

2015

# Increasing Provider Awareness Regarding Act 39 in Middlebury Vermont

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## Recommended Citation

Concannon, Kyle F., "Increasing Provider Awareness Regarding Act 39 in Middlebury Vermont" (2015). *Family Medicine Clerkship Student Projects*. Book 106.

<http://scholarworks.uvm.edu/fmclerk/106>

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**ACT 39 – PROVIDER/PATIENT  
EDUCATION REGARDING THE  
PATIENT CHOICE AND  
CONTROL AT END OF LIFE ACT  
IN END OF LIFE CARE**

**MIDDLEBURY FAMILY HEALTH**

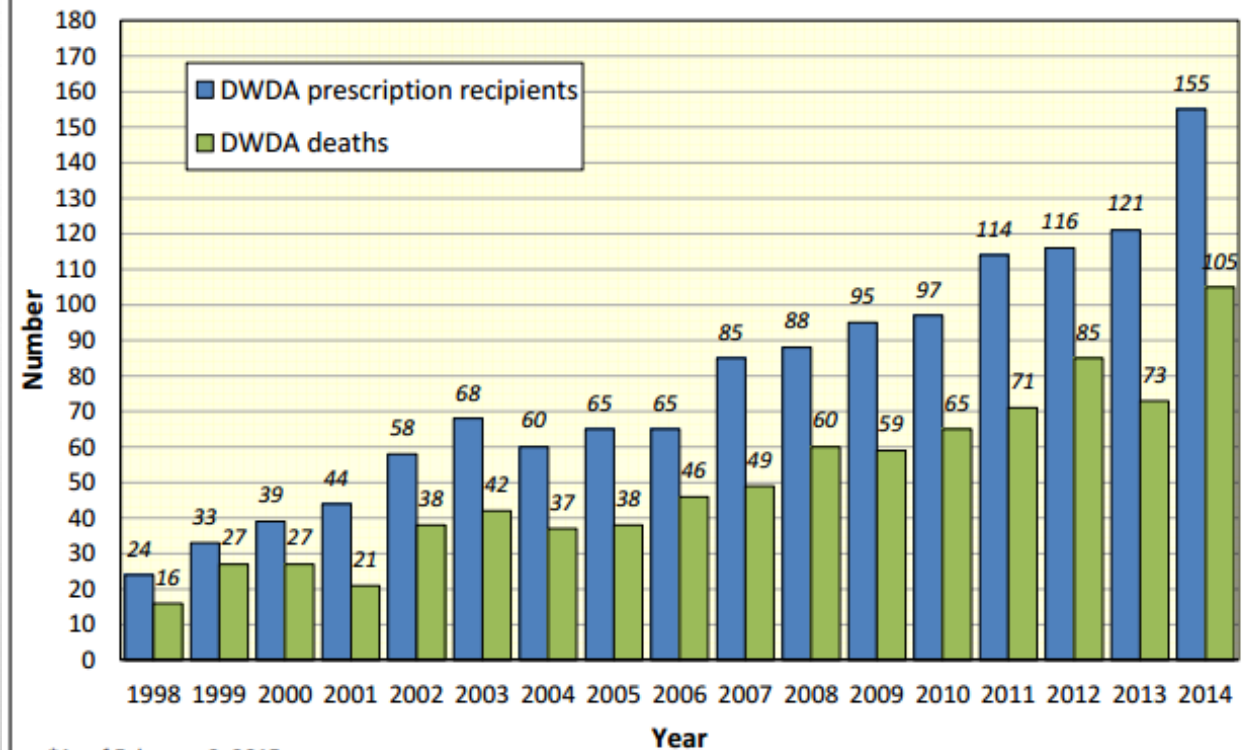
**KYLE CONCANNON - NOVEMBER 2015**

**MENTORS: DRS. BARNARD, PULS, ANDERSON-SWASEY,  
FULLER, LARSON, MILLER.**

# UTILIZATION OF “DEATH WITH DIGNITY” ACT IN OREGON

- Vermont passed Act 39 (Patient Choice and Control at End of Life) May of 2013, however many physicians are unfamiliar with the protocol.
- If Vermont’s trends emulate that of Oregon’s this will become a frequent conversation. At Middlebury Family Health, two patients had requested Patient Choice and Control at End of Life information within 30 days and providers found that they had no resources on hand to guide them in the process.
- After Oregon passed a Death with Dignity Act (DWDA), the following 16 years demonstrated a 6-fold increase in prescriptions and a total of 1173 prescriptions given. This suggests a tremendous need for primary care provider confidence and education in the Patient Choice and Control at End of Life act.

