bivariate relationships between participation rates and the range of sociodemographic predictor variables. Finally, we assessed the relationship between survey method participation and the range of sociodemographic predictor variables. Associations between PFE survey participation outcomes and predictors were then assessed using the Chi-square goodness of fit test.

Results

Study Population

Survey outreach was attempted for 140,994 ambulatory encounters during the study period, representing 82,294 unique patients. A total of 4,667 patient encounters were excluded due to an inability to map reported street address to a census tract. This resulted in 77,627 unique patient encounters for the analysis (Figure 2). Patients involved in the included encounters were predominantly White (76%) and non-Hispanic (95%). (Table 1). Those excluded due to unmappable street addresses were slightly more likely to identify as White (78% vs. 76%) and slightly less likely to identify as Black (9% vs. 12%). There was no statistical difference between those who were included and those who were excluded with respect to language and ethnicity.

Figure 2. PFE Survey Inclusion/Exclusion Classifications

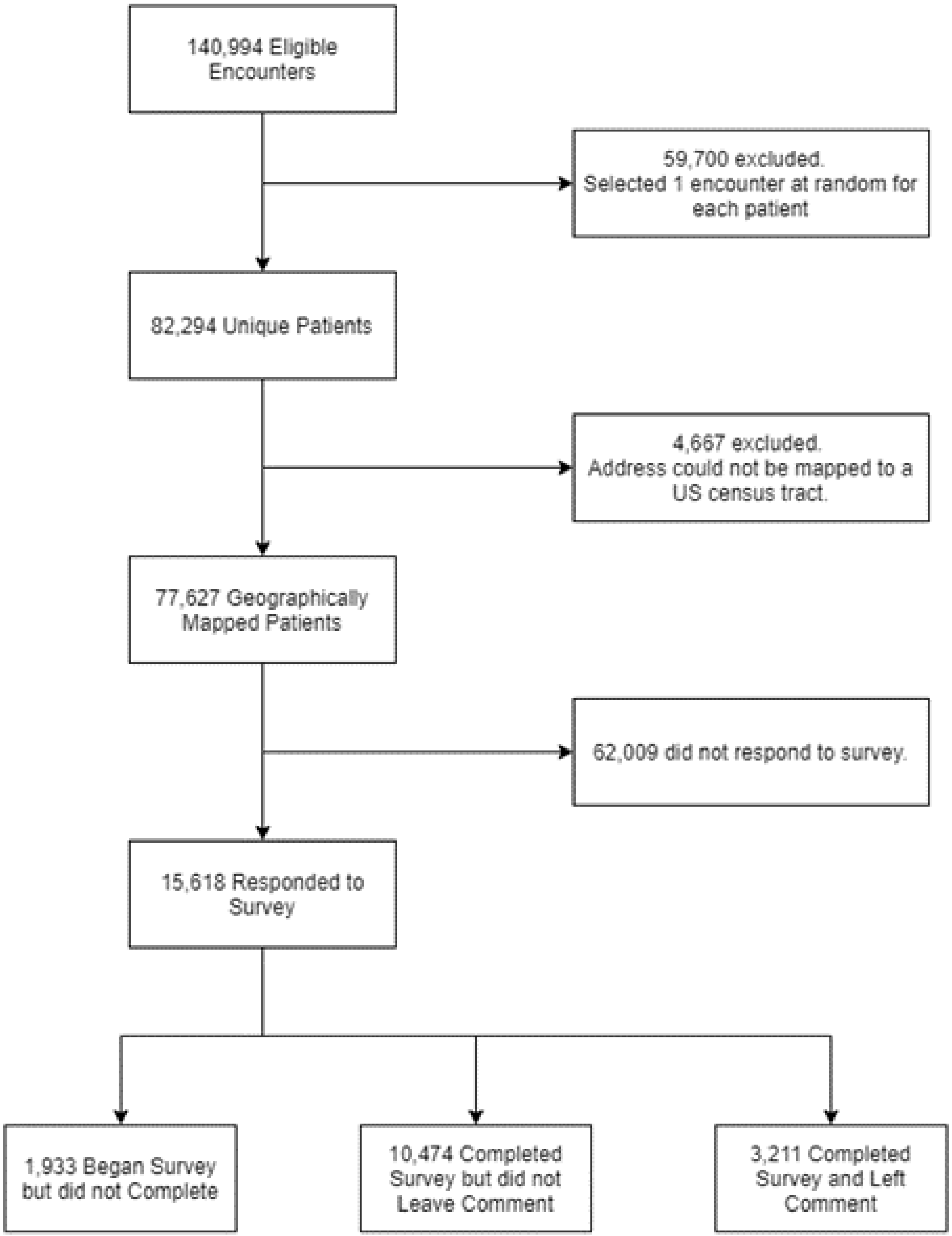

Table 1. Ambulatory PFE Survey Sociodemographic Groupings

Sociodemographic Characteristic		Encounters (%)
Race	White	59,374 (76%)
	Black or African American	9,525 (12%)
	Multiracial	3,503 (5%)
	Other*	3,788 (5%)
	Unknown	1,437 (2%)
Ethnicity	Hispanic	3,901 (5%)
	Non-Hispanic	73,082 (94%)
	Unknown	644 (1%)
Language	English	47,578 (61%)
	Spanish	1,054 (1%)
	Not reported / Other	28,995 (37%)
DPI**		**Encounters (DPI range)**
	Quartile 1	19,500 (0-0.28)
	Quartile 2	19,480 (0.29-0.34)
	Quartile 3	19,296 (0.35-0.43)
	Quartile 4	19,351 (0.44-1)
Total		77,627

