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Variance in Patient Access to Support Persons by Race/Ethnicity and Language Preference: An Analysis of Patient Survey Data

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ABSTRACT

Regulatory and accreditation organizations have advocated open visitation policies and allowance of support persons of patients' choosing, but it is unknown if support is allowed equitably. Data from hospitalized patients were analyzed to determine access to support persons, stratified by patient-reported race/ethnicity, language, sex, age, and education. A multivariate regression model was constructed using race and language, controlling for site and patient sex, education and age. Additionally, sites' policies explicitly allowing support persons were correlated to reports of allowance of support persons. Among 1,196 respondents, 17% reported not being allowed a support person or being unsure. African American patients had 2.4 times greater odds of reporting non-allowance of support than their white counterparts, while speakers of a language other than English or Spanish had 3.9 times greater odds. There were no significant differences noted between sites with a policy allowing patient support persons and those with no policy or one in development. Most patients report being allowed a support person, but African Americans and those speaking a language other than English or Spanish have greater odds of reporting not being allowed a support person. Reliable methods of informing all patients of this right are needed.

Keywords: health disparities, race, ethnicity, limited English proficiency, visitation, patient support

INTRODUCTION

Over the past decade, there have been numerous calls to liberalize hospitals' visitation policies and allow patients greater access to family members and others who can provide social support (Parsapour et al., 2011; Berwick & Kotagal, 2004; Sims & Miracle, 2006; Adams, Herrera, Miller & Soto, 2011). These calls have been based, in part, on empirical evidence showing that increased access to social support may lead to improved emotional resiliency (Meyerowitz, Formenti, & Leedham, 2000) and better health outcomes (Kiley, Lam, & Pollak, 1993). For example, continuous emotional support access in maternity settings can lead to shortened labor and significantly reduced need for caesarian delivery and other interventions, as well as improved maternal and neonatal outcomes (Kennell, Klaus, McGrath, Robertson, & Hinkley, 1991). Given the prevalence of low literacy (Kutner, Greenberg, Jin, Boyle, Hsu, & Dunleavy, 2007) in general and poor health literacy specifically (Parker, 2000; Parker, Ratzan, & Lurie, 2003) a support person might also serve to increase patient safety by helping with basic literacy skills and interpreting health information for patients who have lower literacy or are distraught due to illness or unfamiliar surroundings, though published studies on this are lacking. Despite initial concerns over interference in delivery of care and increased risk of environmental contamination (Cleveland, 1994; Hamner, 1990), in studies the presence of a family member or friend as a support person for patients has not been correlated with increased septic complications and may actually reduce complications for coronary patients (Fumagalli et al., 2006; Morgan, Grant, Craig, Sands, & Casey; 2005; Institute of Medicine, 2001).

In 2010, the Obama Administration released a Presidential Memorandum that tasked the department of Health and Human Services (HHS) with developing rules that prohibit hospitals from denying visitation privileges on the basis of race, color, national origin, religion, sex, sexual orientation, gender identity, or disability (Centers for Medicare and Medicaid Services, 2010a). In response to this call, changes were adopted to the Centers for Medicare and Medicaid Services (CMS)'s Medicare Conditions of Participation regarding visitation rights for patients who are hospitalized. One change, which received a great deal of attention in light of its effects on same-sex partners, was the obligation for hospitals to allow all visitors chosen by patients to enjoy "full and equal" visitation privileges, subject to certain clinical limitations (Centers for Medicare and Medicaid Services, 2010b). Functionally, this means patients are now legally allowed to choose whom they want to be allowed to visit them in the hospital and hospitals cannot limit visitors to legal relatives or opposite-sex spouses. Moreover, hospitals were required to proactively inform patients of these visitation rights.

At about the same time, The Joint Commission went a step further and stipulated that patients must have the right to choose and "access a support person during their care" as part of their new and revised standards on patient- and family-centered care (The Joint Commission, 2010). Beyond the simple right to visit, an individual selected to serve as a "support person" is allowed to stay with the hospitalized patient 24 hours a day (subject to clinical appropriateness), providing advocacy, assistance and comfort.

Since these changes were adopted, it seems likely that many hospitals will have adopted new or revised policies regarding patient access to a support person during their hospital stays. However, it is not known whether or to what extent patients are aware of these changes. Nor is it known whether patients from minority racial, ethnic and language backgrounds are equally aware of their right to have a support person stay with them while they are hospitalized.

