



Do young adults complete health care proxies before anesthesia?

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ABSTRACT

Background: Health care proxy (HCP) completion rates by older adults are relatively low; however, not much is known about proxy completion rates by younger adults.

Objectives: This study aimed to identify HCP completion rates amongst 18–21 year old young adults without intellectual disabilities admitted to a pediatric hospital peri-anesthesia care unit (PACU) and determine whether there was an association with any demographic factors.

Methods: Retrospective chart review was performed to describe demographic variables, presence of HCP, and relationship to proxy. The relationship between demographic groups and HCP completion was analyzed by chi-square analysis for categorical variables and student t-test for continuous variables.

Results: Overall, 31.4 % (128/408) of patients completed an HCP, and younger patients were more likely to have done so. Analysis showed no statistically significant relationship between other demographic variables and HCP completion. A majority of patients identified a parent as their proxy.

Conclusion: Less than one third of young adult patients admitted to a children's hospital perioperative care unit completed a health care proxy. Other than age, there was no statistically significant difference in demographic variables between those who completed and did not complete a health care proxy. Further research is needed to validate these findings in other clinical settings and drive targeted initiatives to increase advance care planning among young adult patients.

1. Introduction

The American Academy of Pediatrics (AAP) has identified adolescent patients as a group with unique health care needs.¹ A recently reaffirmed AAP report on transition from pediatric to adult care recommends discussing patient rights and supporting autonomous decision-making; however, it does not discuss health care proxies.¹ The AAP policy on pre-operative evaluation outlines the need to discuss pre-existing do-not-resuscitate (DNR) orders prior to surgery and anesthesia, but completion of health care proxies is again not mentioned.²

Health care proxies are relevant to all adults, 18 years and older, who have specific health care wishes. Completing a health care proxy can also serve as a simple initial step in a young adult's transition to the increased responsibilities of adulthood. Medical visits and pre-operative visits provide an opportunity for young adults to explore this new role while surrounded by knowledgeable medical staff and non-medical

support persons who may accompany them. However, practitioners often do not discuss health care proxies with their patients until they are older adults and/or have a clinical indication for end-of-life discussions.^{3,4}

According to the United States National Center for Health Statistics, the top three causes of mortality for patients ages 15–24 for the most recent year available are accidents, intentional self-harm, and assault.⁵ These events do not allow for premeditated and deliberate discussion over time during a health decline as is possible for many older adults. In addition to the unique morbidity and mortality of young adults, they are in a unique stage of social transition as their relationships shift between those of family, friends, and significant others. Under certain state laws outlining decision-making for incapacitated adults, there are scenarios in which health care decisions might be made by someone the patient would not otherwise designate to make decisions. In one study, 18 % of patients indicated a health care proxy who was not their legally

Abbreviations: PACU, Post-Anesthesia Care Unit; HCP, Health Care Proxy.

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designated next of kin.⁶

A meta-analysis by Yadav et al. demonstrated 36 % of adults had completed any kind of advance directive (living will or health care proxy).⁷ Another meta-analysis showed 80–90 % of adult patients had some awareness of advanced care planning, but only 10–41 % had named a proxy or completed other documentation.⁸ Literature shows adults might not complete health care proxy forms due to age, self-reported health status, lack of knowledge about health care proxies, availability of proxies, or input from involved family members.³ Unfortunately, there is little research on the topic of health care proxies for young adults. Prior research has shown young adults desire additional information about advanced care planning and view it as a worthwhile endeavor.⁹ Despite having discussions about advanced care planning, like quality of life and mechanical support, most young adults do not have health care proxies.^{10,11} This study aims to fill this gap by investigating which young adults, 18–21 years old, complete a health care proxy during pediatric peri-anesthesia care unit (PACU) admission and if any demographic variables are associated with completion of health care proxy forms. Further, this study aims to determine the relationship between young adult patients and who they designate as their health care proxy.

We hypothesized that young adults who completed a health care proxy would be demographically similar to those who did not. We also hypothesized that young adults would be less likely to appoint a parent as their proxy as they gain independence and socially transition away from them.

2. Methods

An IRB-approved retrospective chart review of 18–21 year old patients admitted to the PACU of an urban, tertiary care children's hospital in New York City between 1/1/17 and 12/31/19 was conducted. Admission to the PACU at our institution includes patients undergoing moderate to deep sedation as well as general anesthesia for medical procedures, surgery, or imaging studies, and encompasses their pre-anesthesia and post-anesthesia care. The initial cohort was identified through a prospectively maintained institutional clinical research database (Clinical Looking Glass™) to determine which patients met the study criteria. Cancelled surgical encounters were not analyzed. This unit was selected due to existing unit practice to ask all adult patients if they would like to identify a health care proxy at the time of unit admission. Patients with an ICD-10 diagnosis code of intellectual disability or developmental delay were excluded because the heterogeneity of these diagnoses and nature of chart review do not easily allow researchers to gain a nuanced understanding of each individual's capacity at the time of surgery. Patients who did not sign their own surgical consent were also excluded, as this was used as a surrogate of patient capacity as determined by the clinical team at the time of consent.

