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DATA SUMMARY
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End Stage Liver Disease (ESLD) hospitalizations, deaths, and liver transplantations are examined in this report.

Highlights

- An expanded set of ICD-10 codes were used to define ESLD for this study.
- Between 1999 and 2003 there was a significant increase in ESLD morbidity, but non-significant trends in ESLD mortality and in liver transplantations.
- Males experienced significantly higher ESLD morbidity and mortality, and also significantly higher liver transplantation rates than females.
- American Indians/Alaska Natives and Hispanics/Latinos had significantly higher ESLD death and hospitalization rates, but lower liver transplant rates.

End Stage Liver Disease (ESLD): Morbidity, Mortality, and Transplantation California, 1999-2003

By Jim Sutocky and Sripriya Balasubramanian, M.D.

Background

“Chronic liver disease and cirrhosis” is ranked as one of the leading causes of death in California, resulting in 3,725 deaths statewide in 2002.^{1,2} Liver transplantation is definitive therapy for end stage liver disease (ESLD), resulting in a reduction of morbidity, mortality and improved quality of life. Despite a record number of organ transplants in the United States (U.S.) during 2004, there has been a marked shortage of donor organs compared to patients on waiting lists for transplantation.³ This has resulted in a system of organ allocation that determines the order in which patients on the waiting list are transplanted. A number of revisions in the organ allocation policy in the U.S. have occurred, with the current system being based on the Model for End Stage Liver Disease (MELD) score. The MELD score is an index comprised of laboratory test results for serum creatinine, and bilirubin, and the International Normalized Ratio (INR), which has been shown to predict mortality in the absence of liver transplantation.^{4,5}

Regional variations in liver transplantation within the U.S. based on the size of the transplantation center have been described in detail elsewhere.⁶⁻⁹ Other factors which influence access to liver transplantation have been less well studied.¹⁰ Studies from other parts of the world, where liver transplant center size disparities are less important, suggest that regional/geographic variations exist with respect to access to liver transplantation.¹¹⁻¹² One study from Ireland suggests that likelihood of transplantation may be linked to both economic and geographic advantage, such that patients least likely to be transplanted were those who lived farthest from the transplant center and had the least ability to pay.¹³

A study of liver transplant recipients in the pre-MELD era in the U.S. found that racial disparities existed in listings based on severity of liver disease, with Caucasians more likely to be listed as status 2A vs. 2B, with 2A receiving a higher priority for listing.¹⁴ Another study found that African-American patients were less likely to be referred to liver

transplantation centers, were sicker at the time of referral, and were more likely to die while waiting for liver transplantation.¹⁵

Socio-economic factors influencing likelihood of transplantation are less well studied than racial factors. A time-series study involving a statewide analysis of liver transplantation in North Carolina revealed that a lower socio-economic status, assessed in this study by median income of home address zip code, had a detrimental effect on likelihood of liver transplantation.¹⁶ Another study suggested that a better socio-economic status may be associated multiple listings, i.e., listing at more than one transplantation center, which in turn is associated with a greater likelihood of transplantation.¹⁷

Methods

Mortality data for the time period 1999-2003 were extracted from the Death Statistical Master files maintained by the California Department of Health Services.¹⁸ Morbidity data were extracted from the Patient Discharge Data files supplied by the California Office of Statewide Health Planning and Development for the time period 1999-2003.¹⁹ California liver transplantation center and individual case data were provided by the United Network for Organ Sharing (UNOS), Organ Procurement and Transplantation Network (OPTN).²⁰ ESKD and transplantation data were tabulated by age, gender, and race/ethnicity. Age-adjusted rates per 100,000 population were calculated by the direct method using population denominator data supplied by the California Department of Finance and adjustment weights from the 2000 U.S. Standard Population.²¹⁻²²

The ICD-10 code set used to define ESKD for this report was adapted from Kim, et al (2002).²³

Table A. ICD-10 code set used to define End Stage Liver Disease (ESKD)

