MARYLAND MOLST FORM: FINDINGS FROM A STATEWIDE EVALUATION

In 2015, MHECN conducted a statewide evaluation of the Maryland Medical Orders for Life-Sustaining Treatment (MOLST) form use. This chart review study was funded by the Office of Health Care Quality, Maryland Department of Health and Mental Hygiene. All adult, non-psychiatric hospitals, hospices, home care agencies, and dialysis centers were asked to take part, along with a random sampling of half of the nursing homes (NH) and assisted living facilities (ALF) in Maryland. A total of 1959 chart reviews were received, with 1654 of these (84%) having an active MOLST form coupled to the chart review. A total of 2,069 MOLST forms (active or voided) were collected. Each facility also completed a facility demographic form. Below are highlights from the study. The full report is available on MHECN’s website (http://www.law.umaryland.edu/mhecn, click on MOLST study).

MARYLAND MOLST SUCCESSES

The ability of the MOLST program to achieve its true goal of improving end-of-life care will take time. The first stage of this process involves getting clinicians to know what the MOLST form is and when and how to complete it. Positive findings from the study indicate that most facilities are using the MOLST form. For example, 86% of patients discharged from the hospital for whom a MOLST form was required had a completed MOLST form on file.

IDENTIFIED AREAS TO IMPROVE MOLST FORM USE

Ideally, each patient with a MOLST order should have an advance directive [whether a living will or appointed durable power of attorney for health care (DPOA-HC) or both]. As a patient’s health irreversibly declines, clinicians writing MOLST orders should spend time identifying the patient's goals of care and which orders on page 1 and page 2 of the MOLST form are consistent with those goals. The following MOLST study findings indicate areas needing improvement:

- Advance directives continue to be under-used, with only 31% of hospital
patients, 45% NH, and 65% ALF having notation in their medical record of having an advance directive (with fewer actually having the advance directive available). Given that the process of selecting a DPOA-HC is simpler than completion of a living will, there may be advantage in promoting this as a first step in advance care planning.

• 68% of adults who died during hospitalization and 79% of nursing home residents who died had no documentation in their medical record before death that they were terminally ill. While many of these deaths were likely to have been unpredicted (e.g., hospital index admissions indicating an acute event), a subset of them likely involved individuals with a terminal prognosis (e.g., end-stage dementia as the patient’s hospital admitting diagnosis). One barrier to translating advance directive preferences into MOLST orders may be clinicians’ ambiguity in determining when a patient is considered to be terminally ill or “imminently” dying—a condition often triggering limitations on life-sustaining treatment in an advance directive that should be reflected in a MOLST order.

• 70% of hospitalized adults discharged to a MOLST qualifying facility had no orders on MOLST page 2, indicating that page 2 may be under-used when MOLST orders accompany patients discharged from the hospital. In particular, the “Other orders” section on page 2 of the MOLST form is seldom used, with active MOLST form “other” orders absent on a majority of MOLST forms (98% of hospital, 93% of NH, 94% of ALF, 73% of hospice, 94% of home health, and 99% of dialysis center MOLST forms).

• A minority of MOLST forms from hospitals (37%), ALFs (41%), and home health (12%) noted documentation in the medical record of what informed the MOLST completion. Clinicians in all facilities can do a better job documenting in the medical record what informed how the MOLST form was completed.

• Most MOLST forms are improperly voided (79% overall), with some required voiding component missing (e.g., a line through the form, initials, or date). This has significant implications for tracking the current MOLST order.

• The fact that most patients (82%) for whom at least one MOLST order form was completed only had one MOLST form may indicate that the form is not being voided and new orders written when warranted by a change in the patient’s condition and/or treatment preferences.

• 51% of MOLST forms were completed based on a conversation with the patient (65% for active MOLST forms in hospital chart reviews). Given the lack of documentation of the conversation underlying the MOLST orders, patients may not be truly informed of the MOLST options that should be presented to them.

• Only five instances were noted of two physicians certifying that a treatment was medically
ineffective during a patient’s hospital stay, whereas there were 49 such certifications in long-term care facilities. There were only 13 instances of this criterion being selected as the basis for the MOLST orders [i.e., in accordance with Maryland’s Healthcare Decisions Act (HCDA)]. This raises the question of whether the HCDA provision (i.e., not providing medically ineffective treatment) may be underutilized, particularly in hospitals.

**IMPLICATIONS FOR PRACTICE**

Implications from this first phase of funding point to improving the quality of the conversation informing MOLST orders, documenting the conversation that informed the MOLST orders in the patient's medical record, encouraging patients to appoint a health care agent as an initial step in advance care planning, writing orders on page 2 of the MOLST form more frequently, and ensuring that MOLST forms are properly voided when a patient's wishes or conditions change, with a new order being written at that time. MHECN plans on pursing a second phase of MOLST form evaluation. Check our website for updates.

MHECN thanks all the members of our AMAZING MOLST study advisory panel, MOLST study volunteers, and chart reviewers who contributed to this study! We could not have done this without you!