*"Other" Race represents "Hispanic" 46%, "Asian" 43%, and "Other" 11%
**DPI (Deprivation Index) is a composite measure of socioeconomic deprivation based on census tract level data collected in the American Community Survey. Quartile 1 represents the least deprived census tracts.

Response, Completion, and Comment Rates

Overall, the survey response, completion, and comment rates were 20.1%, 17.6%, and 4.1% respectively (Table 2). Response rates differed across each sociodemographic variable. White families responded 19.6% of the time compared to 19.3% of Black and 18.8% of Multiracial families. Hispanic (30.3%) and Spanish speaking families (40.1%) had higher response rates than the overall cohort. Those that were identified as living in more deprived areas were more likely to respond compared to families living in less deprived areas per the DPI. All differences were statistically significant (p <.0001).

Completion rates differed across racial, ethnic, and language groups, but not by DPI. Among racial groups, differences in completion rates were even more disparate than for response rates. White families (17.6%) were more likely to complete the survey compared to Black (15.6%) or Multiracial families (16.1%). Similar to the response rates, Hispanic (24.9%) and Spanish- speaking families (32.5%) had higher completion rates than the overall cohort.

In addition to being more likely to respond to and complete a survey, White families (4.3%) were also the most likely racial group to leave a comment. While Hispanic and Spanish-speaking families were more likely to respond to and complete a survey, their comment rates (3.1%, 1.8% respectively) were significantly lower compared to non-Hispanic (4.2%) and English-speaking families (3.9%). Comment rates decreased as social deprivation within the DPI increased.

Families that had lower email response rates were less likely to have a valid email address on file with the hospital. (Table 3). Responses via email were over four times more likely to include a comment compared to those via IVR. White families were the most likely to respond to the survey via email (35.5%) while Black families were less likely (19.3%). Similarly, Non-Hispanic and English-speaking families had much higher rates of utilizing email as their survey method. Rates of participation via email decreased as the social deprivation within the DPI increased.

In addition to being more likely to respond via IVR, Hispanic (5.1%) and Spanish-speaking families (2.9%) were less likely to leave a comment on IVR surveys. Similarly, more deprivation in the DPI coincided with lower comment rates via IVR surveys. The higher rates of responses via IVR in Hispanic families, Spanish-speaking families, or families experiencing higher levels of deprivation could be attributed to the of lack of valid email (Table 3).

Table 2. Ambulatory PFE Survey Response Rates by Sociodemographic Grouping

Sociodemographic Characteristic		Response Rate	P value	Completed Rate	P value	Comment Rate	P Value
Race	White	19.6%	<.0001*	17.6%	<.0001*	4.3%	<.0001*
	Black or African American	19.3%		15.6%		3.2%	
	Multiracial	18.8%		16.1%		4.0%	
	Other	30.1%		24.2%		3.8%	
	Unknown	24.2%		20.2%		5.0%	
Ethnicity	Hispanic	30.3%	<.0001*	24.9%	<.0001*	3.1%	<.001*
	Non-Hispanic	19.6%		17.2%		4.2%	
	Unknown	22.8%		20.5%		5.9%	
Language	English	18.3%	<.0001*	16.2%	<.0001*	3.9%	<.0001*
	Spanish	40.1%		32.5%		1.8%	
	Not Reported/ Other	22.4%		19.4%		4.5%	
DPI**	Quartile 1	19.7%	<.0001*	17.7%	0.0665*	4.8%	<.0001*
	Quartile 2	19.1%		17.0%		4.4%	
	Quartile 3	20.2%		17.6%		3.9%	
	Quartile 4	21.5%		18.2%		3.5%	
Total		20.1%		17.6%		4.1%	

* All p values calculated using a chi squared test.

Discussion

Our study illustrates variation across sociodemographic groups in how they participate in PFE surveys. This significant variation was noted in the overall response rates, completion rates, and likelihood to leave a comment. Black and Multiracial respondents had lower than average response and completion rates compared to White and other race respondents. Black, Multiracial, Hispanic, and Spanish-speaking respondents, along with those classified as most deprived census tracts, were less likely to complete the survey upon responding. Our study adds to the body of literature given the paucity of data on how different populations respond in different ways when asked to complete PFE surveys after encounters within healthcare systems.