Figure 1: DWDA prescription recipients and deaths\*, by year, Oregon, 1998-2014



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## COST OF END OF LIFE CARE IN VT AND CAUSE MORTALITY

### Vermont Mortality in 2012

U.S. LEADING CAUSES OF DEATH, 2012	TOTAL DEATHS	DEATH RATE***	STATE RANK*	U.S. RATE**
1. <a href="#">Heart Disease</a>	1,206	150.6	37 <sup>th</sup>	170.5
2. <a href="#">Cancer</a>	1,325	165.0	27 <sup>th</sup> (tie)	166.5
3. <a href="#">Chronic Lower Respiratory Diseases</a>	364	46.3	19 <sup>th</sup> (tie)	41.5
4. <a href="#">Stroke</a>	281	35.9	30 <sup>th</sup>	36.9
5. <a href="#">Accidents</a>	333	47.4	14 <sup>th</sup> (tie)	39.1
6. <a href="#">Alzheimer's Disease</a>	284	36.3	5 <sup>th</sup>	23.8
7. <a href="#">Diabetes</a>	168	21.4	26 <sup>th</sup>	21.2
8. <a href="#">Influenza/Pneumonia</a>	81	9.9	46 <sup>th</sup>	14.4
9. <a href="#">Kidney Disease</a>	21	2.6	50 <sup>th</sup>	13.1
10. <a href="#">Suicide</a>	87	13.0	30 <sup>th</sup> (tie)	12.6

- IN 2014 VERMONT SPENT OVER \$1.5 BILLION IN MEDICAID.
- IN 2009 VERMONT SPENT OVER \$940 MILLION IN MEDICARE.
- OVER 25 PERCENT OF MEDICARE COSTS ARE TYPICALLY SPENT ON THE 5% OF RECIPIENTS WHO DIE EACH YEAR.
- GIVEN THAT VERMONT HAS A HIGH PERCENTAGE OF OLDER INDIVIDUALS, IT IS POSSIBLE THAT WE SPEND MORE THAN AVERAGE ON END OF LIFE CARE.

# 4a

## PRIMARY CARE PHYSICIAN CONSIDERATIONS:

- KM - “I DIDN’T EVEN KNOW VERMONT HAD IT [THE PATIENT CHOICE AND CONTROL AT END OF LIFE ACT] UNTIL A PATIENT TOLD ME THE OTHER DAY ABOUT IT. I DID MY TRAINING IN PHILADELPHIA SO I DIDN’T EVEN KNOW ABOUT IT. IT’S NOT SOMETHING I WOULD KNOW HOW TO SET UP ON MY OWN. I WOULD LIKE MORE INFORMATION.”
- EF – “I HAVE NOT HAD A PATIENT SINCE THE ACT HAS BEEN IN PLACE THAT IT WOULD BE WARRANTED FOR. PRIOR TO THAT BEING ENACTED, THERE WERE SEVERAL PATIENTS THAT WOULD HAVE BEEN VERY HELPFUL FOR THAT TO HAVE BEEN ENACTED. SINCE IT DOESN’T COME UP THAT OFTEN FOR US I WOULD PROBABLY WORK WITH A PALLIATIVE CARE SPECIALIST. “
- WP – “I THOUGHT THERE WAS NEVER A TIME I WOULD NEED THIS BECAUSE I THOUGHT HOSPICE CARE WAS SO GOOD. THIS IS THE FIRST TIME IT CAME UP FOR ME [REFERRING TO A PATIENT WHO RECENTLY REQUESTED THE END OF LIFE MEDICATION]. MY TAKE HAS ALWAYS BEEN THAT WITH GOOD HOSPICE CARE YOU CAN MAKE SURE PEOPLE ARE COMFORTABLE AND HAVE GOOD END OF LIFE CARE. SO IT’S DEFINITELY A SHIFT IN MY THINKING. BUT I ALSO HAVEN’T DEALT WITH ANYONE WHOSE HAD ALS BEFORE, AND ITS NOT A DISEASE OF PAIN SO MUCH AS PROGRESSIVE DISABILITY, WHICH DOESN’T LEND ITSELF TO HOSPICE AS MUCH AS IT DOES TO ACT 39.”

4b

# PALLIATIVE CARE PHYSICIAN AND PATIENT CONSIDERATION

- PALLIATIVE CARE PHYSICIAN DB – “I BELIEVE THERE IS A NEED FOR BROAD EDUCATION ACROSS THE STATE. THE PASSAGE OF THE LAW PROVIDES AN OPPORTUNITY TO EDUCATE PROVIDERS, NOT ONLY ABOUT THE IMPORTANT STEPS OF THE LAW, BUT ALSO ABOUT THE IMPORTANCE OF EXCELLENT END OF LIFE CARE, COMMUNICATING ABOUT PATIENT PRIORITIES AND IDENTIFYING AND TREATING SUFFERING.”
- ACT 39 PATIENT KS – “I NEVER THOUGHT I WOULD ACTUALLY NEED THIS BUT NOW I’M 93 AND CANCER PAIN, I HEAR, IS MUCH DIFFERENT FROM OTHER PAIN. AT THIS POINT I REALLY JUST WANT IT AS AN OPTION FOR IF I EVER REALLY DO NEED IT. I WANT TO MAKE SURE I HAVE THE OPPORTUNITY TO TAKE IT BEFORE I AM PHYSICALLY UNABLE TO [REFERRING TO THE SELF-ADMINISTER STIPULATION OF THE LAW].”

