



VERMONT ETHICS NETWORK

Health Decisions

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Working to promote ethics as a core component of health care and health care decision-making

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Childhood Immunizations: Parental Choice or Societal Obligation?

By Dr. Robert Macauley

The issue of childhood immunizations required for school entry has been passionately debated in the Vermont legislature this year. By way of background, all states have a “medical exemption,” by which a child who has a medical contraindication to a vaccine is not required to receive it. Forty-eight states also have a “religious exemption,” according to which parents who belong to a religious group which is opposed to immunizations may choose not to immunize their child. Vermont is one of 20 states which also has a “philosophical exemption” which allows parents to refuse immunizations for non-religious reasons. A bill was introduced in the Senate (S.199) which would have removed the philosophical exemption eliciting support from medical groups (such as the Vermont Medical Society and the Vermont chapter of the American Academy of Pediatrics) and protest from groups such as the National Vaccine Information Center and the Vermont Coalition for Vaccine Choice.

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Is There a Role for Multi-Facility Ethics Committees in Vermont?

William Nelson and Emily Taylor

Early this year VEN formed a Task Force to explore the potential for, and interest in, multi-facility ethics committees in Vermont. The concept of having an ethics committee in a health care facility to assist staff and patients with addressing ethical challenges is well established. The often-stated purpose of an ethics committee is to provide a forum to discuss ethical conflicts with a multidisciplinary group of professionals who have knowledge and skills in applied health care ethics. Such committees traditionally focus on ethics education, policy development, and case consultation.

Despite the long-standing recognition of the importance and benefits of ethics committees, and the requirement by the Joint Commission for health care facilities to have a mechanism to address ethics conflicts, ethics committees are still primarily found in larger, urban hospitals.

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Immunizations (continued from page 1)

From an ethical point of view, there are important arguments on both sides. The philosophical exemption is founded on the belief that parents are ideally suited to determine what is in the best interests of their children. (Here it is important to note that “informed consent” is not relevant to this debate; parents may give “informed permission” for their child’s medical treatments, but this is based not on the patient’s beliefs or values but rather on their sense of what is best for that child.) When parents make a choice that is harmful to their children, the state has an obligation to intervene. As the Supreme Court famously stated in 1944: “Parents may be free to become martyrs themselves. But it does not follow they are free, in identical circumstances, to make martyrs of their children before they have reached the age of full and legal discretion when they can make that choice for themselves.”

However, parents are generally granted more latitude in the realm of preventive (as opposed to curative) treatment including immunizations. Hence the non-medical exemptions in many states.

While defenders of the “philosophical exemption” cite the importance of individual rights, critics appeal to public health ethics. Immunizations have eradicated some diseases entirely (such as smallpox), and the frequency of other diseases has been markedly reduced. Here the concept of “herd immunity” is pivotal. While no vaccine is 100% effective, if a sufficiently high percentage of a population is highly likely to be immune, there are not enough pockets of susceptible persons to create and sustain an epidemic. Viewed in this light, the claim of some that the philosophical exemption has no impact on vaccinated children is clearly erroneous. A small percentage of vaccinated children are not immune to the disease, and certain other children *cannot* receive the vaccine because of medical contraindications. Unvaccinated children, then, are not only at risk themselves of contracting serious diseases; they also are much more likely to spread the disease to other children, including those who may have been vaccinated.

The Vermont Senate passed a bill which would have removed the “philosophical exemption” to required childhood immunization for school entry. The Health Care Committee of the House, however, did not vote in favor of that legislation. Instead, the House passed a bill which would require parents to annually sign a form (which acknowledges the risks of not vaccinating) in order to utilize the philosophical exemption and would also require schools to report aggregate immunization rates of their students. A conference committee initially adopted the House’s bill with the added provision that the Commissioner of Health would have power to suspend the philosophical exemption if vaccination rates fell below 90% for Measles/Mumps/Rubella or Diphtheria/Pertussis/Tetanus vaccinations. The House was reluctant to accept this initial compromise, and the subsequent (and final) compromise adopted by the Legislature adhered closely to the original House bill, and thus leaves the philosophical exemption intact.

