Issue 2

April 2018

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VA Portland Health Care System Health Services Research & Development

What to Do When A Patient With Serious Advanced Illness Stops Eating

and Drinking

When a terminally ill patient requests options for hastening death, what is a clinician to do? One option that deserves close consideration is the refusal of all food and liquid, according to CIVIC's **Dr. Linda Ganzini**.

Called Voluntarily Stopping Eating and Drinking (VSED), it is a patient-driven process that is slow enough to allow patients to "say goodbye" – or change their mind along the way. Both of these features can make it an advantageous option for patients with advanced illness wishing to hasten death. VSED does not directly require clinician participation or approval. Still, clinician involvement is vital to alleviate the potential discomfort of VSED and to provide support for caregivers, according to Dr. Ganzini and a team of experts who recently published a review on VSED in the JAMA-Internal Medicine.

Although legal in every state, there are important ethical considerations. For instance, how should VSED be handled when a patient becomes mentally incapacitated due to illness or

Table. Options to Potentially Hasten Death

Potential Last Resort Option	Current Legal or Ethical Status in United States and Canada
Medications such as opiates for severe pain/dyspnea used proportionately	Legal and ethically accepted
Stopping or not starting life-sustaining therapy	Legal and ethically accepted
Palliative sedation, potentially to unconsciousness	Legally accepted Ethically controversial if patient or physician's intention is to hasten death
Voluntarily stopping eating and drinking	Not illegal; legality not tested Ethically controversial
Physician-assisted death (aka physician-assisted suicide or medical aid in dying)	Legal in 6 US states; all of Canada Illegal in >30 states and uncertain in others ¹¹ Ethically controversial
Voluntary active euthanasia	Illegal in all US states Legal in Canada Ethically controversial

or age-related diseases (e.g., dementia, Alzheimer's disease, etc.)? What are the implications when caregivers become involved in the withholding food and liquid from patients deemed mentally impaired?

Dr. Ganzini believes these issues will only become more a frequent consideration as baby boomers age and the number of older, terminally ill patients rises. Currently, baby boomers make up roughly 20% of the U.S. population.

Read more about Dr. Ganzini's study HERE



Upcoming Events

HSR&D CIVIC Research Conferences, Fridays from 9:30 a.m. – 11:00 a.m. Room 214, Building 6. Unless otherwise noted.

April 20th, 2018
Dr. Ben Morasco Presents:
Cannabis and Pain.
Drs. Vincent Fan and Dave Coultas Presents:
A Community Health Worker Intervention for COPD.

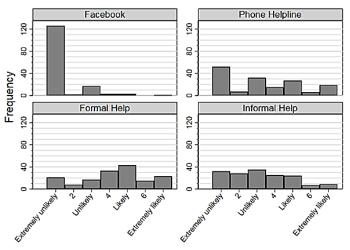
April 27th, 2018 Dr. Jennifer Barton Presents: Impact of Whole Health on Veteran Experience.

May 4th, 2018 Dr. Steve Dobscha Presents: A Research Project Related to Veterans at Risk for Suicide.



Do Veterans Turn to Facebook When Having Suicidal Thoughts?

It has become common to hear anecdotes of Veterans and others posting messages on Facebook prior to suicide. Given this, one might wonder if Facebook is perceived as a source of help when experiencing an emotional crisis.



This figure shows how likely veterans were to use four different possible sources of support if they were experiencing suicidal thoughts.

CIVIC's **Dr. Alan Teo** explored whether Veterans seek out help on Facebook more so than other sources of support.

Results showed that veterans strongly favor more traditional forms of help, such as a healthcare professional or supportive family member, not Facebook.

In the study, published in the *Journal of Medical Internet Research*, Dr. Teo and colleagues surveyed 270 military veterans with symptoms of major depression about their help-seeking intentions. They found that three out of four who used Facebook were "extremely unlikely" to seek help from Facebook friends if experiencing suicidal thoughts. Even among frequent Facebook users or those experiencing a more and more mild emotional problem, the vast majority of Veterans said they would stay away from Facebook.

