FROM THE FIELD

Caring for Patients with a History of Illicit Intravenous Drug Use: Ethical Obligations from Bedside to Boardroom

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A few years ago, Infection Control in one of our ministries asked for an ethicist's perspective of whether it was ethically permissible to unilaterally remove a peripherally-inserted central catheter (PICC) from a person who tampered with it and who had a history of illicit intravenous drug use. The tampering concern was precipitated by regulations on reimbursement that suggested if a hospital's central-line associated blood stream infection (CLABSI) rates reached a certain point, there would be a financial penalty.[1] Immediately, the question transcended clinical ethics and entered into the organizational realm, which necessitated careful consideration of the mission and core values of our Catholic health system. This initial conversation with Infection Control morphed into a more than a year-long project, involving several different departments across our ministries.

Key questions were: How should one think of the ethical obligations toward such a patient? What informs those parameters? The narrative of this project involved a complex pattern of socialization, criminalization, medicalization, moralization, and other ways of thinking about persons who use drugs, their health, and the obligations to care for them.[2] In the end, the ethical analysis revealed that it would be permissible to remove a PICC from a patient *if* there was demonstrable evidence s/he tampered with the device *and* caregivers exhausted all available efforts to solicit the patient's willing engagement and support the patient's ability to engage in the care plan.

Situations

A typical clinical scenario involves a young adult patient who presents with a life-threatening infection (e.g., osteomyletis or endocarditis) that requires days to weeks of antibiotic therapy

delivered intravenously. These patients often have altered mental statuses when they present to the hospital and the PICC lines are started either as an emergency intervention or with the permission of a surrogate. As the patient regains alertness, he or she typically becomes more conversant and engaged.

Often times, these patients use tobacco products along with intravenous (IV) drugs. This reveals a critical tension in caring for this patient population: smoking while receiving care.[3] In Oregon, our hospital campuses are non-smoking facilities. This means that patients who decline nicotine replacement therapy and insist on continuing to smoke have to leave the premises. Does this mean a discharge [against medical advice]? A temporary leave (aka, a "hall pass")?

Clinicians raise concerns about this patient population because of their history of using IV drugs and the presence of the port (PICC) on their person that gives them direct access to their bloodstream. Situate these concerns in the hospital setting where there is concern about diminished reimbursement for what is already likely to be a long hospitalization, and the moral distress can be palpable. Clinicians worry that patients may use their PICCs to inject illicit drugs or other substances (we have observed fecal matter, applesauce, and other substances). Sometimes the worry is more about the infection risk than about the use of drugs *per se* though the worries are often concomitant and inseparable.

While patients who do not have history of IV drug use may be discharged home or to a skilled nursing facility, concerns for patient safety for this patient population often result in patients remaining hospitalized in the acute care setting.[4] Consideration of a second-line antibiotic may reflect sub-standard treatment.[5] Surgeons may also dispute the number of times a heart valve may be replaced.[6] Moreover, too few skilled nursing facilities in our major metropolitan area accept patients who are both medically complex and have a history of substance use. Prolonged hospitalization seems to further complicate patient care. Leaving the nursing unit for a 'smoke break' constitutes a highly risky venture, may be logistically challenging, and reflects continuation of behavior that undermines both the patient's health as well as caregivers' efforts.

Background

Space does not permit a thorough exploration of the context and care provided for these patients.[7] Suffice it to say that any ethical analysis should reflect three levels of discourse: the interpersonal level (caregivers and patients);

institutional level (hospitals/systems, caregivers, and patients); and social level (health care industry, law enforcement, and the community).

For purposes of this essay, I describe the ways an ethics consultation service may address these cases. The framework I use here is based on ethnographic research that suggests caregivers do not necessarily request ethics consultation when there is a clear and concise ethical dilemma, but rather when there is a disruption in patient care (or an anticipated disruption).[8] In this way, one may describe *ethically significant* disruptions without needing caregivers to identify the particular issues involved.[9] The nature of ethics consultation in these cases may relate to any one or more of the following disruptions:

- **Ambiguity around patient preferences**: e.g., whether the patient wants to enter into recovery for substance use, or whether the patient wants help to survive the infection;
- **Patient does not demonstrate interest in medical recommendations**: e.g., whether the patient agrees with or desires to engage in provider recommendations (patients who do not demonstrate such an interest are often labeled as "noncompliant" or "nonadherent");
- **Patient needs are unaccommodated**: e.g., whether the patient had / has access to housing, financial security, social support, or other outpatient services;
- **Ambiguity of institutional policies**: e.g., confusion over whether or how to implement (or enforce) non-smoking, discharge process, visitor restrictions, or search of patient belongings policies; and
- **Ambiguity over scope of service**: e.g., whether to remove a PICC and discharge the patient.