METHODS

We analyzed data from the Communication Climate Assessment Toolkit (C-CAT), a validated tool for assessing the communication climate in a hospital or clinic. The C-CAT was developed by a multi-stakeholder group with guidance from an expert advisory panel (available at <https://ethicalforce.org>) and was validated in a multi-year, multi-site, national field test (Wynia, Johnson, McCoy, Griffin, & Osborn, 2010). Nine sites provided data in 2011 for the present study, including hospitals, pediatric centers and a community cancer center located in urban and suburban areas. Survey distribution was performed by staff at participating sites, with sampling and data-collection guidance provided by consultants trained in survey sampling and data-collection methodologies. Surveys were available in English, Spanish, Hmong and Somali. Survey language was determined by staff at each site and most sites intentionally oversampled limited English proficiency (LEP) patients to provide sufficient data for stratification. Parents or guardians were asked to complete surveys at all pediatric centers and for children under 18 years of age. Varying survey distribution techniques were used—most sites distributed surveys to patients at discharge from hospital while one site opted to have surveys mailed to patients' homes—and overall the sampling method should be considered as using a convenience sample.

Site-level staff did not consistently track the number of surveys actually distributed on-site, such that it is not possible to calculate an accurate denominator to determine the response rate. As such, response rates reported herein are obtained by using the number of surveys shipped to each site as the denominator and the number of surveys returned for analysis as the numerator. This provides a very conservative estimated response rate, which can be considered a “minimum response rate,” as it is unlikely that all surveys shipped were fully distributed at all sites. No personal health information was collected in the survey, all surveys were anonymous, and parents/guardians of minor children were instructed to complete the surveys for minors. Respondents' demographic characteristics, as reported by respondents, were compared to site-level demographics to ensure the representativeness of patient respondents at each site. Additionally, information about support person policies was collected in an organizational policy workbook, which was completed by a team at each site with knowledge of organizational policies around patient engagement and communication.

Table 1. Respondent Demographics*

	N	Sex		Age			Education	
		Male (%)	Female (%)	<18 yrs. (%)	18-64 yrs. (%)	≥65 yrs. (%)	<12 yrs. (%)	≥12 yrs. (%)
All Patients	1,196	323 (28)	771 (68)	21 (2)	829 (71)	184 (17)	157 (14)	893 (79)
Race/ Ethnicity**								
White	570	183 (32)	382 (67)	4 (1)	413 (72)	126 (22)	34 (6)	517 (92)
Hispanic/ Latino	192	40 (21)	150 (78)	8 (4)	152 (79)	11 (6)	50 (26)	132 (69)
African American	218	60 (28)	155 (71)	5 (3)	156 (72)	38 (19)	44 (20)	164 (75)
Language preference								
English	960	286 (30)	662 (69)	17 (2)	697 (73)	177 (18)	100 (10)	818 (85)
Spanish	90	14 (16)	74 (82)	4 (4)	72 (80)	3 (3)	40 (44)	43 (48)
Other	25	7 (28)	16 (64)	0 (0)	18 (72)	3 (12)	11 (44)	10 (40)

* Demographics are respondent-reported. Where percentages do not total 100, respondents did not provide demographic data.

** Respondents could select multiple categories.

For this study, our dependent variable was a single patient survey item: Were you allowed to have a friend or family member stay with you if you wanted? (Yes/No/Not Sure). We first conducted bivariate frequency analyses on this item by patient-reported race/ethnicity, language preference (“In what language would you like to talk to your doctor?”), sex, age, and education. Based on the identification of significant differences in allowance of a support person, we then constructed a multivariate regression model to examine further the independent impact of race/ethnicity and language variables on the dependent variable. The model controlled for demographic factors and patient-reported education, and a site variable was included in the regression model to control for clustering by site. All analyses were performed using IBM SPSS Statistics 19.

RESULTS

A total 1,196 patient respondents at the 9 sites completed the patient survey, representing an overall minimum response rate of approximately 18%. Site-specific response rates ranged from 10% to 31%, though it is likely that the true response rates were higher (see Methods). Demographic and language preference data were provided by respondents and are shown in Table 1. Among the respondents, 19% were Black/African American, 51% White, and 16% Hispanic/Latino. English was widely preferred, but 8% preferred Spanish and 2% preferred another language. 29% were male, and 15% had not graduated high school. Table 2 shows that the majority of respondents reported being allowed a support person, though 6% reported that a support person was not allowed and 11% reported being not sure if they were allowed a support person.