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**SECOND ANNUAL INTER-PROFESSIONAL, INTER-FAITH ETHICS CONFERENCE FOCUSES ON AGING**

“*You shall rise up before an elderly person, and show respect for the aged.*” —Leviticus 19:32

On November 2, 2015, University of Maryland faculty from the schools of dentistry, law, medicine, nursing, pharmacy, and social work, and clergy from the Christian, Jewish, and Muslim faiths, participated in the Second Annual Interprofessional Forum on Religion and Ethics in Health Care: How to Maintain Dignity, Respect and Familial Cohesion as our Loved Ones and Patients Age. This article reports on comments that conference panelists made in response to a case study involving aging parents and their adult children grappling with health care decisions as each parent’s health status declined.

**How Might a Pharmacist Help?**

Chanel Whittaker, PharmD, University of Maryland School of Pharmacy

As individuals age, the importance of individualizing their medication regimen, rather than applying a “one-size-fits-all” approach, becomes more important. Pharmacists recognize the value of a thorough medication review using a holistic approach that is based on a patient’s goals of care. For example, at the end of life, when the focus of care is on comfort rather than life-extension, pharmacists may recommend stopping medications when burdens of continuing them outweigh benefits. Pharmacists also help to tailor how aggressively an elderly person’s chronic disease is managed. For example, guidelines for managing high blood pressure may call for aggressive dosing of antihypertensive medications to bring a patient’s blood pressure down to target levels. The risk here is that oversooting the target may cause blood pressure levels to get dangerously low. Likewise, a more aggressive approach to bringing elevated blood sugar levels down in diabetics risks causing too-low blood sugar levels. Fluctuating blood pressure and blood sugar—particularly low values—increases the risk of falls, particularly in older persons. For some, falls may present more of a health danger than excessively high blood pressure or blood sugar. So, a higher-than-recommended blood pressure or blood glucose target may be appropriate if reducing fall risk is a priority for a particular patient. Pharmacists may also take into account burdens on caregivers when adjusting a patient’s medications. For example, adjusting a patient’s diabetes medications may require more frequent blood glucose monitoring, which has implications for caregivers overseeing such monitoring. The pharmacist will consider what is most important to the patient and caregivers to achieve a balance between optimizing management of medical conditions and minimizing harmful effects (e.g., medication side effects, caregiving burden, excessive cost).
What the Physical Therapist Contributes

Vincent Conroy, PT, DScPT, University of Maryland School of Medicine, Department of Physical Therapy & Rehabilitation Science

Many times people don’t think of involving physical therapists until a triggering event occurs, but a preventive or proactive role should be considered well before a crisis occurs. Physical therapists evaluate a patient’s health status and disease management to maximize independence and functional ability. For example, assessing the risk of falls and other events that could impair the patient’s functional status can lead to adaptations that improve the quality of life—both for the patient and for the caregiver. Where is the bathroom? How many daily steps are required for chores and activities of daily living (like toileting or bathing)? Are there railings (outside and inside)? Are there rugs or different carpet piles that may present a tripping hazard? Sometimes adaptations that improve physical functioning also improve sleep quality, and this can have a positive impact on cognitive functioning. It can also benefit the caregiver, which is an important consideration. Something as simple as having a physical therapist train caregivers how to use proper body mechanics can be helpful.

Tips From a Geriatric Dentist

Janet Yellowitz, DMD, MPH, Director of Geriatric Dental Programs at the University of Maryland, Baltimore College of Dental Surgery

Dentists have a lot to contribute to the care of aging seniors. Yet, routine dental appointments are often neglected in older adults. This is unfortunate, because dental pulp has nerve tissues and as we age, our dental pulp recedes. This means an older person can have bad gum disease or tooth decay and not feel it. Also, as we age, our bone recedes and gets resorbed. This impacts how dentures fit. Ill-fitting dentures can impact an elder’s nutritional status and lead to weight loss, mouth sores, and even social isolation. Although geriatric dentistry is not widely accessible, regular dental checkups should remain a part of an elder’s health maintenance strategy. Dentists’ observations made during routine dental visits can provide valuable information to those involved in the care of a patient.

A Geriatric Nurse Weighs in on Unsafe Driving

Beth Galik, PhD, CRNP, University of Maryland School of Nursing

One challenge of caring for an aging loved one is finding the right balance between respecting the individual’s autonomy and minimizing harms to individuals and society. Concerns regarding whether an elder can safely drive a motor vehicle provides one example. Driving is typically associated with being an independent adult, so having this independence taken away is no small thing. Yet, changes brought on by aging eventually impact one’s driving competency. Elders often dismiss others’ concerns that their driving is impaired and resist giving up their driving privileges. What should one do with a concern about an older person’s driving? One strategy that may succeed with elders who have grandchildren or other young ones in their lives is to ask, “Would you feel comfortable driving [child’s name] to [basketball practice] if you thought [he, she] might be in danger?” Grandparents are often more protective of their grandchildren than their own children. You could ask their health care provider to give them information about sources of impaired driving, along with a prescription to get evaluated, as well as follow-up resources. The Department of Aging in each city or county has its own resources, so these should be consulted. You can encourage the person to get evaluated at the Motor Vehicle Administration (MVA), or you can notify MVA yourself. The latter will get better traction if you don’t do it anonymously. MVA will send a letter to the individual, will ask for his or her medical records, and will have the person undergo a motor vehicle driving capacity test. This may result in driver’s license removal or restrictions on the license (such as no driving at night). This option doesn’t cost anything, but it can be perceived as antagonistic. Occupational therapists have resources to conduct a driving evaluation, first with simulators and then a road test. Good Samaritan Hospital, Sinai Hospital, Johns Hopkins Howard County General Hospital, and Suburban hospital offer these evaluations. These reports are reportable to MVA but are often perceived as less antagonistic than going through the MVA directly. Unfortunately, this is not covered by insurance; costs vary, but generally run about $300.

