

Advance Directives and HIV: A Current Trend in the Inner City

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Abstract Throughout the 1980's, HIV antiretroviral therapy was non-existent or insufficient, and patients admitted to hospitals were frequently terminal. In 1988 we evaluated the HIV related hospitalizations at the Lutheran Medical Center in Brooklyn, New York, and found that only 1.3 % of the patients had an advanced directive/living will. Fifty percent of the patients expired during their hospitalization. To assist health care professionals during this serious illness, medical decisions were needed from the patients and, at other times, from family members and/or significant others. Subsequently, patients were approached to discuss advance directives (AD). With the introduction of the Highly Active Antiretroviral Therapy, medical management has decreased HIV mortality. Patients may have started having different perceptions on the need for an AD. The study design was submitted to the Institutional Review Board (IRB), and the IRB granted a HIPPA waiver because this was a retrospective study which delinked the study data from any identification of the patient. The chart reviews were conducted to ascertain the existence of an AD for all patients admitted at the Lutheran Medical Center, Brooklyn, NY from 2004 to

2011. One hundred eighty-two patients were identified from their discharge codes for HIV or AIDS. The median age was 47 years (range 22–85 years). Median time since HIV diagnosis was 9.5 years (range 0–28 years). Ninety-two percent lacked an AD on admission. From the thirty patients that were older than 54 years of age, only four of them had an AD prior to admission. During hospitalization only 11 patients out of 187 enacted a new AD, which decreased the overall percentage of patients lacking an AD to 86.3 % (pre and during admission). The majority of HIV infected patients hospitalized lacked an AD. Our data did not indicate a greater predominance of ADs from a private practice or clinic setting. ADs did not increase with increasing age. Moreover, with longer years with an HIV diagnosis, the number of ADs did not increase. Our results would indicate that a different approach is necessary to adequately address ADs with this specific population, especially as their longevity increases.

Keywords Advance directives · Increased longevity with HIV · Lack of health care proxy and HIV · DNR and AIDS

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Introduction

Advance directives (ADs) have received greater attention in the community with the aging of the US population. Discussions and counseling on ADs are extremely valuable even before the onset of a serious disease [1–3]. Current recommendations advise health care professionals to discuss ADs with their patients [4–6]. Under a stable and caring environment an individual is able to explore and decide on future care options. This process diminishes uncertainties for family members carrying out a patient's

decisions. It is strong rationale why ADs can enhance good medical care.

Throughout the 1980's the AIDS impact on the health care system was over-whelming. HIV antiretroviral therapy was virtually non-existent or insufficient, and critically ill patients often presented with an opportunistic infection or cancer (such as Pneumocystosis, cryptococcosis, tuberculosis, cryptosporidiosis, Kaposi's sarcoma). Many newly diagnosed patients with AIDS were either mentally unprepared to receive the information of a terminal disease or not able to make decisions to direct their critical care. With dismal therapeutic outcomes, health care providers often felt impotent which compounded the situation.

In 1988 we published a study on the proportion of HIV/AIDS patients who had a do not resuscitate (DNR) order. As a case sample we focused on one inner city hospital, the Lutheran Medical Center (LMC) located in Brooklyn, New York. We found that during their hospitalization 50 % of the patients died, and only 1.3 % had DNR orders [7]. The aforementioned study emphasized the need to address DNR orders during a hospitalization. Subsequently, in 1988 patients admitted to the newly established AIDS unit at LMC were approached on the subject of ADs that included not only DNR but also living wills and health care proxies. This process decreased the uncertainty of management that faced the patients, their families and physicians [5, 7].

In 1999 Walker described that in the general non-hospitalized population, the existence of ADs ranged from 15 to 25 % [8]. In an HIV population, Weissman [9] reported in 1999 that at three ambulatory care settings (HMO, Clinic, Group) ADs existed in 39, 34 and 27 % of the patients respectively. Many articles addressed ADs during the early years of the AIDS epidemic [10–12].