<u>Description</u>	<u>ICD-10 codes</u>
Viral hepatitis	B15-B19
Primary liver cancer	C220, C222-C224, C227, C229, C457
Esophageal varices	I85
Fulminant liver disease	K720, K762
Chronic liver disease and cirrhosis	K70, K73, K74
Hepatic coma	K729
Portal hypertension	K766, K770
Hepatorenal syndrome	K767
Other sequelae of CLDC	K660, K721, K753, K768, K778
Hepatitis, unspecified	K658, K710-K719, K758, K759
Other specified liver disorder	K719, K761, K764, K765
Unspecified liver disorder	K769

Results

Mortality (Table 1, Figure 1)

A total of 6,808 persons died in California during 2003 as a result of ESLD at a rate of 20.1 per 100,000 population, an increase from the 5,574 deaths reported during 1999 at a rate of 18.2 per 100,000.

ESLD death rates for males were significantly higher than those for females, and death rates for American Indians/Alaska Natives were significantly higher than those for all other racial and ethnic populations. Hispanics/Latinos experienced the next highest ESLD death rates, followed by African Americans/Blacks. The lowest ESLD death rates were observed for Whites and for Asians/Pacific Islanders. These numbers are significantly greater than those reported in the leading cause of death tabulations for California, since leading cause of death statistics use only ICD-10 codes K70, K73, and K74 (chronic liver disease and cirrhosis) according to National Center for Health Statistics protocols.²⁴