The Multi-Faceted Social Worker Evaluation

Jessica Rowe, LCSW-C, Jessica Rowe Eldercare Consulting, LLC

Social workers recognize that most individuals are not cared for in isolation, but within a family structure. Family dynamics can present a challenge, and must be addressed to optimize care for an elderly individual with chronic health conditions. One problematic assumption is that everyone in the family should contribute equally. This is usually not possible. Typically, a primary caregiver emerges—often a child. Caregiving tasks are often taken on so gradually that the primary caregiver doesn’t realize how much she’s doing. This person can become angry and resentful if she doesn’t come to accept her own and others’ limits. Social workers are able to help families work things out earlier on by facilitating a family meeting. This can allow each family member to learn about the patient’s situation and needs, voice concerns, identify available resources,
and negotiate how he or she will contribute.

Social workers are accustomed to educating patients and families about available resources and options. Family members often mistakenly assume that the family is responsible for all the caregiving needs, so educating them about available resources is important. Simply correcting misinformation may be helpful (e.g., that “hospice kills patients” or that “nursing homes are horrible”). When someone asks that “everything be done” for a loved one, what does this mean? What ultimate goal is hoped for? One helpful practice is to write a list of questions to bring to health care provider visits (for example, what would happen if a particular medication is stopped?). Simple tips can make a difference in enhanced family cohesion, such as reminding caregivers that decisions about health care interventions for a patient should be based on the patient’s values and preferences rather than on the caregivers’ wishes. Another useful practice is to encourage family members to thank the primary caregiver for all that she is doing. Sometimes this simple act can mitigate the accumulation of resentment that can grow into larger family conflicts.

**Advance Directives & Maryland Law**

Jack Schwartz, JD, University of Maryland Carey School of Law

“It’s always too soon until it’s too late.” - The Conversation Project, [http://theconversationproject.org/](http://theconversationproject.org/)

Less than a third of Marylanders have completed an advance directive. Since advance directives are intended to communicate end-of-life treatment preferences, they become more relevant the closer one gets to the end of his or her life, and so are relevant to the topic of aging. An advance directive that is completed based on a thorough understanding of its purpose and application has the best chance of helping to avoid ethical conflicts in end-of-life decision-making. Sadly, opportunities are all too often missed to identify and document a patient’s end-of-life treatment preferences, or to appoint a durable power of attorney for health care (i.e., health care agent) while a patient retains the decision-making capacity to do so.

All members of the healthcare team can weigh in to help figure out what’s best for a patient when there is disagreement among family members about what to do and the patient lacks decision-making capacity. If the disagreement continues, the law in Maryland also provides two conflict resolution mechanisms. First, if surrogates with the same authority (such as adult children) disagree about the course of care for their family member, an ethics committee consultation can be requested. If the ethics committee provides a recommendation and the attending physician follows that recommendation, there is legal immunity for the physician (protecting him or her from litigation). Second, in Maryland law, if physicians consider an intervention to be “medically ineffective” (meaning it would not save the patient from impending death), then it need not be offered, even if surrogates demand it. This protects the moral agency of physicians to not provide non-beneficial treatments that fall outside of the medical standard of care, even if surrogates insist on them.

**A Physician’s Insights Into End-Of-Life Communication**

Conrad May, MD, Department of Medicine, University of Maryland

In an ideal world, everyone would have a primary care provider who knows him well and communicates competently with him about his health care priorities and preferences. However, this ideal is far from our reality. All too often, such conversations happen after a medical crisis occurs, which is a difficult time to approach this emotionally charged and nuanced topic. Also, with so many healthcare providers involved, each may think the other is having this important conversation. Now that Medicare is reimbursing for end-of-life conversations, this may change. But we need to ensure that more clinicians are trained in discussing end-of-life preferences with patients and families, and we need to improve how health care services are coordinated among all of the subspecialties.

One tool intended to enhance end-of-life care by improving how end-of-life orders are transferred across healthcare settings is Maryland’s Medical Orders for Life-Sustaining Treatment (MOLST) form. While an advance directive documents a person’s end-of-life preferences for the future, the MOLST form translates a patient’s preferences into medical orders that guide end-of-life care right now. MOLST orders travel with the patient from one health care facility to the next. However, they are only as good as the conversation and evaluation that informed how they were completed.
Healthcare chaplains and members of the clergy are routinely faced with ethical questions and dilemmas from those who seek their counsel. At the November 2, 2015 conference, *How to Maintain Dignity, Respect and Familial Cohesion as Our Loved Ones and Patients Age*, at the University of Maryland, a panel of experts representing Judaism, Christianity, and Islam provided insights on how their faith traditions provide guidance to patients and families facing challenges brought on by an aging family member’s health status. There is great diversity of religious interpretation and practice in each faith tradition. Thus, panelists focused on scriptural insights and general themes and cautioned that respecting this diversity of belief and interpretation is important when trying to support patients and families across the lifespan. Below are some of these general themes and insights.

