

## **A survey about Advance Directives among underserved urban population: Attitudes and perceived barriers**

**Lama El Zein, MD, FAAFP, FAAHPM<sup>1</sup>, Noémie Le Pertel, DACM, MS, MPH, MAPP, L.Ac.MPH<sup>2</sup>, Susan X. Lin DrPH<sup>3</sup>, David Rosenthal, PHD<sup>4</sup>**

1. Physician at Summit Medical Group and Assistant Professor of Medicine at the Center of Family and Community Medicine, Columbia University Medical Center (CUMC)
2. Clinical Research Project Manager at Columbia University Medical Center- NY
3. Assistant Professor of Medicine at the Center of Family and Community Medicine, Columbia University Medical Center (CUMC)
4. Associate Professor at the Center of Family and Community Medicine at CUMC and Associate Professor of Clinical Health Policy and Management, Mailman School of Public Health, Columbia University

Please address all correspondence to Lama EL Zein, MD, 150 Park Avenue, Florham Park NJ 07932, Tel 973-538-5210, Email: le2218@cumc.columbia.edu

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### **ABSTRACT:**

An aging population and the multitude of potential comorbidities make the completion of Advance Directives (ADs) more pertinent than ever. This study's objective was to develop a greater understanding of the perceived barriers of completing ADs in primary care settings in a predominately Hispanic, inner-city immigrant population. The survey was administered in a community-based clinic over a 12-week period (February 1, 2014 to May 3, 2014) and analyzed in 2015. Main findings indicate that AD completion rates are still low, especially in minority communities. Our study results suggest a need for interventions to increase AD discussion in urban primary care settings.

## **INTRODUCTION:**

The changing demographics of the United States (an ageing population with an increased life expectancy and more chronic comorbidities) coupled with advances in the medical field increase the need for patients to discuss their end-of-life care with their primary care providers<sup>1</sup>. Documentation of an advance directive (AD) (including living wills, power of attorney, health care proxy and do-not-resuscitate consents) is considered a crucial part of patients' rights<sup>2,3</sup>. Currently, national AD completion rates remain low, varying between 5-15%<sup>4,5</sup> despite the fact that many patients, specially the elderly, prefer to have such discussions when they are relatively healthy and with mainly their primary care providers<sup>4,6</sup>.

Many studies have examined the cause of the low rate of AD completion and have identified a number of contributing factors. Among physicians, lack of time and proper communications skills, perceived low health literacy of patients, and uncertainty about illness severity and prognosis, rank as the top barriers towards completing AD<sup>1,4</sup>. As for patients, distress when discussing end-of-life issues, technical difficulties with the completion of the document itself, the perception that family members and physicians know their wishes without actual discussions, are often reported<sup>4,6</sup>. Patients, who are older, are married and have a higher educational level, and physicians with longer time in clinical practice are among the factors associated with higher AD completion rates<sup>4</sup>. The role of race is unclear however. Whereas there is evidence to support that being White is associated with a higher likelihood of AD completion<sup>4</sup> in contrast to being African American and Latino<sup>7</sup>, other studies have not found race as a confounding variable<sup>3</sup>. Others still point to being born outside the US as a more important barrier<sup>8</sup>.

This cross-sectional study aims at describing patients' knowledge about ADs and identifying perceived barriers in getting ADs completed among an urban Hispanic immigrant population.

## **METHOD:**

Study design: A cross sectional survey study of patients seen in a community-based clinic.

Population and setting: The study was performed in a family medicine residency program in New York City. The center serves an urban, underserved population for whom English may not be their primary language.

Survey instrument: We developed a survey with twelve questions that collected information about patients' demographics, their knowledge about ADs, the process of completion and its barriers.

Data collection and analysis: Patients (ages 18 and above) registering for any visit at the clinic during a 12-week period (February to May 2014) were given a survey in their preferred language, be it Spanish or English. Patients self-administered the survey in the waiting area with occasional help of a research assistant. The Investigation Review Board at Columbia University approved the study. Descriptive statistics were used to analyze the results in 2015.

## **RESULTS:**

### *Knowledge of AD*

A total of 166 patients were surveyed and 129 surveys were analyzed. Thirty-seven had incomplete survey data, and thus were excluded from analysis. Among those included in the study, 46 patients (36%) knew what ADs were. Twenty-one (46%) of the 46 patients had at least one type documented. A summary of their demographics is presented in Table 1. With regards to the content of an AD, among the 46 patients who knew about AD, 6-9% did not know what cardiopulmonary resuscitation (CPR), ventilator, feeding tube, intravenous (IV) fluid or IV antibiotics were. Twenty-six percent did not know what a defibrillator meant.