Significant differences were noted between White and African American/Black patients’ rates of reporting not being allowed to have a support person: 4% of White patients reported not being allowed a support person, compared to 11% of Black patients ($p=0.001$) and 6% of Hispanic/Latino patients ($p=0.2$). Results from the multivariable model confirmed this finding, with African American/Black patients having more than two-times greater odds of reporting not being allowed a support person (OR 2.39, 95% CI 1.767-6.997, $p<0.001$) compared to White patients, while significantly different odds were not found for patients of Hispanic/Latino ethnicity. Results from the bivariate and multivariate analyses are shown in Table 2.

Regarding language, 6% of English speakers thought they were not allowed a support person, compared to 4% ($p=0.3$) of Spanish speakers and 17% ($p=0.02$) of those speaking a language other than English or Spanish. Despite the small sample size (25 individuals reported speaking a language other than English or Spanish), this difference remained significant in the multivariable model, in which speaking a language other than Spanish or English resulted in a nearly four-fold greater odds of reporting not being allowed a support person compared to English speakers (OR 3.896, 95% CI 1.169-12.984, $p=0.027$). Reporting a preference for speaking Spanish did not result in a significant difference from English speakers’ odds of reporting access to a support person. No significant differences were observed by sex, age, or education.

Site level data (not shown) demonstrated a range of performance, with between 2% and 14% of patients at each hospital reporting not being allowed a support person, so the multivariable model included adjustment for these site-level differences. Sites also reported whether they had an existing policy that explicitly “permits a support person (a friend or family member, designated by the patient) to be present with the patient throughout their stay.” Of the 9 sites reporting data for this study, 4 reported having a policy in place that was “working well,” 4 reported policies “in development” or “in need of improvement,” and 1 reported not having such

a policy. Analyses to identify differences in patient reports of being allowed a support person according to whether or not the hospital had an explicit policy to that effect did not reveal any significant differences (table 2).

Table 2 – Patient-Reported Access to Support Persons by Patient Demographics and Hospital Policy, Bivariate and Multivariate Responses

	“Were you allowed to have a friend or family member stay with you if you wanted?”				
	Bivariate results				Multivariate results**
	No (%)	Yes (%)	Not Sure (%)	P-value (X ²)	Non-allowance of support OR (95% CI)
All Patients	71 (6)	914 (82)	125 (11)	N/A	N/A
Race/ethnicity					
White	22 (4)	459 (86)	56 (10)	Referent	Referent
Hispanic/Latino	11 (6)	159 (86)	15 (8)	0.202	1.196 (0.847-4.537)
African American	23 (11)	155 (75)	28 (14)	<0.001	2.39 (1.244-4.593)
Language					
English	53 (6)	747 (73)	106 (12)	Referent	Referent
Spanish	3 (4)	77 (91)	5 (6)	0.315	0.644 (0.172-2.409)
Other	4 (17)	16 (70)	3 (13)	0.02	3.896 (1.169-12.984)
Sex					
Male [R]	21 (6)	260 (81)	42 (13)	Referent	N/A**
Female	48 (6)	642 (83)	81 (11)	0.776	
Age					
<18 yrs.	1 (5)	18 (86)	2 (10)	0.502	
18-64 yrs.	51 (6)	700 (84)	78 (9)	Referent	
≥65 yrs.	12 (7)	139 (76)	33 (18)	0.471	
Education					
<12 yrs.	14 (9)	127 (81)	16 (10)	Referent	
≥12 yrs.	52 (6)	737 (83)	104 (11)	0.214	
Hospital Policy*					
“Working well”	27 (5)	439 (85)	49 (10)	Referent	
“In devel.” or “needs improv.”	41 (8)	424 (80)	71 (13)	0.08	
No policy	3 (5)	51 (86)	5 (8)	0.9	

*Hospitals were asked whether they had a policy allowing for 24-hour access to a support person and whether that policy was working well or needed to be improved (4 had policies in place and working well, 4 had policies in development or needing improvement, and 1 had no policy).

