REPORT TO THE THIRTIETH LEGISLATURE

STATE OF HAWAII

2020

PURSUANT TO ACT 2, SESSION LAWS OF HAWAII 2019

(HB2739 H.D. 1)

Prepared by the Department of Health

Office of Planning, Policy, and Program Development

July 1, 2020

Executive Summary
The information compiled in this report covers the collection period from January 1, 2019 through end of December 31, 2019.

During this reporting period, there were a total of thirty (30) qualified patients who received aid-in-dying prescriptions of which twenty-three (23) patients died. Of those patients who died, there where fifteen (15) patients who ingested the aid-in-dying medication. DDMP2 was the primary medication prescribed with DDMA being least prescribed. There were no complications cited.

Some form of cancer was cited as the underlying illness for the majority of patients who died. The status of three (3) qualified patients who received the aid-in-dying medication is unknown. An unknown patient status occurs when a follow-up form is not received by the Department. Follow-up forms are dependent upon the patient's designee to return the form to the attending physician who then mails the form to the Department as report #2.

The eligibility process from the first oral request to the date of receipt of the written prescription was an average of 35 days with the shortest period being 21 days. The average waiting period between the first and second oral request was 28 days ranging from 20 days to 100 days. Patients who received services from within large, well-networked organizations had the shortest waiting periods compared to private practicing providers in the community. Thirteen (13) attending physicians wrote prescriptions during this reporting period. Only one (1) attending physician was located on the neighboring islands on Hawaii Island.

2020 Preliminary Review

Given the implementation of the law is still quite new in Hawaii, the Department is providing the following data for information awareness purposes. From January 1, 2020 through June 26, 2020, there was a total of twenty-four (24) qualified patients who received medical aid-in-dying prescriptions which is an increase from last year compared to this time last year. Thirteen (13) patients ingested the prescribed medication whereas DDMP2 is still the most prescribed. It took an average of 39 days from the first oral request to the date of receipt of the written prescription request whereas one patient process took 179 days. There was also one complication of the prescribed medication, DDMP2, where the patient took over 6 hours until death compared to the 4 hours which is "outside of the clinical guidelines" as cited by the attending provider.

During the 2020 year, there were also five (5) new attending providers. One of the attending providers reside in Maui. Amongst the consulting provider group there were two (2) new physicians on the neighbor islands who could also serve as attending physicians, one on Kauai (Lihue) and another on Hawaii island (Waimea).

Introduction

Act 2, Session Laws of Hawaii (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.

Details of the eligibility process may be accessed on the DOH's website:
http://health.hawaii.gov/opppd/ococ/

OCOCA Advisory Board

The DOH implemented Act 2 by establishing a five-member OCOCA Advisory Board that held its first meeting on July 31, 2018 followed by consecutive meetings on August 31, 2018, November 29, 2018, and December 7, 2018.

The OCOCA Board Members are listed in the table below:

Member Role	Board Member
Chair – Director of Health	Bruce S. Anderson, Ph.D.
Medical Educator	Lee Buenconsejo-Lum, M.D.
Palliative Care Specialist	Rae Seitz, M.D.
Non-Medical Community Member	Malachy Grange
Hospice Care Specialist	Brenda Ho

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.

Permitted Interaction Groups:

Two permitted interaction groups were established following board approval. One permitted interaction group was formed to review and comment on the development of the website and forms. The second permitted interaction group was formed to address community resources. Under the review, guidance, and final approval of the OCOCA Advisory Board, the website and its forms were finalized and made accessible online before the law went into effect on January 1, 2019.

Board Meeting Minutes:

Board meeting minutes may be accessed here: https://health.hawaii.gov/opppd/meetings-reports/

OCOCA Advisory Board discussions resulted in the development of a website to 1) inform both patients and their families, and health care providers of the law and its process; and 2) provide forms for both providers and patients implement the process, document eligibility, and report information required under Act 2. To start the eligibility process, patients and providers must access the website and download its forms here: https://health.hawaii.gov/opppd/ococ/

On the website, patients are informed to start early and talk with their attending physician. Patients are strongly encouraged to enroll in hospice to ensure all end of life care options are available to them and to become familiar with eligibility requirements as he or she works closely with their attending physician and his or her health care team. Health care providers are also informed on the website about the law, the eligibility timeline, and criteria, and the OCOCA required forms reportable to the DOH.