**Insights from a Christian Perspective**

*Rev. David Harness, BA, M.Div, University of Maryland Medical Center*

*The days of our life are numbered, so teach us to count our days that we may gain a wise heart.* - Psalms, 90:12

A central challenge for Christians is to reconcile their dual obligation to value human life as sacred and to accept their own mortality. Christians are taught not to fear death because of Christ’s sacrifice. However, in the clinical setting, this can create a conflict when medical staff believe a patient’s death is imminent and the goals of care should switch to maximizing the patient’s comfort, but the family insist that “everything be done” to keep the patient alive. Sometimes loved ones will invoke religious language. For example, they may say, “God has the last word,” or “God can work a miracle.” How should the health care team respond? Chaplains of all faith traditions recognize the value of sitting with patients or family members, listening to their stories about their loved one, giving them a refuge and a safe space to share their feelings and concerns, to pray, to hope. This often helps them transition their hope toward realistic ends, and to identify what is most important to them in the remaining time they have with their loved one. What gives the family meaning and purpose? What unfinished business is there to attend to (spiritually, emotionally)? Stories from the New Testament provide several different lessons on balance: the importance of caring for others in need should be balanced with efforts to take care of ourselves; the duty to save an individual life should be balanced with the duty to be good stewards of collective resources; and the imperative to hold life as sacred should be balanced with acceptance of death when medicine has reached its limits.

**Insights from an Islamic Perspective**

*Tahara Akmal, BA, MA, Reading Health, Reading, PA*

*“Your Lord has commanded that you worship none but Him, and that you be kind to your parents. If one of them or both of them reach old age with you, do not say to them a word of disrespect, or scold them, but say a generous word to them. And act humbly to them in mercy, and say, ‘My Lord, have mercy on them, since they cared for me when I was small.’” (Quran, 17:23-24).*

Muslims are taught to revere their elders. Figuring out how to balance duties to oneself, to one’s own spouse or children, and to one’s parents can be stressful. Muslims will look to the Quran for spiritual guidance first, then to the teachings of the Prophet (the Hadith). These two sources comprise Sharia, an Arabic word meaning “Path to what is ethical and good.” Muslims are taught that their bodies are a trust that they must maintain through good self-care practices. Islam calls Muslims to be kind and merciful. There are 114 chapters in the Quran, and all but one of them starts, “In the name of God, most gracious and merciful.” Mercy is tied into everything. For example, Muslims are allowed to withhold and withdraw life-sustaining treatment at the end of life and to receive pain treatment to reduce suffering, even if this hastens death. While Muslims make every effort to save life, they also believe that death is part of life’s journey. Islamic law even allows withdrawing or withholding life support to avoid prolonging the dying process in order to free up an ICU bed for someone else who would benefit more from it. When someone is dying, Muslims believe that angels descend and say “Amen” to everything that is spoken, so they avoid negative statements and focus instead on positive ones in these moments.

Given the post-911 anti-Muslim bias, some Muslims may not divulge that they are Muslim, fearing mistreatment. It’s important to gain the patient’s and family’s trust. Asking patients to talk about what’s meaningful to them is a good way to connect. When people are hopeful for a miracle, for healing, we should never take away their hope. When we compete with God, we lose. Remain present, and reinforce that doctors have done everything they can. A chaplain may affirm, “I’m hoping with you and I’m praying with you.” The chaplain could also ask, “And what if our prayers aren’t answered?” One suggestion is to replace the word “but” with “and,” as in: “I hear you’re praying for a miracle, and...”
I have these test results to share”). This orients the patient or family member to the medical reality while allowing for them to remain hopeful. However, hope evolves. Sometimes family members who demand that “everything be done” to keep a dying loved one alive need to be educated that at some point, medical treatments will cause more harm than benefit to the patient. This evokes the Islamic word of jihad. Contrary to popular belief, jihad doesn’t mean holy war, it means struggle. Everything a Muslim faces in life is a jihad, whether an outer struggle or an inner struggle. Islam offers support and guidance for those struggling with medical decision-making within a family in times of health crises. Two very helpful resources are the Islamic Association of North America and the Islamic Society of North America.

**Insights from a Jewish Perspective**

*Rabbi Shmuel Silber, MA, Institute for Jewish Continuity; Suburban Orthodox, Congregation Toras Chaim*

**The Hebrew word for “respect” is etymologically related to the verb “to beautify.” We must not just respect the elderly, but we must beautify their life. –Rabbi Silber**

In Hebrew, the word for someone who is elderly is zakein – one who has acquired wisdom. Jews respect elders because they’re wiser and closer to Hasidic revelation. From a Judaic perspective, caring for a parent is a privilege, not a burden. However, caregiving duties are often distributed unevenly among family members. As an elderly patient’s health declines, resentments among those who take on a larger share of the caregiving duties can threaten familial peace. Maintaining familial peace is a core value in the Jewish tradition. Family members negotiating the care of an elder should be encouraged early on to commit themselves to maintaining familial peace by embracing mutual respect and the value of compromise. Knowledge that children are getting along is a gift to a parent. Another antidote to family discord is to encourage family members who are less actively involved in caregiving duties to express gratitude to the primary caregiver(s).