**The model included patient race/ethnicity, language preference, age, sex, years of education and site (all demographic variables were patient reported).

DISCUSSION

Patients who self-identify as African American/Black, as well as those who report speaking a language other than English or Spanish, report significantly higher rates of believing that they would not be allowed a support person to stay with them if they wanted. Although this study can not pinpoint the underlying dynamics driving this finding, two potential explanations deserve attention. First, it could be that all patients are in fact equally allowed to have a support person, but some patient groups are not being made effectively aware of this right in a consistent manner. Supporting this interpretation is the fact that many sites reported already having policies specifically allowing a support person, as recently required by The Joint Commission. It is noteworthy that several sites’ policies were either in development or in need of improvement at the time of the patient survey, and data collection took place around the same time that the

new Joint Commission standards related to allowance of a support person began taking effect in mid-2011.

Why might some patients not be aware of their right to a support person? The Joint Commission has established expectations that patients be informed of their right to a support person, yet organizations have flexibility in how they make this information available: some might simply post a “patient’s bill of rights” in waiting rooms, or provide information about this right along with many other written documents provided to patients (The Joint Commission, 2011). Our data cannot determine how aggressively each hospital is working to disseminate information about this right, but the variance in patient reports of not being allowed a support person by site (2-14%) demonstrates that some sites are more effectively informing patients of this right than others. Of note, there are significantly higher rates of limited literacy and health literacy among minority racial/ethnic groups and those with limited English proficiency (Kutner et al., 2007; Neilsen-Bohlman & Kindig, 2004). This could contribute to lower awareness of support person policies among racial, ethnic and language minority patients, especially if information about these policies is delivered in written form.

The second potential explanation for our findings is that there could be an actual disparity in rates of allowance of support persons by race and language. Again, most sites reported either having a policy allowing support persons or working to develop/improve such a policy; presumably these policies would apply to all patients regardless their race, ethnicity or language background. Remarkably however, we found no significant differences between rates of reporting the allowance of support persons according to whether or not a site already had an explicit policy or was in the process of developing or implementing one. If having a policy doesn’t change patient awareness, it could be that *staff* are not aware of the existence of a uniform policy, which might lead to differential allowance of support persons within the organization. If true, this could contribute to broader reports of experiences of lower support among hospitalized African American patients (Hamilton, Moore, Powe, Agarwal, & Martin, 2010). Alternately, some staff members might be aware of this policy but still choose to not inform some patients of this right. Supporting this hypothesis are qualitative data submitted by some sites, which suggest that nursing staff sometimes oppose the loosening of visitation policies. While nursing staff frustration with open visitation policies has been reported elsewhere (Chakma & Ocampo, 2011), we did not routinely collect information on these issues at the study sites and so we are unable to assess the prevalence or impact of such hypothesized staff attitudes across different sites.

Finally, it is important to recognize that whether patients incorrectly believe they would not be allowed a support person or are actively disallowed a support person, the result is likely to be the same. Patients who believe they are not allowed a 24-hour support person are unlikely to benefit from this right, regardless of the source or accuracy of this belief.

This study has some important limitations. First, while data-collection was performed under the guidance of trained consultants and the sample size is relatively large, each site used variable survey distribution methodologies, which precludes the calculation of accurate response rates, and the sites were self-selected from only New England, the Atlantic Seaboard, and the Upper Midwest. For these reasons, our data should be considered to represent a convenience sample and the degree to which our findings reflect the experiences of patients nationally is not known. Future studies on larger and more nationally representative samples will be needed to confirm our findings. Additionally, data were not collected on some patient characteristics that might have a bearing on the allowance of a support person, such as sexual orientation, gender identity, and marital status.

CONCLUSION

The majority of patients report being allowed to have a support person stay with them during their hospitalization if they wanted one. However, African American/Black patients and those who speak a language other than English or Spanish had significantly greater odds of reporting not being allowed a support person. These differences remained significant even after adjusting for several potential confounding factors, including clustering by hospital. Our findings suggest that merely adopting hospital policies allowing support persons will not be enough to alleviate these patient-reported disparities. Health care organizations should consistently inform both staff and patients, in writing and orally, and using clear, easy-to-understand language, of the right of patients to have a support person stay with them while they are hospitalized.