Results point to the importance of maintaining traditional venues for psychological support, including the Veterans Crisis Line and direct health care services for the vast majority of Veterans.

Read more about Dr. Teo's Study HERE

Getting Patient Perspectives on What Respect Means in Healthca

How do you define respect? Findings from a new study by CIVIC's **Dr. Somnath Saha** suggest patients' views on respect are wide-ranging – and seem to be missing from the ways in which healthcare providers think about respect.

While patients' emphasize things such as honest explanations, handling lateness, trusting patient's selfknowledge, and asking patient questions, in healthcare settings the definition is traditionally limited to that of respect for patient autonomy, that is, giving patients the authority to make decisions about the care they receive.

In the qualitative study, published in the journal *Patient Education and Counseling*, Dr. Saha and colleagues

solicited multiple viewpoints from male, female, African-American, Latino, and white participants. While all groups defined respect as being treated as a unique person, and as an equal by their clinician, there were also prominent differences between the groups. For instance, although all groups cited listening as a way of showing respect, African-American participants emphasized this in light of often feeling their concerns were dismissed. They also described clinicians trusting patients' self-knowledge as an important aspect of respect.

For Latino participants, respectful treatment included clinicians' showing concern for them through close attention to their medical conditions. For example,



one participant said, "respect means...he asks me 'How are you? How have you felt? Explain to me your problem."

The researchers note that how respected a patient feels directly impacts their well-being. For all patients to feel respected, the study suggests that we incorporate diverse patient perspectives on respect into the education of healthcare professionals.

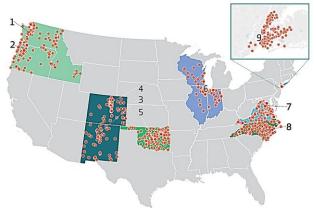
Read more about Dr. Saha's study HERE

Taking Innovation To Scale In Primary Care Practices: EvidenceNOW and HealthCare Extensionsthe ENCs provided support in four primary areas: 1)

With health care costs in the United States rising to unsustainable levels, high-value health care is critical. The EvidenceNOW initiative has begun to undertake this priority as described in a recent Health Affairs article by CIVIC's **Dr. Sarah Ono** and colleagues. Through an OHSU study (PI: Deborah Cohen) involving Dr. Ono, the EvidenceNOW initiative has demonstrated that the Cooperative Extension Service model, most widely recognized in agriculture, can be applied to health care. The article suggests that health care extensions may improve the quality of primary care practices and help bridge the divide in quality between urban and rural practices.

The EvidenceNOW initiative sought to help primary care practices deliver standard cardiovascular prevention efforts through external support. To do this, each primary care practice worked with EvidenceNOW Cooperatives (ENCs) and the ENC's community-based agents to identify areas for improvement through technical assistance, education, audit and feedback, and quality improvement coaching. Despite differences in available resources and degrees of external support, the ENCs provided support in four primary areas: 1) connecting with the community; 2) identifying performance gaps; 3) bolstering motivation, capacity, and resilience among practice members; and 4) quality improvement and translation to practice.

Health care extensions may be a cost-effective way to improve the quality of care across diverse communities. Notably, the extension model can be scaled-up to the national level while retaining local flexibility. Currently, the EvidenceNOW initiative involves twelve states. For more information: <u>www.escalates.org</u>



Read more about Dr. Ono's article HERE

<u>CIVIC Member Highlight: Rachel Matsumoto, MS.</u>



Rachel Matsumoto began working at CIVIC in September 2017 as a Research Assistant. Rachel's job for the Center include duties such as assisting **Drs. Jennifer Barton** and **Sarah Ono**, and helping with core CIVIC administrative tasks. Prior to joining the CIVIC team, Rachel received her Master's degree in psychological science from Montana State where her research centered on improving women's experiences in male-dominated domains. Aside from research, she thoroughly enjoys cooking and all things penguin. Her office is in building 6, room 311. She usually has snacks so swing by and say "hi!"