### *Process and barrier of ADs*

Thirty-three percent of those who had an AD documented reported having more than

one type of AD with living will and health care proxy being the most common combination. Among respondents who had knowledge about ADs, 43% thought it is extremely important to have one. Those who reported having knowledge about ADs but did not have one documented (N=25), 20% reported not wanting one, 16% thought they didn't need one, 16% didn't know how to start one, 20% feared their doctor would not pay attention to their medical care if they became critically ill and 28% trusted their families would make the appropriate decisions when needed. In terms of perceived needed resources to complete an AD, 23% of patients thought their primary care provider should be involved in discussing ADs, 67% wanted their family to be involved and 30% thought the process should at least involve a lawyer. As for who patients think should initiate discussions about ADs, 41% thought they should be the one starting the discussion, 39% preferred a family member to start the conversation and another 35% would leave it up to their primary care doctor.

#### **DISCUSSION:**

To our knowledge this is one of the few studies aimed at assessing AD status among primary care patients in an urban health center primarily serving Hispanic patients with Medicaid coverage. A substantial percentage of our patients (67%) who knew about ADs were less than 50 years of age but the completion rate among patients above 75 years of age was the highest (75%), which is comparable to other studies<sup>4</sup>. In our population, 16% reported AD documentation, also comparable to population-based estimates in the literature<sup>4</sup>. Despite some initiatives in New York State<sup>9</sup> to provide patients with information about AD during their outpatient visits, the percentage of AD completion among our study population remains similar to or even lower than the national average<sup>4,9</sup>. A potential cause is that majority of our population are Hispanics who tend to have lower AD completion rates compared with Whites<sup>10</sup>. In addition, this suggests that past interventions such as passive education (distribution of educational pamphlets, reading material) may not be enough to maximize AD completion and active providers' participation is needed<sup>4</sup>.

Consistent with data in the literature<sup>6</sup>, patients in this urban minority setting think

they don't need ADs because they assume that their family members will know what they would want. Studies have shown that patients prefer to discuss such sensitive issues with a provider who "knows them"<sup>2</sup>. Because elders prepare for death by checking their financials, some of them feel comfortable discussing ADs with a lawyer helping them through those financial arrangements<sup>6</sup>. In our study, one third of patients would prefer involving a lawyer. While lawyers are not legally needed to complete ADs, patients' belief in the need for lawyers might be an additional barrier in an underserved population as most patients might not be able to afford one.

This study has several limitations including the use of a convenient sample, the small sample size of patients, the absence of survey completion rate and the reporting bias related to self-administered questionnaires. However, given the scarcity of data about ADs among Hispanic patients, this study adds some new information to the AD literature in this particular population.

In summary, in an underserved academic health center, active and culturally sensitive interventions targeting patient education and involving primary care providers regarding the content and the process of ADs (initiation, documentation, essential personnel for completion) are needed in order to further address identified barriers. Future studies exploring links between continuity of care and AD completion rate, focusing on perceptions of patients as well as their treating doctors regarding potential barriers, would be essential in understanding the stagnant completion rate in the last decade despite all efforts towards improving the rates of documented ADs in the US.

**TABLE 1:** AD knowledge and status by demographic characteristics

	<b>n=129 (%)</b>	Participants with knowledge of ADs n=46(%)	% in each category	Participants with a documented AD among those with knowledge of ADs n=21(%)	% in each category
<b>Age</b>					
<29	52(40%)	17(37%)	32.7	5(24%)	29.4
30-49	39(30%)	14(30%)	35.9	7(33%)	50
50-69	28(22%)	11(24%)	39.3	6(29%)	54.5
70+	10 (8%)	4(9%)	40	3(14%)	75
<b>Gender</b>					
Male	38(30%)	15(33%)	39.5	5(24%)	33.3
Female	91(70%)	31(67%)	34.1	16(76%)	51.6
<b>Race/Ethnicity</b>					
Hispanic	101(78%)	36(78%)	35.6	16(76%)	44.4
White	4(3%)	2(4%)	50	1(5%)	50
Black	20(16%)	7(16%)	35	4(19%)	57.1
Other	4(3%)	1(2%)	25	0(0%)	0
<b>Education Level</b>					
High school or less	59(46%)	18(39%)	30.5	7(33%)	38.9
Some college or higher	69(54%)	28(61%)	40.6	14(67%)	50

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