A useful lens through which to see the ethical issues is that of the three components of **therapeutic relationships** among caregivers and patients: the *bond* [of the clinical encounter], the shared *goals* [of care], and the *care* [or interventions offered and accepted].[10]

- BOND: The *bond* between caregiver and patient in the clinical encounter corresponds to these ethical issues:
  - Caregivers may attribute the medical condition, burdens, or woes of a patient in **an *ad hominem* explanatory model;**[11]
  - The first issue relates to a second: that **the patient is solely culpable for his or her limited or lack of engagement** in care;
  - **Mutual trust** may be in short supply, and while a lot of literature has emphasized how much providers need to trust patients, it is asked much less whether and how patients can trust providers;[12]

- **Mutual respect** may also be limited, this is often reflected in chart lore and caregiver labeling of patients;
- **Clinical empathy** could be a remedy to many of the issues above, its lack may be the source of them, too;[13]
- **Moral distress** or the emotional distress accompanying a perceived threat to one's integrity occurs for a variety of reasons internal and external to one's exercise of conscience;[14] and
- Caregivers risk **patient abandonment** if they "give up" too readily or discharge the patient from service before arranging for or offering alternatives for the patient.

- GOALS: The *goals* of caregiver and patient may not always align, and there may or may not be overlap between what each party is willing to negotiate. The issues include:
  - Caregivers may believe that such patients cannot be helped in any way, this is **therapeutic nihilism**;
  - Caregivers may think about **harm reduction** and yet may still remain steadfastly attached to their own goals for the patient; and
  - Patients and caregivers may simply have **disparate, divergent, and/or irreconcilable goals**. Sometimes the goals and the differences between them may not be explicit.
- CARE: The *care* or interventions provided also may involve a degree of negotiation between what caregivers feel is professionally or personally acceptable and what patients are willing or able to accept and tolerate. The issues include:
  - Interprofessional tension may arise when there is variation, for example, from hospitalist to hospitalist in their **willingness to tolerate ongoing substance use** (be it tobacco or heroin) as well as tension between caregivers who may require absolute abstinence as a condition of continuing care whereas others may not;

- Like negotiating goals of care described above, patients and caregivers may have **differing ideas about and willingness to accept and offer interventions as part of a negotiated care plan**. An example is a patient's unwillingness to use or attempt to use nicotine replacement therapy for the duration of hospitalization; and
- Lastly, caregivers may feel or actually become **complicit in the wrong-doing** (e.g., use of illegal or diverted controlled substances).

Ethical and Theological Analysis
Although space does not permit a comprehensive treatment of all the ethical issues, I will describe key principles that have guided our discernment at all levels of our organization.

Respect for Human Dignity. As articulated in the *Ethical and Religious Directives for Catholic Health Care Services* (ERDs), Christian love is the animating principle behind Catholic health care.[15] That is, the caregiving by health care professionals ought to honor the inherent worth of each person irrespective of behavior patterns or social status. We therefore aspire to distinguish the behavior of using drugs from the person in need and avoid the attribution error. Following the Centers for Disease Control and Prevention (CDC), we talk about "persons who use drugs" not "IV drug abusers."

Grounded in this love, mutual respect forms a pillar of the professional-patient relationship. In caring for persons who use drugs, we seek healing and care of the whole person. Quoted in the *Charter for Health Care Workers*, St. John Paul II says, "It is important 'that there be an attempt to get to know the individual and to understand his inner world; to bring him to the discovery or rediscovery of his dignity as a person, to help him to reawaken and develop, as an active subject, those personal resources, which the use of drugs has suppressed, through a confident reactivation of the

mechanisms of the will, directed to secure and noble ideals.'"[16]

Hospitality and the Principle of Toleration.[17] Next, it is also important to recognize the relationship between the moral evaluation of substance use itself and the caring and contexts of caring to ongoing drug use. St. John Paul II indicated that drug use is always illicit because it "implies an unjustified and irrational refusal to think, will and act as free persons."[18] Different commentators have offered various interpretations; some have gone as far as to characterize IV drug use as "intrinsically evil."[19] For purposes of this article, I will take at face value the moral wrongs of illicit drug use; however, I submit that a thorough analysis of the morality of these actions is warranted.

In light of seeing illicit drug use as ethically problematic, the question remains: What are professional caregivers to do? What *can* a health care provider *actually* do to help patients who may not [yet] want to stop using drugs?