Photo Featuring Rachel & Grandma Mats! P.S. Rachel is on the left!

CIVIC Member Highlight: Daschel Franz, BS.



Daschel Franz has been working for CIVIC since the end of September 2017 as a Research Assistant, although you may have seen her around during the Summer as a PVARF intern for **Dr**. **Alan Teo**. Part of Daschel's duties include assisting **Dr**. **Maya O'Neil** and Health Services Research Fellow **Dr**. **Jason Chen**, helping with core CIVIC administrative tasks, and producing CIVIC's Newsletter. Daschel is originally from Eugene, Oregon and graduated from the University of Oregon this past June with a bachelor's degree in Human Physiology. She loves going to Duck games (Sco Ducks!), traveling, coffee, and chubby cats.

<u>CIVIC'S Veteran Engagement Group</u>

CIVIC's Veteran Engagement Group (VEG) is comprised of Veterans from various service eras, branches, and backgrounds who regularly come together to meet with investigators. VEG members provide diverse and individualized feedback to CIVIC investigators at all stages of the research process. The incorporation of VEG member's perspectives, especially as users of the VA healthcare system, can bolster translation to practice and help CIVIC research be more patient-centered.

VEG Member Highlight: John Lind



John Lind is a Vietnam era Army Veteran and has been a member of CIVIC's VEG since its inception in 2015. When asked about his continued commitment to VEG, John shared that his motivation to participate monthly comes from the fact that VEG gives him the opportunity to interact directly with influential VA researchers. John believes that Veteran engagement is important because CIVIC researchers "have specific questions that need a Veteran's answer," and VEG gives him the space to provide representation for the Veteran community. "Talking with researchers about current subjects that are going to be funded or are currently funded was exciting because they wanted to hear our voice." In addition to helping researchers learn what is important to Veterans, John has been

Continued on next page

able to learn about various research topics (such as tinnitus, opiates, and lung cancer), as well as gain insight into the collaborative process of research. "Your voice is important and there's not just one perspective in a room, your background is going to make a difference in how you see things." Aside from VEG, John continues to contribute to the Veteran community by participating as a non-scientific board member of The VA Portland Health Care System Institutional Review Board, and is a lifetime member of the Vietnam Veterans of America and First Cavalry Airmobile.

Fun Fact: John is a marching snare drummer and has been the director of his marching band entitled, "Get a Life Marching Band," for the last 20 years.

If you are interested in presenting, joining, or learning more about CIVIC's VEG, contact the VEG Liaison Rachel Matsumoto (Rachel.Matsumoto@va.gov).

<u>CIVIC Publications</u>

- Quill, T. E., Ganzini, L., Truog, R. D., & Pope, T. M. (2018). Voluntarily Stopping Eating and Drinking Among Patients With Serious Advanced Illness—Clinical, Ethical, and Legal Aspects. *JAMA internal medicine*, *178*(1), 123-127.
- Teo, A. R., Marsh, H. E., Liebow, S. B., Chen, J. I., Forsberg, C. W., Nicolaidis, C., Somnath, S., & Dobscha, S. K. (2018). Help-Seeking on Facebook Versus More Traditional Sources of Help: Cross-Sectional Survey of Military Veterans. *Journal of medical Internet research*, 20(2).
- 3. Beach, M. C., Branyon, E., & Saha, S. (2017). Diverse patient perspectives on respect in healthcare: A qualitative study. *Patient education and counseling*, *100*(11), 2076-2080.
- 4. Ono, S. S., Crabtree, B. F., Hemler, J. R., Balasubramanian, B. A., Edwards, S. T., Green, L. A., Kaufman, A., Solberk, L.I., Miller, W.L., Woodson, T.T., & Sweeney, S. M. (2018). Taking Innovation To Scale In Primary Care Practices: The Functions Of Health Care Extension. *Health Affairs*, 37(2), 222-230.