For both hospital procedures and providers, post-visit PFE survey responses can inform areas of improvement[12] and enhance insights on what patients and families experience when they seek care. Given the weight placed on PFE surveys, it is essential that we understand the potential biases – based on responses and lack thereof – the survey results may introduce. This was the rationale for our study, to connect a range of patient and family sociodemographic characteristics to participation behaviors to more fully understand possible biases. These biases may provide insights into disparities within the healthcare system, identifying barriers to care, distrust in the system, and ultimately factors at the root of differences in health outcomes. More proximally, our findings will inform survey methodology and limit the degree to which interventions in response to PFE surveys do not focus solely on those most likely to share their experience through the survey.

The variation we found may imply that there are differences in the ways people take the survey. Differences in response, completion, and comment rates were partially attributable to differences in survey methods across the sociodemographic groups**.** Our survey is administered after discharge via email or IVR. The different rates of lid email addresses across demographic groups may influence comment rates. There was an increase in response rate as social deprivation increased within the DPI. Previous studies have shown variation in response rates of PFE surveys when completed prior to discharge via a tablet. Surveying prior to discharge by in-clinic tablets was effective in increasing response rates, particularly for those that were non-White, publicly insured, and with lower levels of education, therefore increasing representation within the survey respondents.[13]

Survey fatigue may also play a role in the variation in completion and comment participation rates. In the PFE survey, 14 multiple-choice questions preceded the open response question. The survey length may influence survey completion and desire to leave comments. In our analysis, the decreasing completion rate with increasing social deprivation (which includes estimate of literacy level) supports this theory.

Table 3. Ambulatory PFE Survey Participation Methods by Sociodemographic Characteristics

Sociodemographic Characteristic		Percent with a Valid Email	P Value	Percent Respond-ing via Email	P Value	Percent of Email Respon-dents Leaving a Comment	P Value	Percent Respond-ing via IVR	P Value	Percent of IVR Respon-dents Leaving a Comment	P Value
Race	White	67.7%	<.0001*	35.5%	<.0001*	43.3%	0.330*	64.5%	<.0001*	10.2%	<.01*
	Black or African American	57.6%		19.3%		47.9%		80.7%		8.9%	
	Multiracial	63.8%		30.6%		47.8%		69.4%		9.9%	
	Other	52.1%		17.1%		43.1%		82.9%		6.2%	
	Unknown	49.1%		24.1%		54.8%		75.9%		9.8%	
Ethnicity	Hispanic	45.8%	<.0001*	12.0%	<.0001*	46.5%	0.734*	88.0%	<.0001*	5.1%	<.0001*
	Non-Hispanic	66.3%		33.4%		43.8%		66.5%		10.1%	
	Unknown	59.2%		32.7%		50.0%		67.3%		14.1%	
Language	English	68.2%	<.0001*	31.7%	<.0001*	45.1%	0.292*	68.3%	<.0001*	10.6%	<.0001*
	Spanish	18.9%		2.8%		58.3%		97.2%		2.9%	
	Not Reported/ Other	61.8%		33.9%		42.5%		66.1%		8.9%	
DPI**	Quartile 1	72.3%	<.0001*	40.0%	<.0001*	43.4%	0.812*	60.0%	<.0001*	11.6%	<.0001*
	Quartile 2	67.2%		35.4%		45.5%		64.5%		11.1%	
	Quartile 3	64.0%		30.0%		43.3%		70.0%		8.6%	
	Quartile 4	57.1%		22.8%		43.7%		77.2%		8.0%	
Total		65.2%		31.8%		44.0%		68.2%		9.6%	

* All p values calculated using a chi squared test.

The consequences of biased surveys may be significant within institutions as patient experience ratings can drive change, pointing to areas of potential improvement. Comments may be weighted particularly highly and deemed useful by management.[14] Here, the comment rates demonstrated the most potential for bias within our survey given the discrepancy between groups leaving comments. This is especially significant as free response comments are a major source of service recovery, which is when the institution reaches out to families personally after a negative experience in the healthcare system. With fewer comments, organizations might be unable to address service failures as they are less likely to know when and how something went wrong in the experience. Interventions biased towards those groups who leave detailed comments may leave underrepresented groups even further marginalized in the healthcare system.

Limitations

This study was limited by established exclusion criteria that may influence the generalizability of the results. In an attempt to reduce survey fatigue, exclusions included limits of surveys to some patients and families with frequent utilization of ambulatory services. This may lead to underrepresentation of populations such as medically complex children who see multiple specialties. However, the random sampling at a patient level should minimize the impact of these exclusions. Second, we only compared the sociodemographic characteristics of those families who responded to the survey. We did not compare the characteristics of those who did not respond to survey. Additionally, this is a single institution study, the results of which may not be generalizable to other centers with a different demographic patient mix. While our findings have statistical significance, the clinical significance is still unknown. Further evaluation of our findings to determine clinical significance is necessary.

Conclusion

Sociodemographic differences drive disparities in a range of health outcomes and, in parallel, influence patient experience. Our understanding of the patient family experience has been heavily influenced by PFE surveys. This study identifies significant variation in PFE survey participation, completion and comment rates based on sociodemographic characteristics. Pediatric healthcare systems should exercise caution in interpreting PFE survey results and work to minimize this variation and potential bias in future surveys.

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