From 1995 to 1998, the CDC reported declines of AIDS related deaths by 63 % [13]. In the last decade with the increased number of HIV medications and the Infectious Disease Society of America (IDSA) guidelines [14], effective HIV therapy decreased mortality. The decrease of HIV related hospital admissions has caused some medical centers to close their AIDS specific units [15], and HIV infected patients now receive care on the general medical units.

Since 1999 LMC has been admitting HIV/AIDS patients to the general medical and family medicine units. While HIV is still considered a life threatening disease it is now medically managed as a chronic disease. Currently, this population is now aging with the general population [16, 17]. We wanted to examine the current status of ADs for HIV patients admitted at LMC that serves an inner city population.

The objective of our study was the evaluation of an HIV patient's ADs status (i.e. existence of living will, health care proxy and DNR order). Based on a chart review we

were determined if the AD decision was prior to their hospitalization, and/or during hospitalization.

Methods

A protocol was developed with a screening tool to document the status of an AD made prior to and during admission. Because this retrospective study delinked every patient's identity from his or her collected data, our Institutional Review Board exempted this protocol from a formal review.

ADs were defined as having any of the following: living will (LW), health care proxy (HC) and/or DNR order. We examined the last admission of all HIV patients from 2004 to 2011. This time interval was chosen because it encompassed the period when IDSA revised its guidelines for effective HIV combination therapy [14].

To provide consistency in the review process, only two physicians were chosen to review all the HIV adult charts. Charts were selected based on their International Classification of Diseases hospitalized discharge codes where HIV/AIDS had to be listed as a primary or a secondary diagnosis. Demographics included status of prior care from a private health care practitioners (HCP) or clinic, and the presence of ADs were collected. Information that was not attainable was classified as not available (n/a). The projected sample size was not large enough to determine statistical significance. Our statistical analysis was designed to be descriptive in nature.

Results

One-hundred-eight-two patients' charts were reviewed. All patients were asked if they had existing ADs. More males than females were identified. Ethnic identifiers were missing for 54 % of the cases. In the remaining cases 34 % were classified as Hispanic and 11 % as White. The collection of a patient's race was recorded by the admitting clerk and was not always identified. This accounted for the high percentage of unknowns for the racial background data.

The leading risk behaviors were intravenous drug usage (IVDU) and sexual transmission. The median years of diagnosis of HIV was 9.5 year which ranged from 0 to 28 years (Table 1).

The median age was 47 years old. The years since diagnosis of HIV were available in 74 % of the charts with a median of 9.5 years [ranging from 0 to 28 years]. One hundred fifty-two patients were <55 years old and 10 (6.5 %) of these patients had pre-admission ADs. Thirty patients were ≥55 years old, and only 4 (13.3 %) of these patients had pre-admission ADs (Table 2).

Table 1 Demographics

	All patients n (%) [n = 182]	Patients with no ADs n (%) [n = 157]	Patients with ADs enacted prior and/or during admission n (%) [n = 25]
Male	128 (70.3)	108 (68.8)	20 (80.0)
<i>Age</i>			
Median years (years)	47	47	50
Range (years)	22–85	22–85	33–81
<i>Race</i>			
White	20 (11)	18 (11.5)	2 (8.0)
Black	1 (0.5)	1 (0.6)	0
Hispanic	62 (34.1)	58 (36.9)	4 (16.0)
Other	7 (3.8)	7 (4.5)	0
Unknown	92 (50.5)	73 (46.5)	19 (76.0)
<i>HIV risk behaviors</i>			
Sexual transmission (ST)	18 (9.9)	16 (10.2)	2 (8.0)
IVDU and ST	4 (2.2)	3 (1.9)	1 (4.0)
IVUD	64 (35.2)	59 (37.6)	5 (20.0)
Other ^a	67 (36.2)	55 (35.0)	12 (48.0)
Not recorded in chart	29 (15.9)	24 (15.3)	5 (20.0)

^a Includes patients: with combination of IVDU or ST with a history of Hepatitis (B or C); denial of IVDU and no other risk factor; denial of ST and no other risk factor