Data were collected on demographic variables, including age, sex, marital status, language, race/ethnicity, and insurance type. Age was selected to evaluate evolving social attachments in early adulthood across this group. Sex was incorporated to evaluate if there are differences between men and women in terms of conceptualizing risk of mortality and social attachments. As most patients in this age group are not married, marital status was expected to have little impact within this cohort, but it is an important variable to consider as marital status changes the next-of-kin for a patient without a proxy. Race, ethnicity, and language were utilized as surrogates for variations in cultural belief systems and to evaluate for health disparities and bias. Insurance type (Medicaid vs non-Medicaid) was examined as a surrogate for socioeconomic status and if that impacted the decision to identify a proxy. All demographic variables selected provide the ability to ensure equitable access to and assistance with HCP identification. If significant, groups with lower identification rates could be further studied to identify unique barriers. Unique barriers could in turn be utilized to develop

specific interventions, like increased availability of interpreters and translated forms, community or religious outreach, and medical staff training. The electronic medical record was reviewed to determine whether a health care proxy form was completed and, if completed, the relationship of the young adult to the health care proxy. If not clearly identified on the form or in the medical record, the relationship was categorized as unknown.

Statistical evaluation was conducted. Data were represented as percentages for categorical variables and means for continuous variables. Characteristics of those who designated a health care proxy were compared to those who did not by chi-square analysis for categorical variables and student t-test for continuous variables.

3. Results

3.1. Demographic variables

Four hundred and eight patients met inclusion criteria. The mean age was 19.4 years, and 52.0 % (212/408) of patients identified as female. Most of the cohort (89.0 %, 363/408) were single, English was the most common preferred language (82.8 %, 338/408), 42.1 % (172/408) identified as Hispanic, and 65.7 % (268/408) had Medicaid insurance (Table 1).

3.2. Health care proxy completion rates and identifiable relationships

Less than one third of patients (128/408, 31.4 %) meeting inclusion criteria identified a health care proxy at or prior to the PACU encounter. Of patients who identified a health care proxy, 69.5 % (89/128) designated a parent; a spouse, sibling, or other relative were each selected by 1 patient (<1 % each). The relationship of the patient to the health care proxy named in the medical record could not be determined for 28.1 %

Table 1
Demographic characteristics.

Patient Characteristics	Cohort (n = 408)	
Age (in years) ^a	18	119 (29.2 %)
	19	101 (24.8 %)
	20	88 (21.6 %)
	21	100 (24.5 %)
Sex	Male	196 (48.0 %)
	Female	212 (52.0 %)
Marital Status	Single	363 (89.0 %)
	Married	4 (1.0 %)
	Domestic Partner	3 (0.7 %)
	Divorced	1 (0.2 %)
Language ^b	Unknown	37 (9.1 %)
	English	338 (82.8 %)
	Spanish	50 (12.3 %)
	Other/Declined	20 (4.9 %)
Race ^c	Black or African American	74 (18.1 %)
	White	55 (13.5 %)
	Asian	8 (2.0 %)
	Other/Declined	271 (66.4 %)
Ethnicity ^d	Spanish/Hispanic/Latino	169 (41.4 %)
	Not Spanish/Hispanic/Latino	139 (34.1 %)
	Other/Declined	100 (24.5 %)
Insurance Type	Medicaid	268 (65.7 %)
	Non-Medicaid	138 (33.8 %)
	Other	2 (0.5 %)

^a Does not total to 100 % due to rounding

^b Groups with fewer than or equal to 5 (Arabic, Bengali, Other) were merged with "Unavailable" and "Declined" as documented in the medical record.

^c Groups with fewer than or equal to 5 (Other Pacific Islander) were merged with "Other," "Declined," "Unavailable," and "N/A" as documented in the medical record

^d Groups with fewer than or equal to 5 (Dominican, Puerto Rican) were merged with "Declined," "Unavailable," and "N/A" as documented in the medical record.

(36/128) of patients.

3.3. Association of demographic variables and completion of health care proxy

In comparing young adults who identified a health care proxy to those who did not designate a proxy, only age was statistically significant ($p < 0.001$), with younger patients within this age range more likely to have identified a proxy. The demographic variables of sex, language, race, ethnicity, and insurance type were not significant. This analysis is summarized in Table 2.