Medical professionals can sometimes resent when a family calls in a religious leader for guidance on medical decisions. This is a mistake. It’s common for Jews to ask their rabbi for advice about medical decisions. Rabbis will often then ask, “What did your doctor say?” Medical professionals need to respect the role that faith plays in a patient’s decision-making, and the importance of collaborating with religious leaders in figuring out the right thing to do for a particular patient. If the doctor tries to place a wedge between a family and their faith beliefs, the family is likely going to defer to their faith. Building trust is essential in order to effectively and compassionately persuade a patient or family to consider medical recommendations, and respecting how faith informs decision-making is essential to this trust-building.

Judaism recognizes that medical treatment need not be provided if it only serves to prolong the dying process. But health care providers and religious leaders may need to work together to help a patient or family know when this moment has arrived. Jews do two things after death: they rend their clothing (the body is a garment of the soul; death is a remnant of the garment) and they ask for forgiveness from loved ones. Rabbis encourage using the momentum during a health crisis to bring the family together, to ask for forgiveness before death comes, to say things that haven’t been said before. However, this comes more easily to some than to others. Rabbis embrace hoping for a miracle. But they counsel those seeking their guidance that God can work a miracle in many ways. Modern science is always evolving. Sometimes hope comes from the supernatural, and sometimes from scientific discovery. The answer to prayer may be unexpected. A son praying at his mother’s deathbed for God to cure her may get a different answer to his prayer. God may grant the miracle of the child apologizing to his mother (or her to him) as she takes her last breath, granting peace for both at the moment of death. A rabbi will reassure those facing grief and loss that regardless of how God answers their prayers, they are beloved and held in God’s warm embrace.
The case study featured in this issue of the Newsletter was reprinted in full in the print version with permission from The American Journal of Bioethics, 15(1), pages 69-76. In this pdf version, we present a summary of the case and an example of how the consultation may be documented, based on the AJOB commentaries on the case. We used the Ethics Case Consultation Summary Template developed by the Veterans Health Administration’s (VHA) National Center for Ethics in Health Care, available at http://www.ethics.va.gov/docs/integratedethics/Ethics_Consultation_Ethics_Case_Consultation_Summary-Sample-20070228.pdf. Thanks to Barbara Chanko and Ken Berkowitz from VHA’s National Center for Ethics in Health Care for their helpful feedback on this adapted ethics consultation summary!

This template reflects the IntegratedEthics “CASES Approach” to ethics consultation (C= Clarify the request; A=Assemble the relevant information; S=Synthesize the information; E=Explain the synthesis; S=Support the consultation process). The VA considers this template to serve multiple purposes (e.g., promoting strong and consistent ethics consultation processes, recordkeeping and documentation, a guide for communicating information to those involved, a quality improvement tool to ensure that steps in the consultation process are not missed, and an educational resource for others who access the ethics consultation summary in the patient’s medical record). Items marked with * are REQUIRED fields for the VA hospitals using this template. This template can be used to generate a complete ethics consultation record, and can be used to create an ethics case consultation summary that is placed in a patient’s medical record (that is, not all the content in the ethics consultation record should be included in the consultation summary that goes in the patient’s medical record). Each individual ethics consultation service should have its own established process for conducting, summarizing, and documenting ethics consultations.

CASE SUMMARY

A 45 year old Jehovah’s Witness with non-ischemic cardiomyopathy underwent a heart transplant after signing a “statement of refusal” of blood products before the surgery, prompting management using a blood-sparing transplant protocol. There is some ambiguity about the patient’s commitment to avoiding blood products to save his life. During the procedure, the cardiology transplant surgeon believes the patient may need a life-saving blood transfusion, and requests an emergency ethics consultation to inform whether this would be ethically permissible (Bruce, 2015).

ETHICS CASE CONSULTATION TEMPLATE

NOTE: Data provided here are either taken from the referenced AJOB articles or fabricated for the purpose of demonstrating an example of an ethics case consultation summary.

CLARIFY

Requester Data

* Requester’s first name: Sondra
* Requester’s last name: Edwards
Job Title: Cardiology Transplant Surgeon

Role in the case:
[ ] Physician – Staff
[ ] Physician – Trainee
[ ] Nurse – NP
[ ] Nurse – Other
[ ] Social worker
[ ] Clinical staff – Other
[ ] Management
[ ] Patient
[ ] Family/Significant Other
[ ] Other

ADVANCE MEDICAL DIRECTIVE

1. I , make this advance directive as a formal statement of my wishes. These instructions reflect my values and informed decisions.

2. I direct that no blood transfusions (whole blood, red cells, white cells, platelets, or blood plasma) be given to me under any circumstances, even if deemed necessary to preserve my life or health. I accept non-blood expanders, non-blood drugs that control hemorrhage and stimulate the production of blood cells, and other non-blood management.

3. This directive is an exercise of my right to make medical treatment in accord with my deeply held values and convictions. I am one of Jehovah’s Witnesses, and I make this directive out of obedience to commands in the Bible, such as “Keep abstaining . . . from blood.”—Acts 15:29, 39.