# 5

## INTERVENTION AND METHODOLOGY

- WITH THE GOAL OF INCREASING CONFIDENCE AND COMFORTABILITY AROUND DISCUSSING THE DWDA AMONG PATIENTS WHO QUALIFY AND WOULD BE GOOD CANDIDATES, A DOCUMENT WAS PROVIDED TO THE PRACTITIONERS OF MIDDLEBURY FAMILY HEALTH.
- THE DOCUMENT INCLUDED THE FOLLOWING:
  - AN ABRIDGED, EASY TO UNDERSTAND, PROTOCOL INCLUDING THE FUNDAMENTAL STEPS OF ACT 39.
  - ONLINE RESOURCES/HOTLINE FOR GUIDANCE IN DISCUSSING END OF LIFE CARE INCLUDING ACT 39.
  - COPIES OF THE REQUIRED DOCUMENTATION.
  - OREGON'S DWDA FREQUENCY AND DEMOGRAPHIC STATISTICS FROM 1998 TO 2014.
  - STATISTICS REGARDING VERMONT PHYSICIAN SENTIMENT REGARDING ACT 39 FROM A STUDY PUBLISHED IN 2007 FROM THE UVM COLLEGE OF MEDICINE.
  - TOP 10 CAUSES OF MORTALITY IN VERMONT IN 2012

# 6

## PHYSICIAN RESPONSE

- DB – “THE PACKET IS HELPFUL IN THE NUTS AND BOLTS OF THE LAW. HAVING FOLKS UNDERSTAND THE REQUIREMENT AND STEPS FOR REPORTING ARE VERY HELPFUL.”
- LL – “I THOUGHT THE SUMMARY WAS COMPLETE AND CONCISE WHICH IS HELPFUL. THE LAW ITSELF IS VERY REDUNDANT AND THE SUMMARY HELPED WITH THAT. I SUGGESTED HE MAKE IT AS A CHECK LIST AND KEEP IT IN CHRONOLOGICAL ORDER. THIS WILL BE VERY HELPFUL AS WE MOVE FORWARD WITH THE FIRST PATIENT THAT I HAVE HAD REQUEST THIS.”
- WP – “THE ACT 39 PACKET IS A CONCISE COMPILATION FOR PRACTITIONERS. IT GIVES VALUABLE INFORMATION FOR ANYONE WHO MAY BE ASKED ABOUT THE LAW AND PRACTICAL INFORMATION FOR THE PROCESS IF A PATIENT ELECTS TO USE THIS OPTION FOR CARE. “



# 7

## EFFECTIVENESS/LIMITATIONS

- SUBJECTIVELY, THE INTERVENTION WAS EFFECTIVE IN INCREASING PHYSICIAN AWARENESS AND CONFIDENCE IN DISCUSSING ACT 39 AMONG THOSE WHO RECEIVED THE INFORMATION PAMPHLET.
- LEGISLATURE MAY CHANGE IN THE COMING YEARS. THIS WILL REQUIRE AN UPDATE OF THIS INTERVENTION.
- A VERY LIMITED PORTION OF VERMONT CLINICIANS RECEIVED THIS INTERVENTION.
- THERE IS CURRENTLY NO PUBLISHED DATA ON THE USAGE OF ACT 39 IN VERMONT.
- MANY PATIENTS STILL DO NOT KNOW ABOUT THE ACT PRIOR TO ASKING ABOUT ALTERNATIVES DURING END OF LIFE CARE CONVERSATIONS.
- THERE WAS NO PROCESS IN PLACE TO INTEGRATE THIS INFORMATION INTO REGULAR PATIENT CARE AT A SPECIFIC POINT.

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## RECOMMENDATIONS FOR FUTURE PROJECTS

- DISTRIBUTE INFORMATION TO A LARGER SCOPE OF PATIENTS/PROVIDERS.
- WORK ON INTEGRATING ACT 39 OPTION INTO THE TRADITIONAL END OF LIFE CONVERSATION.
- ASSESS THE GENERAL POPULATION PERCEPTIONS AND LEVEL OF AWARENESS OF THE ACT.
- THERE IS A STATEMENT IN THE LAW THAT INDIVIDUALS MUST BE CAPABLE TO MAKE THE DECISION AT THE TIME OF REQUEST. THIS MAKES IT HARD IN MANY PROGRESSIVE DISEASES IF INDIVIDUALS WOULD LIKE THE OPTION WHEN THEY DO HAVE CAPACITY AND THEN LOSE CAPACITY AS THERE DISEASE PROGRESSES. A FUTURE PROJECT COULD WORK IN SOME REGARD ON THIS DILEMMA.

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