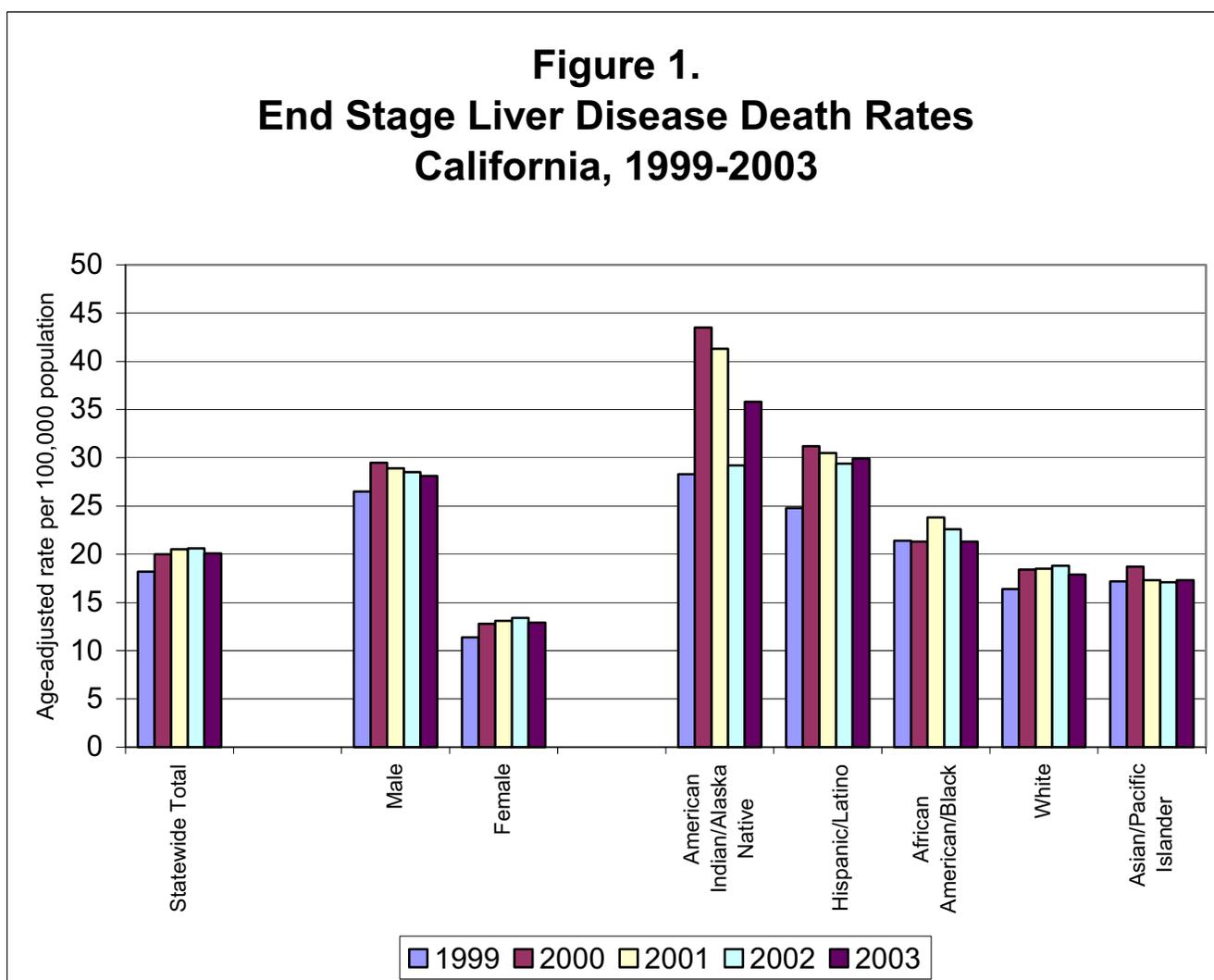


Table 1. End Stage Liver Disease Deaths and Death Rates, By Place of Occurrence, California 1999-2003

	1999		Lower	Upper	2000		Lower	Upper
	Deaths	Rate ¹	95% C.I.	95% C.I.	Deaths	Rate ¹	95% C.I.	95% C.I.
CALIFORNIA TOTAL	5,574	18.2	17.7	18.7	6,310	20.0	19.5	20.5
Race-Ethnicity								
African American/Black	378	21.4	19.2	23.6	391	21.3	19.2	23.4
American Indian/Alaska Native	55	28.3	20.7	35.8	74	43.5	33.2	53.9
Asian/Pacific Islander	525	17.2	15.7	18.7	613	18.7	17.2	20.2
Hispanic/Latino	1,383	24.8	23.5	26.2	1,707	31.2	29.7	32.8
White	3,226	16.4	15.8	17.0	3,515	18.4	17.8	19.0
Other/Unknown	7	DSU	-----	-----	8	DSU	-----	-----
Gender								
Female	1,879	11.4	10.9	12.0	2,114	12.8	12.3	13.4
Male	3,785	26.5	25.7	27.4	4,196	29.5	28.6	30.4

	2001		Lower	Upper	2002		Lower	Upper
	Deaths	Rate ¹	95% C.I.	95% C.I.	Deaths	Rate ¹	95% C.I.	95% C.I.
CALIFORNIA TOTAL	6,489	20.5	20.0	21.0	6,737	20.6	20.1	21.0
Race-Ethnicity								
African American/Black	448	23.8	21.5	26.0	451	22.6	20.5	24.8
American Indian/Alaska Native	83	41.3	32.1	50.5	67	29.2	21.9	36.4
Asian/Pacific Islander	600	17.3	15.9	18.7	629	17.1	15.8	18.5
Hispanic/Latino	1,777	30.5	29.0	32.0	1,856	29.4	28.0	30.8
White	3,578	18.5	17.9	19.1	3,724	18.8	18.2	19.4
Other/Unknown	3	DSU	-----	-----	10	DSU	-----	-----
Gender								
Female	2,211	13.1	12.5	13.6	2,338	13.4	12.8	13.9
Male	4,278	28.9	28.1	29.8	4,399	28.5	27.7	29.4

	2003		Lower	Upper
	Deaths	Rate ¹	95% C.I.	95% C.I.
CALIFORNIA TOTAL	6,808	20.1	19.6	20.6
Race-Ethnicity				
African American/Black	437	21.3	19.3	23.4
American Indian/Alaska Native	90	35.8	28.2	43.5
Asian/Pacific Islander	653	17.3	15.9	18.6
Hispanic/Latino	1,986	29.9	28.5	31.3
White	3,618	17.9	17.3	18.5
Other/Unknown	14	DSU	-----	-----
Gender				
Female	2,317	12.9	12.4	13.4
Male	4,491	28.1	27.2	28.9

SOURCES: CA Department of Health Services, Death Statistical Master Files, 1999-2003;

CA Department of Finance, Demographic Research Unit, *Population Projections by Race/Ethnicity for California and Its Counties 2000-2050*, May 2004.