We have found guidance in the Principle of Toleration,[20] which articulates a foundational rationale for *a harm reduction philosophy of care*. Harm reduction aims to minimize the risks and reduce the harmful effects of certain behaviors that undermine and threaten health and well-being. Such an approach is relevant in settings wherein the ideal, recommended care and hoped for outcomes are not likely to be feasible. Harm reduction is about *how* caregivers engage patients 'while they wait' for different circumstances or choices to manifest.

It is essential, however, to distinguish the ethical Principle of Toleration from an attitude of indifferent tolerance. As David Hollenbach notes, the behaviors of mere non-interference reflect tolerance: a 'live and let live' attitude.[21] The principle, in contrast to the attitude, seeks new circumstances, new choices, and not mere non-interference. Thus, the proper correlative attitude is *hospitality*: the loving care, the welcoming invitation to change, and the endurance of wrongs (committed by others) that may be too burdensome or harmful to change (see below).[22] I argue that individual health (in the long run) and the common good are best served

when we apply the principle through the healing arts animated by Christian love and an attitude of hospitality.

Social Justice and Meeting the Demands of Fidelity of Relationships. In the biblical tradition, one may describe *justice* generally as "fidelity to the demands of a relationship."[23] What does this mean in the clinical encounter between a professional caregiver and a person who uses drugs with a life-threatening infection? Arguably, the role of the ethicist in such circumstances is to navigate the dynamics of such relationships as 'an ally for social justice'.[24] For example, this may mean making explicit such things as no one is obligated to do the impossible and thus there is no ethical obligation to provide non-beneficial treatment or disproportionately harmful treatment. It may also mean, as it did in our practice setting, that use of tools such as "behavior contracts" need to have an element of mutuality and reciprocity. It also means helping caregivers recognize that, after the team has exhausted all attempts to create a therapeutic relationship, the therapeutic relationship itself may not be sustainable – even in a harm reduction mode – and that is beyond their control. It may also mean that if a patient wishes to make a choice that is not in his or her interests, imposing a care plan, detaining the patient in the hospital, or forcing treatment is ethically problematic.[25]

It is important to note that in a mission-driven organization that identifies itself as providing excellent care *especially to the poor and vulnerable*, there is a certain 'burden of Mission' that may weigh on the conscience of caregivers and be a source of moral distress itself. This may sound heretical – and it should in a certain sense sound that way – but the role of an ethicist is often in the uncomfortable position of having to say 'you have done enough.' As evidence that such a reality is in fact within our heritage, we have found in our archives an episode wherein the Sisters of Providence demonstrated that they did all that they could for a person who suffered from substance use disorder and yet the Sisters could no longer sustain care for him and he had to be "dismissed."[26]

Recommendations

Caring for persons who use drugs and are suffering from a life-threatening infection *and* who continue to be at risk for recurrent bloodstream infections is enormously complicated; it is difficult to overstate the complexity. What are some practical take-aways in service to answering the relevant ethical questions? Our overall strategy has been to position caregivers proactively with a toolkit containing several different tactical approaches that may be used in real-time, or as appropriate, in any given case. The list below is a brief snapshot of this toolkit, which includes some conceptual tactics as well as concrete mechanisms:

- **Framing a Diagnostic Dilemma of Difficult Encounters with Patients**: To avoid labeling patients as "difficult," ethicists encourage caregivers to think of the *encounter* as difficult and then treat the difficulty of the encounter as a diagnostic dilemma: Rule-out psychiatric or neurologic issues, psychosocial stressors, cultural, linguistic, or health literacy issues, logistical challenges, and system-access issues.
- **Managing Moral Distress and Patient Engagement Guide**: Using the VitalSmarts™ *Influencer* framework, I developed a guide to help caregivers assess and manage moral distress; for example, one can use it as a guide to know when all has been exhausted.[27] (See table at the end of this article on pgs. 20-21.)
- **Screening Patients with a Decision-aid**: Nursing staff developed this guide to screen and assess patients for risk of bloodstream infections. One innovation here is that while it is not a policy *per se* it does utilize the same electronic policy database system and easily cross-links to relevant policies thus creating a clearinghouse of applicable policies, too. The other key innovation of this tool is that it seeks to minimize provider-to-provider variation in how care is given to these patients. While it remains to be seen whether there is in fact a demonstrable reduction in such

variation, we already have observed caregivers using a common language and recognition of a care pathway for these patients as well as a recognition of the full array of tools at their disposal.