Following execution of the website and its forms, the DOH received its first completed forms in March 2019. On the first report, it took 48 days between the first oral request to the date of the patient's written prescription. The waiting period between the first oral request and second oral request was 24 days. To date, the average is 34 days between the first oral request to the date of written prescription compared to 48 days. And the current average waiting period is 27 days. The longest waiting period of one patient was 100 days between the first and second oral request compared the minimum requirement of 20 days.

Community inquiries to the DOH are minimal via email or phone call and are responded to promptly. Information requested is generally on the gathering of information about the OCOCA for which the response is either to direct the individual to the website or answered directly.

Reportable Information
The DOH collected the following reportable information during the period January 1, 2019 through December 31, 2019 (envelopes post-dated not later than December 31, 2019). The next report will cover the period January 1, 2020 through December 31, 2020. Below is the reportable information:

- The number of qualified patients for whom a prescription was written: **30**
- The number of known qualified patients who died each year for whom a prescription was written: **23**
- The cause of death of the qualified patient(s): metastatic lung cancer, prostatic carcinoma, head and neck cancer, metastatic malignant melanoma, amyotrophic lateral sclerosis, multiple myeloma, Parkinson's disease, metastatic anal carcinoma, metastatic breast cancer, COPD end state, gallbladder cancer, brain cancer, pharyngeal cancer, esophageal cancer, metastatic pancreatic cancer, and bronchiolar adenocarcinoma.
- The total number of prescriptions written: **30**
- The total number of prescriptions for all years beginning with 2019: **30**
- The total number of qualified patients who died while enrolled in hospice or other similar palliative care program: **19**
- The number of known deaths in Hawaii from a prescription written per five-thousand deaths in Hawaii: **15**
- The number of attending providers who wrote prescriptions: **13**
- Location of attending providers who wrote prescriptions:

Kauai	Oahu	Maui	Hawaii Island
0	12	0	1

- Of the people who died as a result of self-administering a prescription, the individual's:

Age	Education	Race	Sex	Type of Insurance	Underlying Illness
75	blank	Caucasian	Male	Medicare/Private	Prostatic Carcinoma
68	Bachelor	Caucasian	Male	Medicare/Private	Progressive head and neck cancer

83	blank	Caucasian	Female	Private	Metastatic Malignant Melanoma
73	Some college	Asian	Male	Medicare/Private	ALS
64	Doctoral	Caucasian	Male	Medicare/Private	Parkinson’s Disease
76	Bachelor	Native Hawaiian	Male	Medicare/Private	Lung Cancer
85	blank	Asian	Male	Medicare/Private	COPD End Stage
71	blank	blank	Female	blank	Gallbladder cancer
66	blank	Caucasian	Female	Medicare/Private	Brain Astrocytoma
65	blank	Caucasian	Male	Medicare/Private	Pharyngeal Cancer
80	Bachelor	Caucasian	Female	Medicare	Bronchoalveolar Adenocarcinoma
80	Masters	Hispanic/Latino	Male	United Health Care	Parkinson’s Disease
66	Masters	Caucasian	Male	Medicare	Progressive Multiple Sclerosis
80	blank	Caucasian	Male	Medicare	Metastatic Lung Cancer
57	Bachelor	Asian	Male	Private	Metastatic Pancreatic Cancer

Community Education Events

To further inform patients and health care providers, continuing medical education events were held on February 1 and 2, 2019 at the Queen’s Conference Center Auditorium and University of Hawaii, John A. Burns School of Medicine, respectively. Other learning opportunities were provided in the private sector, for example at the annual meeting of the Hawaii Pharmacists Association and the annual meeting of the Health Information Management Association of Hawaii.

On October 21, 2019, a health care provider summit was held to capture feedback from participating health care providers, care navigators and support staff. Notes collected from the facilitated meeting captured the group’s feedback that is summarized in the bulleted items below.

- Recognized the need for patient continuity and navigation such as the use of care navigators to assist patients through the process in identifying and accessing participating providers in the community;
- Recognized the need for continuity and navigation of the process amongst providers in the community versus within large integrated systems such as Kaiser Permanente;
- Recognized the importance of developing relationships amongst community providers in the palliative care, hospice care, and health care provider communities especially in private practice versus large integrated systems such as Kaiser Permanente;
- Recognized the challenges in accessing available and participating health care providers and especially mental health care providers;
- Recognized process recommendations whereas the waiting period is too long (i.e. patient illness progresses whereby he or she is unable to swallow the medications or limited access to attending physicians who then take leave); and
- Recognized concerns about medication disposal and need for information about its process.

Legislative Recommendations

In closing, 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.