NOTES: Liver disease deaths defined by ICD-10 code set (see Table A); underlying cause of death only.

¹ Rate per 100,000 population, age-adjusted using the 2000 US standard population; excludes records with unknown age.

DSU Data Statistically Unreliable due to small number of events.

Morbidity (Table 2, Figure 2)

A total of 28,674 hospital discharges with a principal diagnosis of ESLD were reported in California during 2003, at a rate of 83.2 per 100,000 population. This represents a significant increase from the 23,988 discharges reported for 1999, at a rate of 76.1 per 100,000 population.

ESLD discharge rates among males were significantly higher than those for females, and rates increased significantly for both males and females from 1999 to 2003.

Hispanics/Latinos had significantly higher ESLD hospital discharge rates than all other racial and ethnic populations, followed by African Americans/Blacks. The lowest ESLD discharge rates were observed for the Asian/Pacific Islander population.

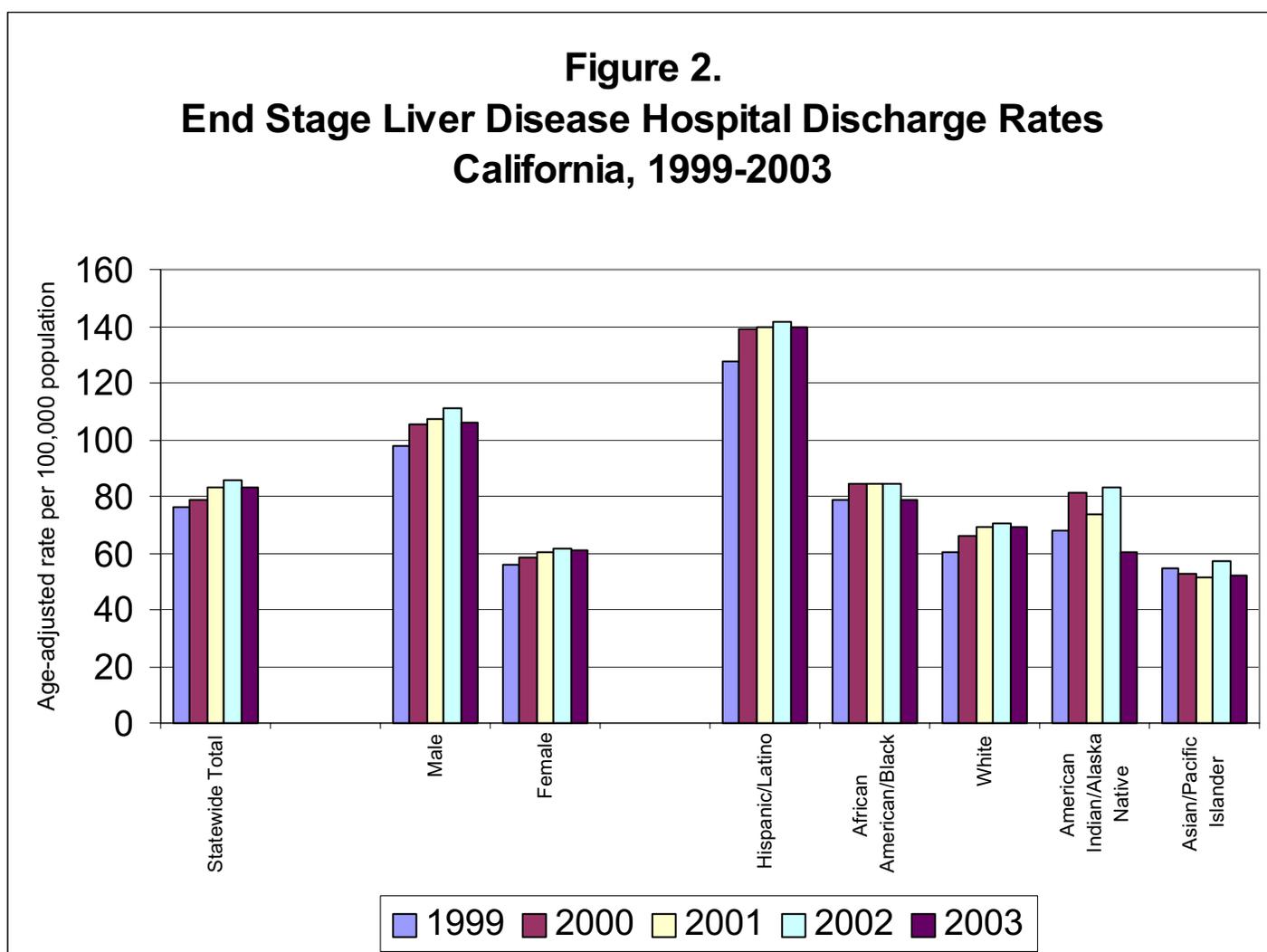


Table 2. End Stage Liver Disease Hospital Discharges and Discharge Rates, By Place of Occurrence, California 1999-2003

	1999		Lower	Upper	2000		Lower	Upper
	Discharges	Rate ¹	95% C.I.	95% C.I.	Discharges	Rate ¹	95% C.I.	95% C.I.
CALIFORNIA TOTAL	23,988	76.1	75.2	77.1	25,555	78.9	77.9	79.8
Race-Ethnicity								
African American/Black	1,513	78.8	74.7	82.8	1,630	84.2	80.1	88.4
American Indian/Alaska Native	138	68.2	56.7	79.7	147	81.3	67.8	94.9
Asian/Pacific Islander	1,766	54.9	52.3	57.5	1,777	52.4	49.9	54.9
Hispanic/Latino	8,197	127.9	125.0	130.8	8,854	138.8	135.6	141.9