Table 2
Comparison of Health Care Proxy identification rates across single demographic characteristics.

Patient Characteristics		Health Care Proxy n = 128 (31.4 %)	No Health Care Proxy n = 280 (68.6 %)	p-value
Age (in years)	18	49 (41.2 %)	70 (58.8 %)	< 0.001
	19	35 (34.7 %)	66 (65.3 %)	
	20	29 (33.0 %)	59 (67.0 %)	
	21	15 (15.0 %)	85 (85.0 %)	
Sex	Male	55 (28.1 %)	141 (71.9 %)	0.17
	Female	73 (34.4 %)	139 (65.6 %)	
Marital Status	Single	119 (32.8 %)	244 (67.2 %)	*
	Married	0 (0 %)	4 (100 %)	
	Domestic Partner	1 (33.3 %)	2 (100 %)	
	Divorced	8 (0 %)	29 (66.7 %)	
	Unknown			
Language ^{a,b}	English	105 (31.1 %)	233 (68.9 %)	0.33
	Spanish	19 (38.0 %)	31 (62.0 %)	
	Other/Declined	4 (20.0 %)	16 (80.0 %)	
Race ^{a,b}	Black or African American	23 (31.1 %)	51 (68.9 %)	0.20
	White	18 (32.7 %)	37 (67.3 %)	
	Asian	5 (62.5 %)	3 (37.5 %)	
	Other/Declined	82 (30.3 %)	189 (69.7 %)	
Ethnicity ^{a,b}	Spanish/Hispanic/Latino	56 (33.1 %)	113 (66.9 %)	0.58
	Not Spanish/Hispanic/Latino	42 (30.2 %)	97 (70.8 %)	
	Other/Declined	30 (30.0 %)	70 (70.0 %)	
Insurance Type ^b	Medicaid	88 (32.8 %)	180 (67.2 %)	0.43
	Non-Medicaid	40 (29.0 %)	98 (71.0 %)	
	Other	0 (0 %)	2 (100 %)	

* Marital status was not analyzed given few patients in "non-single" groups
^a Groups with fewer than or equal to 5 were merged with "Other," "Declined," "Unavailable," and "N/A" groups into Other/Declined
^b Other and Other/Declined groups were not included in analysis

4. Discussion

4.1. General discussion

This study demonstrates young adults have low rates of identifying health care proxies in a specific healthcare setting. Needle et al. conducted a study on adolescents and young adults undergoing hematopoietic stem cell transplantation and found a minority of patients, just 23 %, had completed an advance directive.¹² Their results support our findings that young adults do not often identify health care proxies, even when directly asked by hospital staff who are trained in completing health care proxies. These findings may stem from the overwhelming nature of acute illness, preventing young adults from being able to fully engage in advanced care planning despite knowledgeable staff and a potential trigger. For this reason, it could be preferable to discuss health care proxies while patients are healthy and supported by knowledgeable staff.

We hypothesize that one reason health care proxy completion rates might be low, is that adolescent patients lack the motivation to do so. The risk of anesthetic or surgical complications causing mortality in this age group is low (0.117 per 100,000).¹³ However, the risk of completing a health care proxy is also extremely low while the reward for having the correct person make the correct decisions for a patient who can no longer speak for themselves is immeasurable. This is similar to the rationale behind universal newborn screening for rare disorders where the risk of participating in the screening program is extremely low for each individual infant, but there is a high reward for a small number of affected individuals.¹⁴ This barrier could be addressed through education at the individual patient and population levels.

Some may hypothesize that pediatric providers who care for young adult patients are less comfortable discussing health care proxies with patients. However, pediatric providers usually have the unique opportunity to discuss this topic while patients are healthy. Ideally, these conversations should be with long-term care providers who have developed strong relationships with patients, but they can be done by any medical provider during any medical encounter, as necessary. Prior studies showed that young adults often lack information about HCPs but are eager to learn.^{9,10} Providing this information, time to process the information, and time to make decisions during the transition from pediatric to adult care provides the ability for information sharing to happen in a familiar pediatric setting prior to changing providers and settings. These conversations and decisions can then set up the patient, family, and adult medical team for success during a crisis or acute illness in which the patient is no longer able to make medical decisions. The initial stages of information sharing and greater public health knowledge about advanced care planning may allow patients who are otherwise overwhelmed by an acute illness to identify a proxy. One such setting is the peri-operative area where patients will lose the ability to make their own medical decisions while under anesthesia. While intra-operative rates of morbidity and mortality are low for young adults, decisions may need to be made during an operation or post-operative course while the patient remains incapacitated. Having the correct surrogate make decisions during that time should be a priority.