4. Regarding minor fractions of blood, my instructions are: [initial those that apply]
   (a) ______ I REFUSE ALL
   (b) ______ I REFUSE ALL EXCEPT:

   (c) ______ I may be willing to accept some minor blood fractions, but the details will have to be discussed with me if I am conscious.

5. Regarding medical procedures involving the use of my own blood: I refuse to participate in and have my blood for later infusion. I accept diagnostic procedures such as blood testing.

   My other instructions regarding use of my blood are [initial those that apply]
   (a) ______ I REFUSE ALL
   (b) ______ I REFUSE ALL EXCEPT:

   (c) ______ I may be willing to accept certain medical procedures involving my blood, but the details will have to be discussed with me if I am conscious.

6. Additional Instructions: [this may be left blank]

Mrs Jane Smith
Date of Birth: 08/06/1968
Nationality: British/American
Medical Number: 0808.1968555
I.C.E. CONTACTS:
David (Spouse) 0151 555 5555
Dr Smith (GP) 0151 444 4444

[SEE REVERSE FOR MEDICAL INFORMATION]
DETAILS SUPPLIED IN CASE UKE AND CANNOT BE REVISED

8 Mid-Atlantic Ethics Committee Newsletter
Date of request: November 1, 2011
Time of request: 10:45 AM

Is request urgent (Check one): [X] Yes [ ] No

Requester’s description of the Case and ethical concern, including steps taken to resolve the concern: Patient signed a document refusing blood products based on his JW faith but it’s unclear whether he “really meant it,” and I need to know now whether I can administer blood products to save his life.

Type of assistance requested (Check all that apply):
[X] Forum for discussion
[ ] Conflict resolution
[X] Explanation of options
[ ] Values clarification
[X] Policy interpretation
[X] Recommendation for care
[ ] Moral support

Is the requester the patient’s attending (or primary provider for outpatients)? [X] Yes [ ] No

If not, has the attending (or primary provider for outpatients) been notified? [ ] Yes [ ] No

Patient Data

Patient’s first name: Joseph
Patient’s last name: Nelson
Age: 45
SSN (last 4): 1234
Gender: [X] Male [ ] Female

Care Setting (check one):
[X] Inpatient
[ ] Outpatient
[ ] Extended care
[ ] Other:

Location (e.g., clinic, unit, room):

Clinical service caring for the patient (check one):
[ ] Medical and Subspecialty Care (including Neurology)
[ ] Geriatrics and Extended Care/Rehab Medicine
[ ] Mental Health
[X] Surgical and Anesthesia
[ ] Other:
The ethics question in this case is: Given that the patient’s previously stated preferences as reflected in the “statement of refusal” of blood products that he signed before surgery should be followed out of respect for the patient, but the provider questions whether the patient would want his wishes overridden to save his life and preserve the heart transplanted into him, is it ethically justifiable to give him blood products?

**Consultants**

Primary consultant: Courtenay Bruce  
Other consultants involved in this consultation: Trevor Bibler, Adam Pena

* Primary model for this consultation:  
  [ ] Individual  
  [X] Team  
  [ ] Committee

**ASSEMBLE**

**Information Sources**

*Review of the health record: [X ] Yes [ ] No  
If no, explain why it wasn’t done. A review of the health record is very important in an ethics consultation: The surgeon requested a 30 minute response to this urgent request, so there was only time to scan the patient’s health record.

*Face-to-face patient visit: [ ] Yes [X] No  
If no, explain why it wasn’t done. A face-to-face visit is very important in an ethics consultation: NOTE: patient was under anesthesia and in sterile operating room, so viewed patient through OR window.

Staff (name, role in consultation): Barry Lestor, Anesthesiologist; Doug Williams, Nancy Boxer, Jane Wyler ... OR nurses, Wendy Preston, Transplant Coordinator

Family/friend (name, role in consultation): Janice Nelson (wife)

Other parties (name, role in consultation): None

**The following sources of ethics knowledge were reviewed or consulted:**

[X] Hospital policy  
[ ] Professional codes and guidelines  
[X] Published literature  
[ ] Precedent cases  
[ ] Outside ethics experts  
[X] Other (Specify): JW Literature
**Capacity/Surrogate/Advance Directive**

**Capacity**

* Does patient have decision-making capacity?  
  [ ] Clearly yes  
  [X] Clearly no  
  [ ] Partial/fluctuating/unclear  
  Comments: Patient is under anesthesia

**Surrogate Information**

Has a surrogate been identified? [X] Yes [ ] No  
If no, explain why in comment below.  
Comments:  
Surrogate’s first name: Janice  
Surrogate’s last name: Nelson

Select from hierarchy:  
[ ] Health Care Agent  
[ ] Legal or special guardian  
[X] Next-of-kin (If checked, specify):  
  1) [X] Spouse  
  2) [ ] Adult Child  
  3) [ ] Parent  
  4) [ ] Sibling  
  5) [ ] Grandparent  
  6) [ ] Adult Grandchild  
[ ] Close friend

Surrogate’s phone number(s)  
Home: (713) 555-1212  
Work: (713) 555-1213  
Other:  
Surrogate interviewed? [X] Yes [ ] No [ ] Pending  
Comments: The conversation was rushed due to the urgency of the consultation request.