White	11,648	60.4	59.3	61.4	12,147	65.9	64.8	67.1
Other/Unknown	726	DNA	-----	-----	1,000	DNA	-----	-----
Gender								
Female	9,126	55.8	54.7	57.0	9,538	58.1	56.9	59.2
Male	14,862	97.6	96.0	99.2	16,015	105.7	104.1	107.4

	2001		Lower	Upper	2002		Lower	Upper
	Discharges	Rate ¹	95% C.I.	95% C.I.	Discharges	Rate ¹	95% C.I.	95% C.I.
CALIFORNIA TOTAL	26,946	83.0	82.0	84.0	28,601	85.5	84.5	86.5
Race-Ethnicity								
African American/Black	1,698	84.7	80.6	88.7	1,753	84.3	80.3	88.2
American Indian/Alaska Native	153	73.8	61.7	85.8	192	83.3	71.2	95.5
Asian/Pacific Islander	1,867	51.6	49.3	54.0	2,169	57.1	54.7	59.5
Hispanic/Latino	9,412	139.9	136.9	142.9	10,099	141.3	138.4	144.2
White	12,883	69.0	67.8	70.2	13,374	70.6	69.3	71.8
Other/Unknown	932	DNA	-----	-----	1,014	DNA	-----	-----
Gender								
Female	10,176	60.3	59.1	61.5	10,687	61.6	60.4	62.7
Male	16,769	107.0	105.4	108.6	17,914	110.8	109.2	112.5

	2003		Lower	Upper
	Discharges	Rate ¹	95% C.I.	95% C.I.
CALIFORNIA TOTAL	28,674	83.2	82.2	84.1
Race-Ethnicity				
African American/Black	1,725	79.0	75.2	82.8
American Indian/Alaska Native	147	60.6	50.5	70.6
Asian/Pacific Islander	2,031	51.9	49.7	54.2
Hispanic/Latino	10,522	140.0	137.2	142.9
White	13,313	69.0	67.8	70.2
Other/Unknown	936	DNA	-----	-----
Gender				
Female	10,891	61.0	59.9	62.2
Male	17,783	106.0	104.5	107.6

SOURCES: CA Office of Statewide Health Planning and Development, Patient Discharge Data, 1999-2003;
 CA Department of Finance, Demographic Research Unit, *Population Projections by Race/Ethnicity for California and Its Counties 2000-2050*, May 2004.