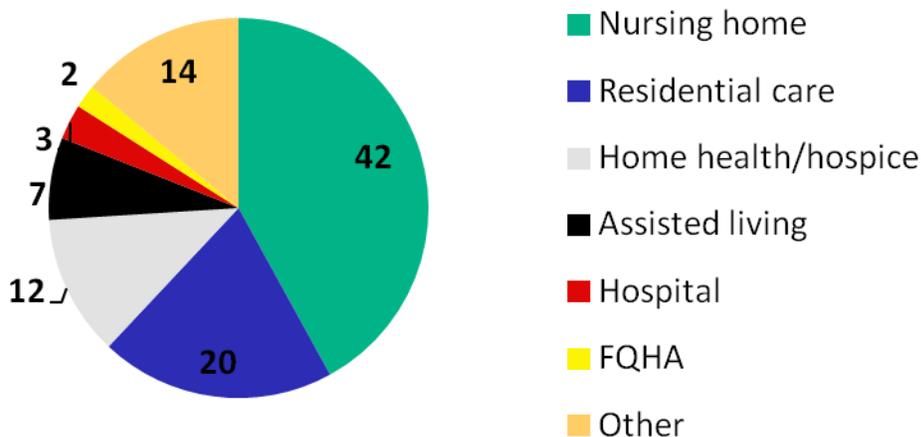
Multi-Facility Ethics Committees (continued from page 1)

There are many rural hospitals throughout the US, including in VT, that either do not have ethics committees or have non-effective committees – and for various reasons, including a lack of resources, such as ethics trained professionals. Additionally, there is a broad array of health care facilities, such as nursing homes and assisted living facilities that do not have ethics committees at all.

Due to the recognized need for effective, competent ethics resources available to staff and patients in all health care facilities, several articles have been published reflecting on alternative models to the traditional ethics committee. These models acknowledge that some health care facilities lack the resources to independently support a traditional ethics committee within their institution and therefore rely on pooling resources between facilities. One model that has been presented in the ethics literature is the multi-facility ethics committees (MFEC). A MFEC provides a forum to reflect on ethical issues – and its membership is composed of professionals from *multiple* health care facilities. For example, a group of six nursing homes might create a “virtual” MFEC composed of 1-2 representatives from each of the six facilities. The representatives might “meet” monthly or quarterly to discuss common ethics issues via established conference calls. There is no single model for a MFEC; the precise structure may vary depending on the specific context of the member facilities.

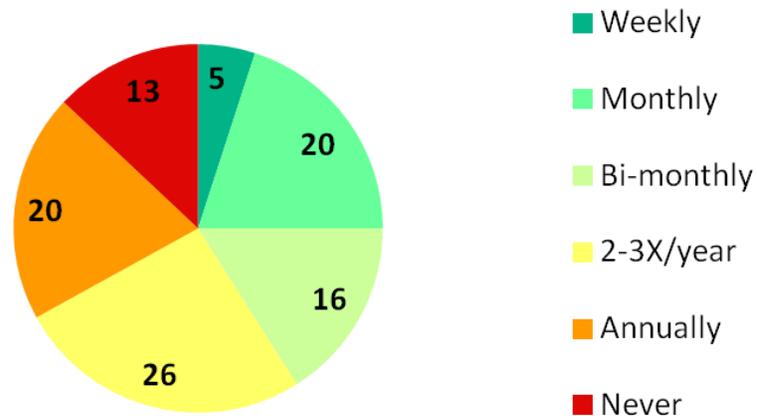
Because there are many health care facilities in Vermont that lack an established ethics committee, the Board of VEN raised the question, “is there a need for MFECs in the state, primarily for the large number of health care facilities that do not have the presence of an in-house ethics committee?” A Task Force was charged with addressing the question by facilitating a survey-based needs assessment.

The Task Force disseminated a survey earlier this year to a wide-range of health care facilities in the state. The majority of respondents were nursing homes, followed by residential care facilities and home health/hospice programs, as noted in the figure below:

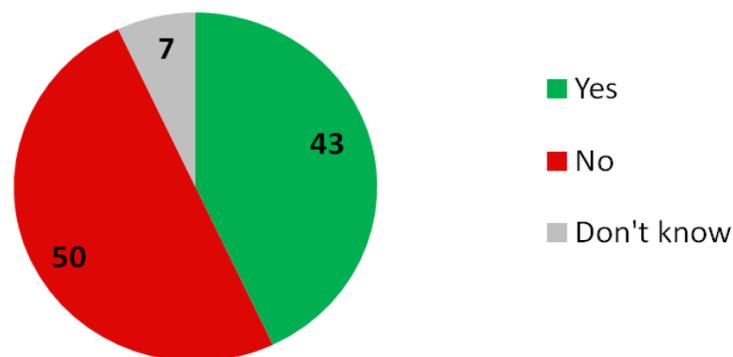


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One of the aims of the survey was to initially assess whether or not health care organizations in the state believed they were encountering ethical conflicts. When survey participants were specifically asked “do you and/or the staff at your facility or health care organization encounter ethical concerns?” the following responses resulted:



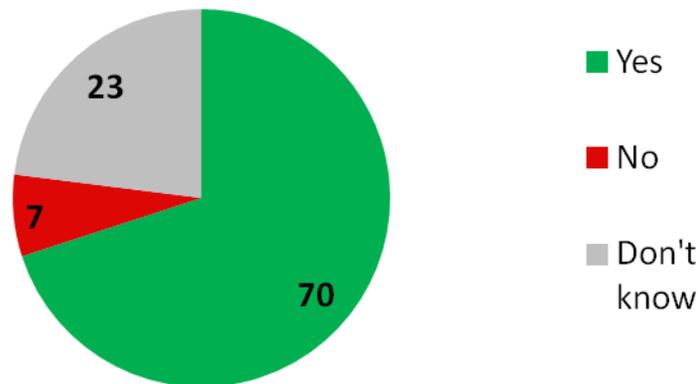
The results revealed that ethical concerns (conflicts, issues) were being encountered on a regular basis – with nearly half of the respondents encountering issues bi-monthly or greater; and a quarter of the respondents acknowledging that they were encountering ethical concerns 2 – 3 times per year. The survey participants were then asked specifically about an ethics mechanism within their own organization: “Does your facility or health care organization currently have a local mechanism, such as an ethics committee, to address/resolve ethical conflicts?”



These responses highlighted that over half of the participants in the survey did not have an ethics mechanism – or weren't sure if they had an ethics mechanism – within their organization for addressing ethics conflicts.

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Because of the established importance and benefit of ethics committees—whether a traditional model or an alternative model, such as a MFEC—the survey results clarified the need for additional resources in this area. Survey participants were finally asked “if a MFEC were available, could such a committee be a potential resource to your facility?”



The survey participants overwhelmingly responded that a MFEC could be a potential resource for their organization, highlighting not only the need, but also the interest in MFEC resources in the state.

Based on the results of the survey, VEN plans to host, at a future date, a meeting for health care facilities staff to come together to explore the concept of MFEC(s) in VT. If you have questions about MFEC please feel free to contact William Nelson at william.a.nelson@dartmouth.edu.

Message from the Board Chair - Penrose Jackson

As the Vermont Ethics Network nears our 26th anniversary, the need for our work continues to grow. At the 25th anniversary we recalled our original question of “Who Lives, Who Dies, Who Decides and Who Pays?” and were intrigued and challenged by the fact that those words ring as true today as they did in the 1980s.

Healthcare reform at both the state and federal levels is reinvigorating old concerns, or, better, “opportunities;” opportunities for VEN to help guide and support meaningful and respectful dialogue. Elsewhere in this newsletter you read about our efforts in leading a multi-facility ethics task force that asks how the value of ethics committee thinking can extend to every Vermont health care facility. You also read about the often-heated childhood immunization debate. I recently heard a piece on Vermont Public Radio that characterized the immunization debate as a test of Vermont’s motto of “Freedom and Unity.” How true.

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Message from the Board Chair (continued from page 5)

All of us are and will continue to be challenged by the rights of the individual versus the needs of the majority. How can we balance the fears of a mother who legitimately fears for the safety of her child with those of the young mother-to-be who similarly fears for the health of the child she carries?

In a different vein, how do we sideline discussions about the costs of end-of-life care to, rather, encourage and support public debate about “most appropriate care?” How do we still fears of rationing while simultaneously contributing to community discussions about the need to curb rising healthcare costs?

Yes, these are challenging times. I believe that VEN’s significant experience and credibility makes us the logical place to have respectful – and occasionally very difficult – discussion and debate. As we have done for over a quarter of a century, we will continue to dedicate ourselves to doing all we can to ensure that people are informed, that they have a “safe place” in which to challenge one another, and that we all do, in fact, continue to keep Vermont as a place of “Freedom and Unity.”

The Emperor of All Maladies: A Biography of Cancer by Siddhartha Mukherjee, MD

A Book Review by Rev. Diana F. Scholl

I was at the funeral of a nurse colleague's husband who had just died of brain cancer after 2 years of valiant chemotherapy and radiation and excellent care at home. John was only 69 years old and in otherwise excellent health having been a hardworking farmer for most of his life. His pastor said that in his last visit with John they were talking about heaven and John said: “There will be no tumors there!”