**Advance Directive**

Review of advance directive? [ ] Yes [ ] No [X] Patient has no advance directive  
Comments:

**Information Summary**

Summarize the information gathered in the following fields. Identify the source of the information when it is important.
Medical facts: 45 y/o man with history of non-ischemic cardiomyopathy for past 5 years; referred to medical center by cardiologist after cardioversion and multiple ablations were unsuccessful in treating ventricular tachycardia; stabilized with medications and an intraaortic balloon pump as a bridge to transplant and put on heart transplant list; after about 1 month in hospital, has orthotopic heart transplant, but after prolonged time on pump his right ventricular function is “mildly decreased” and his hemoglobin level is low (4.5 g/dl). Without a blood transfusion, he may die. (Bruce, 2012)

Patient’s preferences and interests: Patient did not complete an advance directive and is now under anesthesia. His wife states that he is a baptized Jehovah’s Witness but describes him as “inactive,” and someone who expressed a desire to avoid blood products whenever possible, but that: “He always knew that I would consent to giving blood products if it were a life-threatening situation. It was sort of an implicit agreement or understanding we had.” Mrs. Nelson is not a JW. (Bruce, 2012)

Other parties’ preferences and interests: Due to the urgency of the request, there was not enough time to consult with a JW elder. See above regarding wife’s position.

Ethics knowledge: There is a long tradition in ethics and case law supporting the right of a JW to refuse blood products. The JW community has developed extensive resources to support this right (e.g., the JW No Blood Transfusion card and JW Advance Directive), and to minimize the need for blood products through blood conservation and bloodless surgery techniques (Varisco & Scheinin, 2015). However, allowing a patient to die when such a death can be prevented by blood transfusion requires unambiguous evidence that this is the patient’s wish. In addition to respecting an informed refusal and questioning an uninformed refusal of a life-saving blood transfusion, this case also raises distributive justice issues in that there is a shortage of available organs for transplantation (particularly hearts). It’s not just Mr. N’s death that should be considered but others next on the heart transplant list. This has implications for how consent for bloodless organ transplant surgeries should be handled in the future.

* Re-examine the ethics question

Review the ethics question that has been entered and reformulate it, if necessary.

The ethics question in this case is: Same as above

SYNTHESIZE

Formal Meeting

Did a formal meeting take place? [ ] Yes [X] No

*Ethical Analysis

How does the assembled ethics knowledge apply to the consultation, specific information, and the ethics question?

The ethical analysis for this case is: While there is ethical justification for allowing a JW patient to die rather than administering life-saving blood transfusions, this should only be done when it is clear that this is truly what the patient wanted. Given the ambiguity of the patient’s true wishes regarding whether or not he should receive life-saving blood transfusions, along with some evidence that he wanted his wife to consent to transfusions on his behalf if needed, and the urgent need to decide how to proceed, it is ethically justifiable to provide blood transfusions that are necessary to avoid his death and the possible loss of a viable heart for transplant.
Ethically Appropriate Decision Maker

First name: Janice
Last name: Nelson

Explain why they are the ethically appropriate decision maker: A spouse is an appropriate surrogate decision-maker for a patient barring evidence to the contrary.

Moral Deliberation

Describe the options considered and why they were or were not ethically justifiable: There were 2 main options considered in this case: not to provide blood products and risk life-threatening health outcomes/death for the patient, or to provide blood products and maximize the patient’s chances for recovery. The fact that neither the transplant surgeon nor the anesthesiologist had discussed limits of life-saving interventions with the patient before surgery, that the patient had not completed an advance directive or signed a JW No Blood Transfusion card, and that the patient was reportedly not an “active” JW practitioner, creates doubt about the patient’s true wishes. In addition, the patient’s wife described an implicit agreement between them allowing her to consent to blood transfusions on his behalf if needed to save his life. While the possibility exists that the wife (not a JW) may be representing her own rather than her husband’s wishes to use blood products to save his life, there is no other evidence that she is not representing his preferences. Given that death is irreversible, and that hearts for transplantation are in short supply, and that a decision needed to be made quickly, the justification for allowing life-saving blood transfusions is more compelling than the justification for disallowing them and allowing the patient to die.

RECOMMENDATIONS/PLANS

Did the relevant parties reach agreement in the case? [X] Yes [ ] No

*Describe recommendations/plans: Blood transfusions during surgery if needed to sustain/preserve the patient’s life are permissible. Procedures should be put in place in the hospital to ensure that in the future, the process for listing and consenting JW patients for organ transplant includes discussion and documentation about any limits on the use of blood products.

EXPLAIN

COMMUNICATE SYNTHESIS

Was the synthesis communicated to key participants in this case? [X] Yes [ ] No

Comments:

Health Record Note

NOTE: In the VA’s system, a Health Record Note can be generated once the data on this form is entered into ECWeb, VA’s electronic ethics consultation quality improvement database system.

FOLLOW-UP

At some interval after the completion of the ethics consultation, consultants should follow up with the requester and/or other key participants to find out what happened in the case.