NOTES: Liver disease discharges defined by ICD-9-CM code set (see Table A); principal diagnosis only.

¹ Rate per 100,000 population, age-adjusted using the 2000 US standard population; excludes records with unknown age.

DNA Data Not Available; population denominator data not available.

Liver Transplantation (Table 3, Figure 3)

Data from the UNOS/OPTN indicate that 3,927 persons in California were on the liver transplant waiting list as of December 2004, which represented 23 percent of the 17,330 persons nationally on this listing. A total of 3,386 persons in California received liver transplants during the 1999-2003 time period. Of these, 2,060 (60 percent) were males and 1,326 (40 percent) were females. Examined by race/ethnicity, 1,857 (55 percent) of transplanted persons were White, 939 (28 percent) were Hispanic/Latino, 403 (12 percent) were Asian/Pacific Islander, 149 (four percent) were African American/Black, and the remaining 38 (one percent) were either American Indian/Alaska Native, Multiracial, or Other/Unknown.

The largest proportions of liver transplants in California during the 1999-2003 time period were performed at the UC-Los Angeles Medical Center (n=999; 30 percent), followed by the UC-San Francisco Medical Center (n=527; 16 percent), the Stanford University Medical Center (n=354; 10 percent), the California Pacific Medical Center (n=290; 9 percent), and the Cedars Sinai Medical Center (n=226; 7 percent).

Patient discharge data indicate that total charges for liver transplantations (ICD-9-CM principal procedure code 505) exceeded 1.2 billion dollars (\$1,207,482,094) during the 1999-2003 time period, with an average hospital charge of \$385,434. The majority of these charges (61 percent) were expected to be paid by private insurance, followed by Medi-Cal (18 percent) and Medicare (16 percent). The remaining 15 percent of hospital charges for liver transplantations were expected to be paid by individual payers, or by other government and non-governmental sources.