That is about as good a description of heaven as I've ever heard and after reading Dr. Mukherjee's Pulitzer Prize winning book it also sounds pretty accurate. As a clinical layperson I came away with the understanding that cancer is a disease whose very existence is deeply encoded in our DNA and it survives and multiplies in the same way that healthy cells generate and regenerate in order to keep us alive from one year to the next. Here lies the philosophical conundrum as research continues to find ways to end the destruction cancer cells spread yet strives to keep alive the non-cancer cells that are necessary for continued life. Can we destroy cancer without destroying ourselves? Will it take divine intervention, or heaven coming to earth, to allow us to reach the day when humanity can live without tumors?

Dr. Mukherjee writes in the genre of narrative medicine pioneered by many clinicians who are also writers and who believe that the humanities has much to offer not only to those of us who work in health care but also to patients and families.

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The Emperor of All Maladies, Book Review by Rev. Diana Scholl (Continued from Page 6)

The wonderful Literature and Medicine program (a collaboration between Vermont hospitals and the Vermont Humanities Council) is an example of this intersection of disciplines. In this book, the reader gets it all: a fascinating medical history of a disease and those who have battled it (notably Dr. Sidney Farber of Dana Farber fame); a walk through the often very detailed science (and pseudo-science) of early, often inhumane 19th century chemo and radiation to 21st-century cellular biology, genetics, and chemistry which has led to amazing breakthroughs in treatment; as well as patient stories such as the Persian Queen Atossa who ordered her slave to cut off her malignant breast plus the oncologist/author's own patients. Serious science is here for the popular audience as well as the human side of the story – two sides of one coin.

Indeed, it is clear that in order for both good science and good practice to be achieved with such a complex disease as cancer, a solid foundation of good ethics is critical and hence I highly recommend this book to anyone interested in clinical as well as organizational ethics.

The evolution of clinical trials in both their efficacy and their ethical and legal limits is covered in depth as surgeons, chemotherapists, and oncologists of every stripe engaged in President Nixon's "battle against cancer." Dr. Mukherjee describes how the extremely punishing chemotherapy regimes declined as patients became less passive and demanded that effectiveness take into account the patient's experience of the treatment and survival time with quality of life. Access to life saving drugs was pushed ahead of where FDA regulators were originally comfortable as patients argued that it was unethical to deny them a drug that could extend their lives when certain death was assured without it. AIDS was an important player in this ethical push-and-pull between the worlds of the academic research labs, the for profit drug companies, the practicing physicians, and (at long last) the patients themselves. The author also explores patient autonomy and the right to make his/her own decision about treatment. The relationship of trust and honesty between patient and oncologist has definitely evolved over time and is now based in a strong ethical foundation which benefits everyone. You can see that in considering this most complex, iconic, and challenging disease, ethical issues abound!

For more detailed reviews check out the New York Times and the New Yorker. "The Emperor of All Maladies" is a book for all of us, professionals and not, to learn from and consider. Why? Janet Maslin in the Times' review put it this way: "*Cancer has become the price of modern life,' an epidemiologist recently wrote: in the U.S., about half of all men and about a third of women will contract cancer in their lifetime; cancer now ranks just below heart disease as a cause of death in the U.S. But in low-income countries with shorter life expectancies it doesn't even make the top ten.*" Cancer is here to stay so the more we can bring it in out of the cold of stigma and fear, the more likely we will be able to handle it with wisdom and compassion for ourselves or our loved ones if the need arises. And surely that would be a little bit of heaven on earth exactly when we need it.



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To:

News and Upcoming Events

Hospice & Palliative Care Council of Vermont

21st Annual Conference
Lake Morey Resort, Fairlee, VT
Thursday, June 7, 2012

SAVE THE DATE – October 1, 2012
NH-VT Ethics Committee Meeting
Dartmouth Hitchcock Medical Center

DETAILS COMING SOON

Vermont Ethics Network- Annual Fall Conference

We are in the process of planning for a fall ethics conference. Be on the lookout this summer for information regarding date, time, location and featured presenters!

Register Your Advance Directive

Health Care Planning is For Everyone: Start the Conversation today!

- **TALK** to others about your values and future health care wishes.
- **GO** to www.vtethicsnetwork.org for the Vermont Advance Directive Form and for comprehensive information about Advance Care Planning and Advance Directives.
- **COMPLETE** your Advance Directive.
- **REGISTER** your Advance Directive with the Vermont Advance Directive Registry - an easy and secure way to give your health care providers immediate access to your wishes about health care decisions.

For more information about the Vermont Ethics Network, or to order the *Taking Steps* Booklet, contact us by phone at 802.828.2909 or via e-mail at ven@vtethicsnetwork.org.