- **Use of Physical Deterrents**: There are many clinical tactics available to caregivers. Recognizing the persons who use drugs may have diminished control over their wills given how profound physical dependency on the substance may be, caregivers can employ a variety of devices to help deter patients from tampering: for example, alcohol caps and stickers on PICC.[28]
- **Temporalizing Goals and Care**: It may be helpful for patients who show no desire to stop smoking to suggest as a 'temporary measure' nicotine replacement therapy. Perhaps some interpersonal tension may be relieved if patients are not pushed to stop smoking while they recover from an infection.
- **Motivational Assessment and Interviewing:** Ethicists encourage caregivers to engage in both motivational assessment (i.e., readiness to stop drug use and enter recovery) and motivational interviewing (i.e., discovery of patient interests and patient-identified barriers to those interests).[29]
- **Utilizing Empathic Communication**: Empathic communication can not only benefit patients by revealing clinically significant barriers to care but may also aid in caregiver resilience and recognition of what she/he brings to the encounter.[30]
- **Engaging in Care Conferences**: It often appears helpful to conduct team conferences early in admission (and as frequent as needed) as well as early and proactive patient care conferences.[31]
- **Shared Expectations Letter and the Notice of Conditions for Continued Hospitalization**: Ethicists developed two communication documents for attending providers to use during the prolonged hospitalization of

persons who use drugs at risk for bloodstream infections. The first is a letter communicating mutual and shared expectations; the second is a notification of the conditions of continuing hospitalization, including a reiteration of the consequences of not meeting those conditions. Indeed, these two documents replaced a single "care plan contract" document that was a one-time, make-it-or-break-it document. Both documents aspire to be patient-specific, mutual and reciprocal, and serve not as a "contract" but rather as a method of documenting communication and conversation between caregivers and patients.

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[1] Elizabeth Hayes, "Medicare Penalizes Oregon Hospitals for Hospital-Acquired Infections," *Portland Business Journal*, December 10, 2015, http://www.bizjournals.com/portland/blog/health-care-inc/2015/12/medicare-penalizes-oregon-hospitals-for-hospital.html, accessed December 2, 2016.

[2] For a fascinating expose on the relationships between criminalization, medicalization and moralization, see Peter Conrad and Joseph W. Schneider, *Deviance and Medicalization: From Badness to Sickness* (Philadelphia, PA: Temple University Press, 1992).

[3] See Annette S.H. Schultz, et al., "A Qualitative Investigation of Smoke-Free Policies on Hospital Property," *Canadian Medical Association Journal*, December 13, 2011, 183 (18): E1334-E1344; and Annette S.H. Schultz, et al., "An Ethnographic Study of Tobacco Control in Hospital Settings," *Tobacco Control*, 2006, 15:317-322.

[4] See Carolyn Jewell, et al., "Residential Addiction Treatment for Injection Drug Users Requiring Intravenous Antibiotics: A Cost-Reduction Strategy," *Journal of Addiction Medicine*, 2013, 7:271-276.

[5] See Dominik Mertz, et al., "Appropriateness of Antibiotic Treatment in Intravenous Drug Users, A Retrospective Analysis," *BMC Infectious Diseases*, 2008, 8:42, http://www.biomedcentral.com/1471-2334/8/42, accessed December 2, 2016.

[6] J. Michael DiMaio, et al., "Ethical Obligation of Surgeons to Noncompliant Patients: Can a Surgeon Refuse to Operate on an Intravenous Drug-Abusing Patient With Recurrent Aortic Valve Prosthesis Infection?" *Annals of Thoracic Surgery*, 2009, 88:1-8; and Jay A. Jacobson, "The Effect of Patients' Noncompliance on Their Surgeons' Obligations," *Surgical Clinics North America*, 2007, 87:937-948.

[7] See Conrad and Schneider, 110-144.

[8] Susan E. Kelly, et al., "Understanding the Practice of Ethics Consultation: Results of an Ethnographic Multi-Site Study," *Journal of Clinical Ethics*, Summer 1997, 8 (2): 136-149.

[9] This author elaborated on this framework at a paper presented at the annual conference of the American Society for Bioethics and Humanities in 2017 (Washington, DC) entitled, "Ethics and Humanities in the Work of Patient Safety and Quality Improvement: Partners or Problems?"

[10] Michael K.S. Cheng, "New Approaches for Creating the Therapeutic Alliance: Solution-Focused Interviewing, Motivational Interviewing, and the Medication Interest Model," *Psychiatric Clinics of North America*, 2007, 30:157-166. Cheng cites Bordin's definition of the therapeutic alliances as consisting of these three components.