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REFERENCES

- Adams S., Herrera A., 3rd, Miller L, Soto R. Visitation in the intensive care unit: impact on infection prevention and control. *Critical Care Nursing Quarterly*. January-March 2011;34(1):3-10.
- Berwick D.M., Kotagal M. Restricted visiting hours in ICUs: time to change. *Journal of the American Medical Association*. August 11 2004;292(6):736-737.
- Centers for Medicare and Medicaid Services (2010a). Medicare finalizes new rules to require equal visitation rights for all hospital patients [Press release]. Retrieved from: <http://www.hhs.gov/news/press/2010pres/11/20101117a.html>.
- Centers for Medicare and Medicaid Services (2010b). Changes to the Hospital and Critical Access Hospital Conditions of Participation To Ensure Visitation Rights for All Patients. Vol. 42 CFR2010.
- Chakma N., Ocampo J.P. Personal reflection: critical-care visitation and the headache that follows. *Dimensions of Critical Care Nursing*. January-February 2011;30(1):39-40.
- Cleveland A.M. ICU visitation policies. *Nursing Management*. September 1994;25(9):80A-80B, 80D.
- Fumagalli S., Boncinelli L., Lo Nostro A., et al. Reduced cardiocirculatory complications with unrestrictive visiting policy in an intensive care unit: results from a pilot, randomized trial. *Circulation*. February 21 2006;113(7):946-952.
- Hamilton J.B., Moore C.E., Powe B.D., Agarwal M., Martin P. Perceptions of support among older African American cancer survivors. *Oncoogyl Nursing Forum*. July 2010;37(4):484-493.
- Hamner J.B. Visitation policies in the ICU: a time for change. *Critical Care Nursing*. January 1990;10(1):48-53.
- Institute of Medicine (IOM). *Crossing the Quality Chasm: A New Health System for the 21st Century*. Washington, D.C.: National Academies Press;2001.
- Kennell J., Klaus M., McGrath S., Robertson S., Hinkley C. Continuous emotional support during labor in a US hospital. A randomized controlled trial. *Journal of the American Medical Association*. May 1 1991;265(17):2197-2201.
- Kiley D.J., Lam C.S., Pollak R. A study of treatment compliance following kidney transplantation. *Transplantation*. January 1993;55(1):51-56.

- Kutner M., Greenberg E.R., Jin Y., Boyle B., Hsu Y., Dunleavy E. *Literacy in everyday life: results from the 2003 national assessment of adult literacy*. Washington, D.C.: US Department of Education;2007.
- Meyerowitz B.E., Formenti S., Ell K., Leedham B. Depression among Latina cervical cancer patients. *Journal of Social and Clinical Psychology*. 2000;19(3):352-371.
- Morgan G.J., Grant B., Craig B., Sands A., Casey F. Supporting families of critically ill children at home using videoconferencing. *Journal of Telemedicine and Telecare*. 2005;11 Supplement 1:91-92.
- Nielsen-Bohlman L. P.M., Kindig A. *Health literacy: a prescription to end confusion*. Washington, D.C.: Institute of Medicine;2004.
- Parker R. Health literacy: a challenge for American patients and their health care providers. *Health Promotion International*. 2000;15(4):277-283.
- Parker R.M., Ratzan S.C., Lurie N. Health literacy: a policy challenge for advancing high-quality health care. *Health Affairs (Millwood)*. July-August 2003;22(4):147-153.
- Parsapour K., Kon A.A., Dharmar M., et al. Connecting hospitalized patients with their families: case series and commentary. *International Journal of Telemedicine and Applications*. 2011;2011:804254.
- Sims J.M., Miracle V.A. A look at critical care visitation: the case for flexible visitation. *Dimensions of Critical Care Nursing*. July-August 2006;25(4):175-180.
- The Joint Commission. *Advancing Effective Communication, Cultural Competence, and Patient- and Family-Centered Care: A Roadmap for Hospitals*. Oak Brook, IL: Joint Commission Resources;2010.
- The Joint Commission. *R3 Report: Requirement, Rationale, Reference*. Oak Brook, IL: Joint Commission Resources;February 9, 2011 2011.
- Wynia M.K., Johnson M., McCoy T.P., Griffin L.P., Osborn C.Y. Validation of an organizational communication climate assessment toolkit. *American Journal of Medical Quality*. November-December 2010;25(6):436-443.