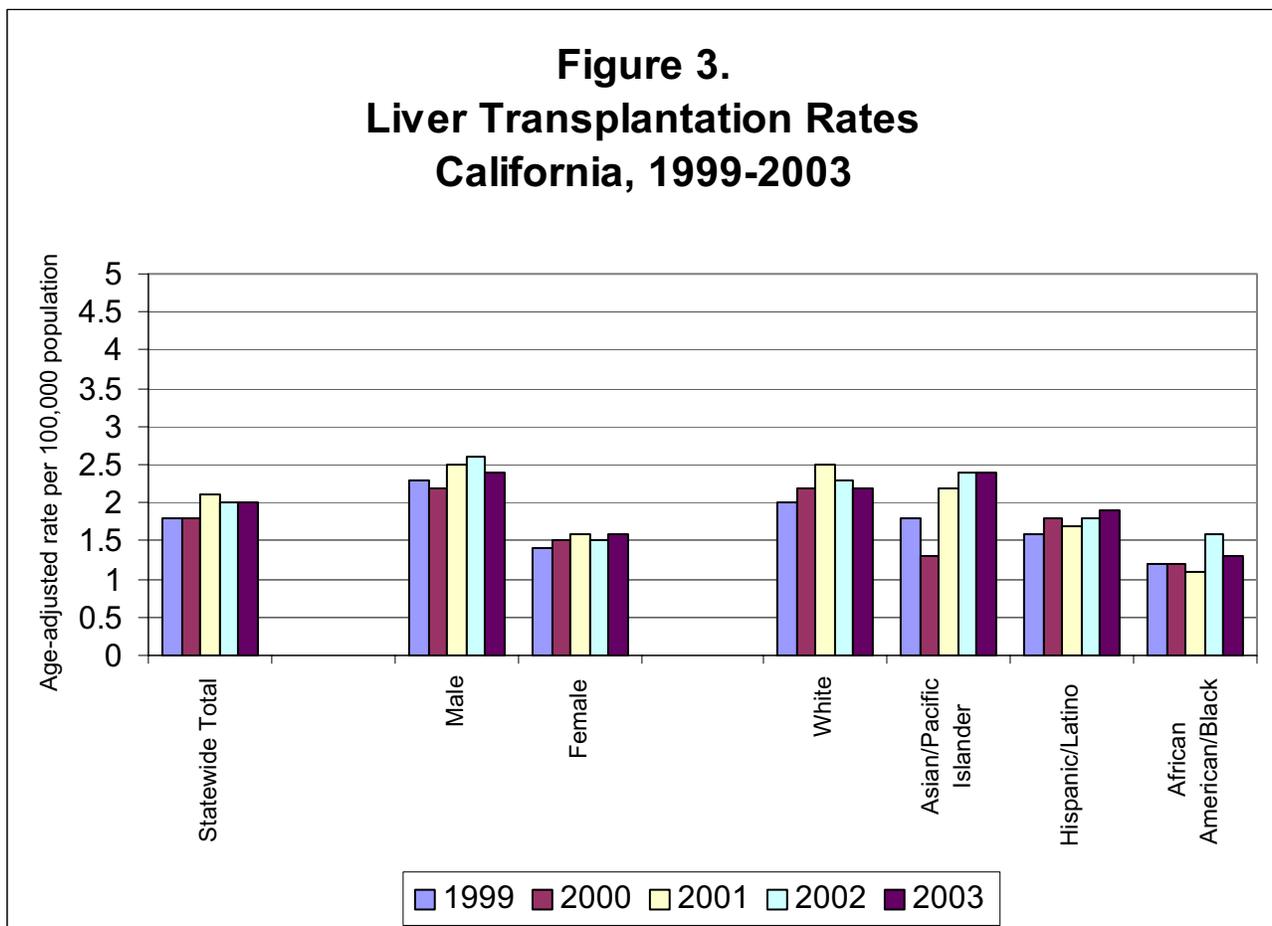


Table 3. Liver Transplants and Transplantation Rates, By Place of Occurrence, California 1999-2003

	1999		Lower	Upper	2000		Lower	Upper
	Transplants	Rate ¹	95% C.I.	95% C.I.	Transplants	Rate ¹	95% C.I.	95% C.I.
CALIFORNIA TOTAL	615	1.8	1.7	2.0	622	1.8	1.7	2.0
Race-Ethnicity								
African American/Black	28	1.2	0.7	1.6	27	1.2	0.7	1.6
American Indian/Alaska Native	4	DSU	-----	-----	1	DSU	-----	-----
Asian/Pacific Islander	68	1.8	1.4	2.2	50	1.3	0.9	1.7
Hispanic/Latino	153	1.6	1.4	1.9	187	1.8	1.5	2.1
White	356	2.0	1.8	2.2	354	2.2	2.0	2.4
Other/Unknown	6	DSU	-----	-----	0	0.0	0.0	0.0
Gender								
Female	235	1.4	1.2	1.6	255	1.5	1.3	1.7
Male	380	2.3	2.0	2.5	367	2.2	1.9	2.4

	2001		Lower	Upper	2002		Lower	Upper
	Transplants	Rate ¹	95% C.I.	95% C.I.	Transplants	Rate ¹	95% C.I.	95% C.I.
CALIFORNIA TOTAL	717	2.1	1.9	2.2	716	2.0	1.9	2.2
Race-Ethnicity								
African American/Black	25	1.1	0.7	1.5	37	1.6	1.1	2.1
American Indian/Alaska Native	6	DSU	-----	-----	2	DSU	-----	-----
Asian/Pacific Islander	89	2.2	1.7	2.7	100	2.4	2.0	2.9
Hispanic/Latino	181	1.7	1.4	2.0	204	1.8	1.6	2.1
White	412	2.5	2.3	2.7	369	2.3	2.0	2.5
Other/Unknown	1	DSU	-----	-----	0	0.0	0.0	0.0
Gender								
Female	287	1.6	1.5	1.8	259	1.5	1.3	1.6
Male	430	2.5	2.3	2.7	457	2.6	2.3	2.8

	2003		Lower	Upper
	Transplants	Rate ¹	95% C.I.	95% C.I.
CALIFORNIA TOTAL	712	2.0	1.8	2.1
Race-Ethnicity				
African American/Black	31	1.3	0.8	1.8
American Indian/Alaska Native	6	DSU	-----	-----
Asian/Pacific Islander	96	2.4	1.9	2.8
Hispanic/Latino	212	1.9	1.6	2.2
White	365	2.2	2.0	2.5
Other/Unknown				
Gender				
Female	288	1.6	1.4	1.8
Male	424	2.4	2.1	2.6

SOURCES: United Network for Organ Sharing (UNOS), Organ Procurement and Transplantation Network (OPTN), December 2004; CA Department of Finance, Demographic Research Unit, *Population Projections by Race/Ethnicity for California and Its Counties 2000-2050*, May 2004.