[11] Contrast this with the observations that trauma informed care and the exposure to toxic stress and adverse childhood events are major risk factors in substance use disorder.

[12] Joseph O. Merrill, et al., "Mutual Mistrust in the Medical Care of Drug Users: The Keys to the 'Narc' Cabinet," *Journal of General Internal Medicine*, 2002, 17:327-333.

[13] Jodi Halpern, "Empathy and Patient-Physician Conflicts," *Journal of General Internal Medicine*, 2007, 22:696-700.

[14] Elizabeth Gingell Epstein and Ann Baile Hamric, "Moral Distress, Moral Residue, and the Crescendo Effect," *Journal of Clinical Ethics*, Winter 2009, 20 (4): 330-342.

[15] United States Conference of Catholic Bishops (USCCB), *Ethical and Religious Directives for Catholic Health Care Services*, 5th edition (USCCB: Washington, DC, 2009).

[16] Pontifical Council for Pastoral Assistance, *Charter for Health Care Workers*, available at https://www.ewtn.com/library/CURIA/PCPAHEAL.HTM, accessed December 2, 2016, #95.

[17] I will set aside the discussion of needle exchanges and safe injection sites. In those cases, a thorough analysis of the moral action of using illicit drugs AND of the principle of material cooperation is warranted. Suffice it to say here, I suspect there is room in our tradition for such approaches. Though, this is not without controversy given the analysis provided by the National Catholic Bioethics Center (NCBC) in this Position Paper: Ethicists of the NCBC, "Cooperation with Moral Evil," February 2013, http://www.ncbcenter.org/index.php/download_file/force/157/311/, accessed December 2, 2016. NB: The most relevant discussion

is on page 2, question 2, which suggests needle exchanges constitutes implicit formal cooperation with evil.

[18] Pontifical Council for Pastoral Assistance, #94.

[19] See this perspective from an Australian commentator: J.N. Santamaria, "Heroin Injecting Rooms and Catholic Health Care Services," *Bioethics Research Notes*, September 1999, 11 (3): http://docplayer.net/11044087-Bioethics-research-notes-11-3-september-1999-heroin-injecting-rooms-and-catholic-health-care-services.html, accessed December 2, 2016.

[20] See Joseph J. Piccione, " 'Tolerance' as a Moral Concept for Catholic Health Care Ministry in a Pluralist World," *Healthcare Ethics USA*, Winter 2015, 12-22.

[21] David Hollenbach, "The Common Good and Urban Poverty," *America*, June 5, 1999. 8-11.

[22] Margaret E. Mohrmann and Lois Shepherd, "Ready to Listen: Why Welcome Matters," *Journal of Pain and Symptom Management*, March 2012, 43 (3): 646-650.

[23] John R. Donahue, "The Bible and Catholic Social Teaching," in *Modern Catholic Social Teaching: Commentaries and Interpretations*, ed. Kenneth R. Himes (Georgetown University Press: Washington, DC, 2005), 14.

[24] I am indebted to Dr. Mark Kuczewski of the Neiswanger Institute at Loyola University Chicago School of Medicine for the term and its relevance to the role of ethicists.

[25] John Tuohey and Jeffery T. Young, "Ethical Considerations in the Risk-Benefit Analysis for Patients with Diminished Capacity," *Journal of Hospital Ethics*, Winter 2009, 1 (3): 20-23. The ethicists at the Providence Center for Health Care Ethics updated this framework and created a poster, which this author presented at the International Conference for Clinical Ethics Consultation in 2014 and is available online(http://oregon.providence.org/~/media/Files/Providence%20OR%20PDF/patientvoicefullposter24x36.pdf) and at the annual conference of ASBH in 2015 (as a paper).

[26] A colleague retrieved this brief story from the Archives of the Sisters of Providence; the story dates back to 1954.

[27] For more information on VitalSmarts™, visit https://www.vitalsmarts.com/influencer/.

[28] For example, Jennifer Ho, et al., "Safe and Successful Treatment of Intravenous Drug Users with a Peripherally Inserted Central Catheter in an Outpatient Parenteral Antibiotic Treatment Service," *Journal of Antimicrobial Chemotherapy*, 2010, 65:2641-2644.

[29] Cheng 2007; and David J. Alfandre, "'I'm Going Home': Discharges Against Medical Advice," *Mayo Clinic Proceedings*, March 2009, 84 (3): 255-260.

[30] Halpern 2007; and Frederick W. Platt and Vaughn F. Keller, "Empathic Communication: A Teachable and Learnable Skill," *Journal of General Internal Medicine*, April 1994, 9:222-226.

[31] Alfandre 2009.