REPORT TO THE THIRTY-FIRST LEGISLATURE STATE OF HAWAII 2021

PURSUANT TO ACT 2, SESSION LAWS OF HAWAII 2019 HB2739 H.D. 1, HRS 327L

ESTABLISHES THE OUR CARE, OUR CHOICE ACT

Prepared by the Department of Health Office of Planning, Policy, and Program Development
July 1, 2021

Executive Summary

This annual report covers data collected for the period of January 1, 2020 through December 31, 2020. Pursuant to Act 2 Session Laws of Hawaii (SLH) 2018 and following each full year, the legislative annual report will be submitted on or before July 1. The required data collected from participating attending physicians are qualified patients who received a written prescription.

In 2020, thirty-seven (37) patients qualified and received aid-in-dying prescriptions. Thirty-two (32) patients were reported to have died of which twenty-five (25) patients self-administered the aid-in-dying medication. Some form of cancer was cited as the primary underlying illness of those patients who died. The status of four (4) qualified patients is unknown. An unknown patient status occurs when a required Follow-up Form or optional Final Attestation Form is not received by the Department. DDMP2 was the primary medication prescribed with DDMA being least prescribed whereas there was one complication with ingesting DDMP2.

Fourteen (14) attending physicians wrote prescriptions during this reporting period. Of those attending physicians who participated, three (3) were located on the neighbor islands: one (1) on Hawaii island and two (2) on Maui. However, regarding patient access for 2019 and 2020, there were a total of twenty-two (22) attending physicians who wrote a prescription in the state.

The eligibility process from the first oral request to the date of receipt of the written prescription was an average of <u>45 days</u>. The average waiting period between the first and second oral request was <u>30 days</u> ranging from 20 days to 164 days. Patients from within large-networked organizations such as Kaiser Permanente had the shortest waiting periods compared to private practicing providers in the community.

During the 2020 year, the Department was invited and participated in two community provider education webinars hosted by Compassion and Choices on June 16, 2020 and November 4, 2020. You may contact Compassion and Choices or access available webinars here.

Introduction

Act 2 SLH 2018 authorized Hawai'i residents with a terminal illness and six (6) months or less to live may request medical-aid-in-dying prescriptions under the OCOCA. To help patients and providers understand the process required by law, the DOH launched a new page on its website where all required forms, instructions, and frequently asked questions can be accessed.

The law establishes eligibility criteria and safeguards to ensure a secure, compassionate, and patient-centered end-of-life process. There are also additional regulatory requirements to address concerns about misuse. Patients interested in seeking a prescription are encouraged to enroll in hospice.

To meet eligibility criteria patients must be:

- 1. Age 18 or older an a Hawai'i resident;
- 2. Able to take the prescribed medication themselves;
- 3. Able to make two oral requests not less than 20 days apart to their attending physician;
- 4. Able to provide one written request after meeting eligibility criteria from all three (3) health care providers; and
- 5. Mentally capable to make an informed decision.

<u>First oral requests:</u> Physicians who receive a request for medical aid in dying from a patient are highly encouraged to document the date of the oral request in the medical record. A participating attending physician can use the date of the patient's first oral request documented in the medical record by another physician.

Provider forms required to be submitted to the Department, details of the eligibility process, and frequently asked questions may be accessed on the DOH's website here: http://health.hawaii.gov/opppd/ococ/

Implementation Review and Analysis

There is no funding appropriated to the Department for its role in implementing, collecting, and reporting requirements under the law. The Department maintains its role by leveraging time as needed from one staff member situated in the Office of Planning, Policy, and Program Development. Despite shifting work priorities and challenges related to organizational demands due to COVID-19, the responsibilities of the Department related to medical aid and dying continued and were met as required.

OCOCA Advisory Board

In 2020, the Department welcomed a new Director of Health, Dr. Elizabeth Char, on September 16, 2020 to replace the former Director Bruce Anderson who retired. The OCOCA Board Members is updated below to reflect the changes.

Member Role	Board Member
Chair – Director of Health	Elizabeth Char, M.D.
Medical Educator	Lee Buenconsejo-Lum, M.D.
Palliative Care Specialist	Rae Seitz, M.D.
Non-Medical Community Member	Malachy Grange, R.N.
Hospice Care Specialist	Brenda Ho, R.N.

OCOCA Advisory Board Staff: There were two DOH employees who served as staff to the OCOCA Advisory Board. Staff members located in the Office of Planning, Policy, and Program Development are Lorrin J. Kim, Chief Policy Officer, and Laura K.M. Arcibal, State Telehealth and Health Care Access Coordinator.

Board Meeting Minutes:

There were no board meetings held in 2020. All board meeting minutes may be accessed here: https://health.hawaii.gov/opppd/meetings-reports/

Community Engagement and Education Events

Community inquiries to the DOH are minimal via email or phone call and are responded to promptly. Information requested is generally from the community requesting data and from providers seeking clarification on a specific process. Responses are resolved directly, and as needed, with guidance from the Deputy Attorney General's office.