Table 2 Medical history

	All patients N = 182	Patients without ADs N = 157	Patients with ADs N = 25
Prior CD4	n (%) ^a	n (%)	n (%) ^a
Yes	152 (83.5)	135 (86.0)	17 (68.0)
No	29 (15.9)	22 (14.0)	7 (28.0)
Prior HIV therapy	n (%) ^b	n (%) ^b	n (%) ^b
YES	130 (71.4)	115 (73.2)	15 (60.0)
No	40 (21.9)	32 (20.4)	8 (32.0)

^a Unknown: CD4 for 1 patients with ADs

^b Unknown: prior HIV Rx status for 12 patients on admission where 10 without ADs and 2 with ADs

Most of the patients received their medical care in a clinic rather than with private medical doctor. The percentage of patients that knew their CD4 count was 83.5 and 71.4 % of patients reported having HIV therapy. The percentage of patients that expired during our hospitalization review was 6.2 %.

On admission the overall rate of patients lacking an AD was 92.4 %.The ADs enacted during their hospitalization

Table 3 Status of advance directive prior to admission

The number of existing ADs prior to admission ^a	
Health care proxy	14
DNR	4
Living will	3

^a ADs numbers have overlap since some patients had HCP, LW as well as DNR

slightly decreased the ADs preadmission rate by 6.1 %. Of the 25 patients that had an AD enacted, 14 were pre-admission (see Table 3).

Of the 11 patients that lacked any form of AD on admission, all 11 enacted a form of AD (Health Care Proxy/Living Will), and 6 also had a DNR ordered during their hospitalization.

Discussion

Studies have examined an HIV population in an ambulatory setting. However, our retrospective study was able to evaluate an inner city population’s AD status when made prior to admission as well as during hospitalization. Our findings reveal that even for a life-threatening condition as HIV that required a hospital admission, ADs continue to be the exception rather than the rule. Some reasons remain speculative: (1) a patient’s fear to face the possibility of death as well as discomfort to discuss it with physicians, family and significant others, (2) physicians may be uncomfortable discussing AD with patients for fear of negative reactions, (3) poor utilization of multidisciplinary teams (who could take some of the burden from the medical doctors), (4) structural problems in an institution, (5) inability of health care providers to communicate the concept of ADs and (6) discussions can be influenced by the setting and the stage of disease.

Ethnicity, nationality, cultural heritage and religious beliefs all can influence the ADs decision process [18–25]. Literature review revealed that non-hospitalized Japanese in Tokyo reported only 15 % with ADs [19]. At two outpatient clinics in Toronto, Canada that the major barrier was patients’ lack of knowledge of ADs [19]. In the US hospitalized patients, from a general population, had a wide range of 1–40 % for AD enactment [8].

Many of the publications on AIDS/HIV and AD were written during the early period, when AIDS/HIV was still an acute disease with high mortality and differed on their designs (i.e. focus groups [24], prospective, and retrospective studies). This makes a comparison of some past articles difficult as well as less relevant to the current environment since the landscape of the disease has changed after 2004.

The majority of HIV patients admitted to LMC lacked ADs. The rates of ADs enacted prior to admission and those enacted during hospital stay were both low. Prolonged years of HIV diagnosis did not seem to influence a decision to enact an AD. The twenty-four patients with ADs had a wide range of age. The age group with pre-hospital AD decisions did not show an increased number of AD decisions as age increased above 55. We had expected the number of ADs to rise with age. The reasons why only 11 patients enacted an AD during admission remain speculative. We recognized the limitations from our retrospective study based on chart reviews.

This raises the question on how ADs are being discussed within the community. While the severity of an illness requiring a hospital admission might influence an AD decision, our rate of ADs only increased by 11 patients in 157 hospitalized patients. Our findings raised the issue regarding the presentation of ADs to the HIV population. Prior approaches of ADs specifically for HIV should be revisited. Larger studies should be conducted in New York City to determine if our results represent a general trend.

Conclusions

Hospital HIV admissions from our inner city community hospital reveal a paucity of Advance Directives. This was not influenced by age or by their length of years with HIV diagnosis. Despite HIV status as a chronic disease, our findings suggest a better approach is needed to effectively address ADs for this population.

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