Comments: It is important to follow-up with the patient, his wife, and the providers after surgery to assess the patient’s response to receiving blood and continue discussions of process improvements to avoid similar miscommunication in the future.
EVALUATE THE CONSULTATION

Critical self-review of the consultation: Evaluations can take several forms. Here you should document your own review of the case: This consultation was unique in that it was requested as an urgent consult. This meant that the information-gathering process was rushed, which increases the risk of missing relevant information that may have affected the ethical analysis and resulted in a different recommendation. There are clearly implications for proactive ethics that this case raises. There is also the question of whether errors were made in assessing the patient’s understanding of the use of blood products during surgery. If this is the case, we should discuss with the team whether the team error disclosure protocol should be implemented.

SELF-ASSESSMENT

Critical self-review of the consultation process: The question of whether to recuse from the consult due to insufficient time allotted for information-gathering and meeting with relevant stakeholders was considered, in order to preserve the professional integrity of the ethics consultants involved (Bibler & Bruce, 2015). However, given the limited options available to the transplant surgeon who requested the consult and the high stakes involved, the consult team decided that proceeding with this “urgent consult” was the “least-bad” option.

SYSTEMS ISSUES

Often ethics consultation cases are symptomatic of underlying issues involving organizational structures and processes that are best addressed at the systems level. Indicate if underlying systems issues were identified. If so, to whom were they referred: Yes, the process for consenting JW patients for organ transplants needs to be reviewed to avoid similar situations from happening in the future. Appropriate follow-up was initiated with Wendy Preston and the transplant team, and a meeting scheduled to discuss next steps. This will be brought to the attention of Maria Riverez (Quality Improvement) and Emilio Jones (Chief of Transplant Surgery).

Comments: None

NOTES

1. For more information on formulating the ethics question, see the VA's Ethics Consultation Primer: http://www.ethics.va.gov/docs/integratedethics/ec_primer_2nd_ed_080515.pdf.
2. In the VA system, a health care agent has a higher rank than an appointed guardian.
3. In the VA system, a close friend is a 4th category and not an extension of the Next of Kin category.
4. If the ethics question and direction of the consultation changes based on new information, the new question should be written here; if not, the ethics consultant should confirm that the ethics question has not changed.

CITED WORK


CALENDAR OF EVENTS

MARCH

14 (12N-1:30pm)
Berman Bioethics Seminar Series: Anita Tarzian, PhD, RN, “The Maryland MOLST Program: Findings from a Statewide Survey and Implications for Practice” sponsored by The Johns Hopkins Berman Institute of Bioethics. For more information, visit http://www.bioethicsinstitute.org/education-training-2/seminar-series.

15 (12N-1:15pm)
"Ethics for Lunch" Panel Discussion: Assessment of Decision-Making Capacity, Moderated by Sharon Owens, CRNP, PhD, sponsored by The Johns Hopkins Hospital Ethics Committee & Consultation Service, Sheik Zayed Tower room 2117 (the Arcade), Johns Hopkins Hospital, Baltimore, MD http://www.bioethicsinstitute.org/efl

15-16
Ethics and Clinical Social Work, a Bioethics Continuing Education Program, sponsored by the Center for Ethics at MedStar Washington Hospital Center, Washington, DC. For more information, e-mail Kahlia.t.keita@medstar.net

17-18
Professional Skills Program in Dispute Resolution, sponsored by The Center for Dispute Resolution at the University of Maryland Francis King Carey School of Law and the Straus Institute for Dispute Resolution at Pepperdine University School of Law. MD Carey Law, Baltimore, MD. For more information, visit http://www.law.umaryland.edu/adrskills

28 (12N-1:15pm)
Berman Bioethics Seminar Series: Jeffrey Kahn, “Mitochondrial Replacement: Ethics, Policy, and Implications,” sponsored by The Johns Hopkins Berman Institute of Bioethics. For more information, visit http://www.bioethicsinstitute.org/education-training-2/seminar-series

APRIL

11 (12N-1:15pm)
Berman Bioethics Seminar Series: Jerry Menikoff, MD, JD, sponsored by The Johns Hopkins Berman Institute of Bioethics. For more information, visit http://www.bioethicsinstitute.org/education-training-2/seminar-series

11-15
Intensive Bioethics Course, sponsored by the Center for Medical Ethics and Health Policy at Baylor College of Medicine & Houston Methodist, Houston, TX. https://www.bcm.edu/centers/medical-ethics-and-health-policy/education/bioethics-intensive

15-17
Interfaces and Discourses: A Multidisciplinary Conference on Islamic Theology, Law, and Biomedicine, sponsored by The Initiative on Islam and Medicine at the University of Chicago, Ida Noyes Hall – Cloister Club, Chicago, IL. For more information, visit https://pmruchicago.submittable.com/submit.

25 (12N-1:15pm)

28-May
Intensive Workshop in Conflict Resolution, sponsored by Penn Department of Medical Ethics and Health Policy, Perelman School of Medicine, University of Pennsylvania, Philadelphia, PA. http://medicalethics.med.upenn.edu/uploads/media_items/take-a-course-form.original.pdf

29 (9:00am - 12:15pm)

MAY

5-6
UAMS Intensive Workshop in Healthcare Ethics: Coping with Capacity, sponsored by the University of Arkansas for Medical Sciences & Division of Medical Humanities, UAMS College of Medicine, Little Rock, AR. http://humanities.uams.edu/education/annual-intensive-workshop-in-health-care-ethics/

6-7

9 (12N-1:15pm)
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