We found an association between age and identification of a health care proxy; younger patients within our cohort were more likely to designate a proxy at the time of surgery. The association between age and likelihood to designate a health care proxy is perhaps due to the fact that patients who are just starting to transition to legal adulthood may still be more heavily reliant on their parents' or guardians' involvement in their health care decisions and overall care compared to older patients who have had more experience making autonomous decisions.

It is known that utilization of health care proxies can be problematic if the proxy is unaware they were designated as such and/or the proxy is unaware of the patient's advanced directives or goals of care.^{15,16} It is unclear from our data if parents designated as health care proxy

physically accompanied the patients. While it might be less preferred compared to the primary health care setting, the PACU setting may present a unique opportunity for goals of care conversations between a patient and their potential proxy to occur prior to surgery as patients are often expected to arrive for surgery with a trusted individual. The young adult can have an open discussion with their accompanying person, presumably a family member or someone who is close to them, about overall goals of care and health care directives with the benefit of a trained medical staff available to address any questions.

Our study demonstrates that young adult patients who did select a health care proxy at the time of surgery most often chose their parent. This result refutes our initial hypothesis that patients would select someone other than a parent as their health care proxy. Perhaps this is because a parent often accompanied the patient to their PACU encounter and was readily available to have informed health care discussions with the patient and health care providers.

4.2. Limitations

This study has several limitations. It was conducted in a single institution with a majority Hispanic population and relatively small sample size. Further, this study only included patients in the PACU prior to undergoing anesthesia and focused on the subset of young adults who continue to receive care in a pediatric setting. These limitations may preclude generalizability to different patient populations, including the broader young adult population. This analysis also excluded patients with intellectual disabilities, many of whom have medically complex conditions which may make their designation of a health care proxy more clinically relevant as compared to counterparts without co-morbid conditions.

Additionally, this study was conducted with data from several years prior to interpretation, which could miss important practice or population changes. However, the authors are not aware of any practice changes within our institution related to HCP identification or documentation. Further, to our knowledge, there have not been any relevant major laws instituted or medical society guidelines published which focused on this issue in the interim. Finally, this institution's health care proxy form does not provide space to identify a patient-proxy relationship, which severely limited our ability to identify patterns in health care proxy relationships in this cohort. We were only able to confidently determine the relationship between the patient and their HCP if the HCP was named elsewhere in the medical record with a clearly stated relationship to the patient, such as parent.

4.3. Conclusions

In conclusion, young adults had low health care proxy completion rates overall. Those who identified a health care proxy were comparatively younger, and they most often designated a parent as their HCP. The limited variation across demographic groups in our study leaves age as the potential primary focus of targeted interventions to increase rates of proxy identification. Interventions at the population level can include public health campaigns as well as incorporating proxy forms as a standard part of all clinic intake and inpatient admission paperwork. Future studies are needed to corroborate our finding that HCP rates are low among the broader population of young adults and that there are no significant variations across demographic groups.

Additionally, we propose that pediatricians, pediatric nurses, social workers, and other members of the pediatric team could be a primary focus of interventions given their potential to assist the youngest adult patients in this process. Targeted interventions could focus on pediatric outpatient offices as well as inpatient facilities. Pediatricians are generally well trusted and often have long-standing relationships with their patients, which may help young adults feel more confident stepping into their new role as the drivers of their healthcare decisions. Ensuring all members of the health team, including administrative staff,

have a baseline knowledge of HCP policies and documentation as well as provide opportunities for patients to complete the necessary forms are interventions which are low-cost and relatively simple. We believe widespread public health education aimed at both patients and providers coupled with quality improvement methodologies aimed at changing standard practice could drastically improve the number of patients who are aware of their right to identify a proxy and ultimately complete a health care proxy form.

Ethics statement

This research was conducted in accordance with ethical standards as laid out by Elsevier and in accordance with The Code of Ethics of The World Medical Association.

This study was approved by the IRB at Albert Einstein College of Medicine, 1300 Morris Park Avenue, Bronx, NY 10461.

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CRediT authorship contribution statement

Dr. Spence designed the study and data collection tool, performed chart review, conducted data analysis, drafted and reviewed the initial manuscript, and approved the final manuscript as submitted. Dr. Serra performed chart review, critically reviewed and revised the manuscript, and approved the final manuscript as submitted. Dr. Gross conceptualized and designed the study, conducted data analysis, drafted the initial manuscript, and approved the final manuscript as submitted.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Data Availability

Data will be made available on request.

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