NOTES: DSU Data Statistically Unreliable due to small number of events.

¹ Rate per 100,000 population, age-adjusted using the 2000 US standard population; excludes records with unknown age.

Discussion

One of the overarching goals of the national *Healthy People 2010* (HP2010) initiative is to eliminate health disparities.²⁵ This goal is supported by specific objectives in 28 Focus Areas, including substance use and abuse. Sustained heavy alcohol consumption is the leading cause of cirrhosis, and some researchers have observed that differences in mortality from liver disease reflect demographic distributions and temporal trends of heavy alcohol consumption in the United States with higher death rates among men, American Indians/Alaska Natives, and Hispanics/Latinos.²⁶⁻²⁸ Changes in alcohol consumption patterns, improvements in disease management and treatment programs for alcoholism, and higher State excise taxes on distilled spirits have all been associated with changes in death rates from cirrhosis.²⁹⁻³²

California data on HP2010 objective 26-2 indicate that cirrhosis death rates have declined somewhat from 11.9 per 100,000 population in 2000 to 11.3 per 100,000 in 2003.³³ Despite this overall decline, gender and race/ethnic disparities persist: death rates for males were twice those for females, and death rates among American Indians/Alaska Natives and among Hispanics/Latinos were three to eight times greater than those for other race/ethnic populations. Furthermore, liver transplantation rates as described in the present report suggest that the racial and ethnic populations most in need of transplants are among the least likely to receive them.

Studies to evaluate the influence of race/ethnicity or socioeconomic status on liver transplantation in California have been sparse, but studies of renal transplantation suggest that payer status (i.e., type of insurance) can impact access to care.³⁴⁻³⁶ It is reasonable to speculate that similar disparities exist in access to liver transplantation in California, and may be linked to racial, ethnic, socio-economic status (including health insurance status), and geographic proximity to transplantation centers. These factors are being examined in a related study expected to be completed this year.³⁷

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Currently more than 18,000 Californians are waiting for a life-saving organ transplant. Tragically, one-third of the persons now waiting for a donation will die due to the critical shortage of organ donors. In response to this need, the Donate Life California Registry was created. At this time, the registry is accessible online via Internet for those wanting to sign up to be a donor. The Donate Life California Registry is seeking to make this tool as accessible as possible for all Californians, and is actively letting the public know about the Web sites: www.donatelifecalifornia.org and www.donevidacalifornia.org (Spanish).

Historically, while signing a donor card and placing a pink "donor dot" on a driver's license has served as an important symbol of one's intent to donate organs and/or tissues, it does not record one's wishes on an actual list or registry. When launched in April 2005, California will join 36 other states in allowing its residents for the first time to officially register their commitments to become organ and/or tissue donors.

A successful donor registry will positively impact California and the nation as a whole - saving lives and greatly cutting the cost of caring for people with end stage organ failure. The Department of Health Services encourages all those interested in organ donation to visit the Web site and register, and to share information on the Registry with others.

This Data Summary was prepared by Jim Sutocky, Research Program Specialist, CDHS Center for Health Statistics, Office of Health Information and Research, 1616 Capitol Avenue, Suite 74.165, MS 5101, P.O. Box 997410, Sacramento, CA 95899-7410, Phone: (916) 650-6871, E-mail: jsutocky@dhs.ca.gov, and by Sripriya Balasubramanian, M.D., Staff Physician, UC Davis Medical Center, 4150 V Street, PSSB #3500, Sacramento, CA 95817, Phone: (916) 734-3759.