Data Collection

Reportable Information

The DOH collected the following reportable information during the reporting period.

- The number of qualified patients for whom a prescription was written: 37
- The number of known qualified patients who died each year for whom a prescription was written:

2019	2020
27	32

- The cause of death of the qualified patient(s): metastatic lung cancer, esophageal cancer, lung cancer, metastatic prostate cancer, corticobasal degeneration, metastatic prostate cancer, cardiac amyloid multiple myeloma, metastatic colon carcinoma, progressive idiopathic pulmonary fibrosis, heart failure end stage, prostate cancer, metastatic lung cancer, progressive bladder cancer, breast cancer stage IV, congestive heart failure, prostate cancer with bone metastases, COPD with cancer, COPD end stage, advanced hypopharynx cancer, metastatic colon cancer, glioblastoma, stage IV castrate-resistant prostate cancer, malignant melanoma, and kidney cancer.
- The total number of prescriptions written: <u>37</u>
- The total number of prescriptions for all years beginning with 2019: <u>67</u>
- The total number of qualified patients who died while enrolled in hospice or other similar palliative care program: 28
- The number of known deaths in Hawaii <u>from a prescription written</u> per five-thousand deaths in Hawaii: <u>42</u>
- The number of attending providers who wrote prescriptions: <u>14</u>
- Location of attending providers who wrote prescriptions:

Kauai	Oahu	Maui	Hawaii Island
0	11	2	1

• Of the people who died as a result of self-administering a prescription, the individual's (Blank indicates no information provided on the form):

Age	Education	Race	Sex	Type of Insurance	Underlying Illness
87	8 th grade	Asian	Male	Medicare/Private	Lung Cancer
80	Some college	White	Female	Medicare	Esophageal
	Some conege	vv iiite	1 chiare	Wiedicure	Cancer
69	Some college	White	Female	Medicare	Lung Cancer
73	Bachelors	White	Male	Medicare	Metastatic Metastatic
13	degree	vv inte	TVIAIC	Wiedicure	Prostate Cancer
76	Bachelors	White	Female	Private	Corticobasal
70	degree	***************************************	Temare	1111446	Degeneration
76	Bachelors	White	Male	Medicare	Metastatic
	degree		112012	1,100,100,10	Prostate Cancer
65	Doctoral	White	Male	Medicare	Cardia Amyloid
					Multiple
					Myeloma
68	Bachelors	White	Male	Medicare	Metastatic Colon
	degree				Carcinoma
85	Blank	Asian	Male	Medicare	Progressive
					Idiopathic
					Pulmonary
					Fibrosis
81	High School	White	Female	Medicare	Heart Failure End
					Stage
80	Blank	Asian	Male	Medicare	Prostate Cancer
54	Blank	Pacific	Male	MedQuest	Metastatic Lung
		Islander			Cancer
82	Blank	White	Female	Medicare	Progressive
					Bladder Cancer
78	Bachelors	White	Female	Medicare	Breast Cancer
	degree				Stage IV
78	Blank	White	Male	Medicare	Congestive Heart
					Failure
77	Some	Asian	Male	Medicare	Prostate Cancer
	college; no				with Bone
	degree				Metastases
74	High School	White	Male	VA	COPD with
					Cancer
69	High School	White	Male	Private	COPD End Stage
73	High School	Asian	Male	Medicare	Advanced
					Hypopharynx
					Cancer
71	Bachelors	White	Female	Medicare	Metastatic Colon
	degree				Cancer

79	Masters	White	Male	Medicare	Glioblastoma
	degree				
73	Some	White	Male	VA	Stage IV Castrate-
	college; no				resistant Prostate
	degree				Cancer
84	Masters	White	Male	Medicare-	Malignant
	degree			Medicaid	Melanoma
66	High School	White	Male	Medicare	Stage IV Lung
					Cancer
94	Unknown	White	Female	Medicare/Tricare	Kidney Cancer

Additional notes regarding the data:

During the 2020 reporting year, the status of four (4) patients is unknown. An unknown patient status occurs when a required Follow-up Form is not received by the Department. If the Department receives the Final Attestation form instead of the Follow-up Form the patient is counted as a qualified patient who self-administered the medication.

The Department is required to collect and report on qualified patients who received a prescription. The data does not include patients who died prior to receiving a prescription, patients who were ineligible, and patients who provided their first oral request and are currently in-process of being qualified.

Legislative Recommendations

In closing, patient access continues to remain a challenge especially for patients on the neighbor islands and due to physician shortages across the state. The DOH recommends the following changes to the OCOCA.

- 1. Waiver of any waiting periods if the attending provider and consulting provider agree that patient death is likely prior to the end of the waiting periods.
- 2. Given access to health care providers is limited, the DOH recommends authorizing advance practice registered nurses to serve as attending providers for patients seeking medical aid in dying.

If you should have any questions regarding the report, please contact the DOH Office of Planning, Policy, and Program Development at 586-4188.