

Living and Dying with HIV/AIDS:

Exceptional and Everyday Health Care Ethics

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MR. SMITH

A 55-year-old man was recently diagnosed with an aggressive lymphoma and HIV/AIDS.

At hospital admission, the physician learns that the patient's spouse does not know that the patient has AIDS. The spouse has late stage Huntington's disease.

Should this information be disclosed to the spouse?

MS. JONES

A 23-year-old woman with perinatally acquired HIV struggles to live with HIV/AIDS. She suffers from severe depression and has persistent history of nonadherence to the ART medication regimen. Admitted that nonadherence could be characterized as passive suicide. Her psychosocial situation is very stressful. Patient has social anxiety disorder and lives with aunt who does not fully trust the health care system. Patient has recently presented with signs of end-stage illness, etc. weight loss, recurring opportunistic infections [VL 135,000 and CD4 81/7%].

Under what circumstances would it be appropriate to shift the focus of the plan to comfort?

Ethics Consultation Service: What is it?

It is a medical center service with the following goal:

“To promote ethically-appropriate, patient-centered care and effective ethical decision-making by Vanderbilt University Medical Center’s (VUMC’s) healthcare providers and patients, their surrogates and family members.”

- VUMC Policy OP 20-10.19

Who can contact the Ethics Consultation Service?

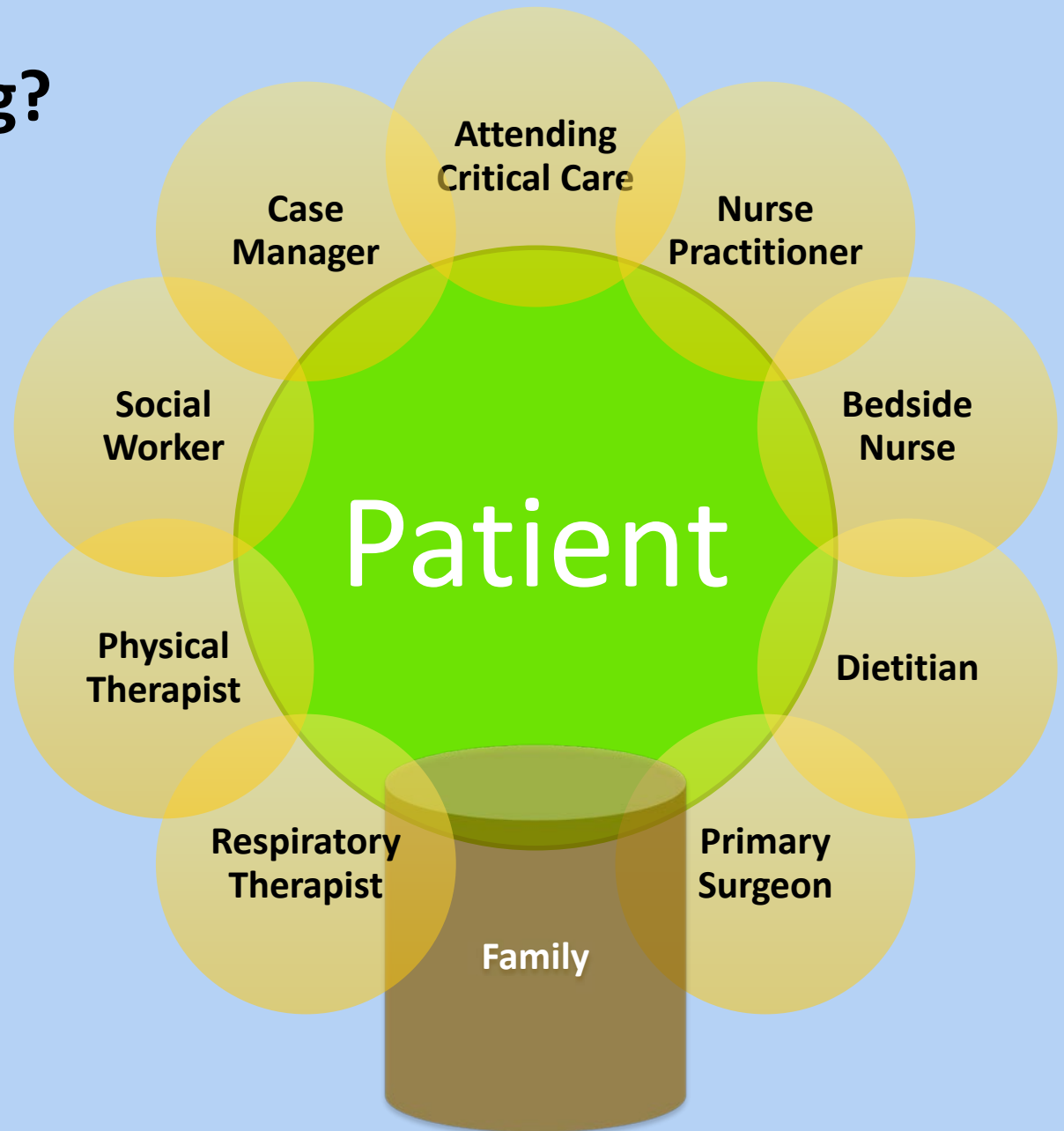
“Clinical ethics consultation is available to, and may be requested by, any member of the VUMC faculty and staff, as well as by all patients, and their surrogates and family members.”

-VUMC Policy OP 20-10.19

What happens when you call...

- Ethics consultant calls you back as soon as possible
- Ask questions / gather relevant information
- Create opportunities to have conversation with involved parties
- Identify clarify relevant concepts (e.g. confidentiality, privacy, informed consent, best interest, resuscitation status)
- Clarify related concerns (e.g., implications of societal values, law, ethics, and institutional policy)
- Help to identify and build a range of morally acceptable options within the context
- Assist involved individuals in clarifying their own values

What is shared decision making?



Risk Factors for Shared Decision Making

1. High stake decisions
2. Uncertainty
3. Complexity
4. Time
5. Family configuration
6. Team configuration
7. Different opinions

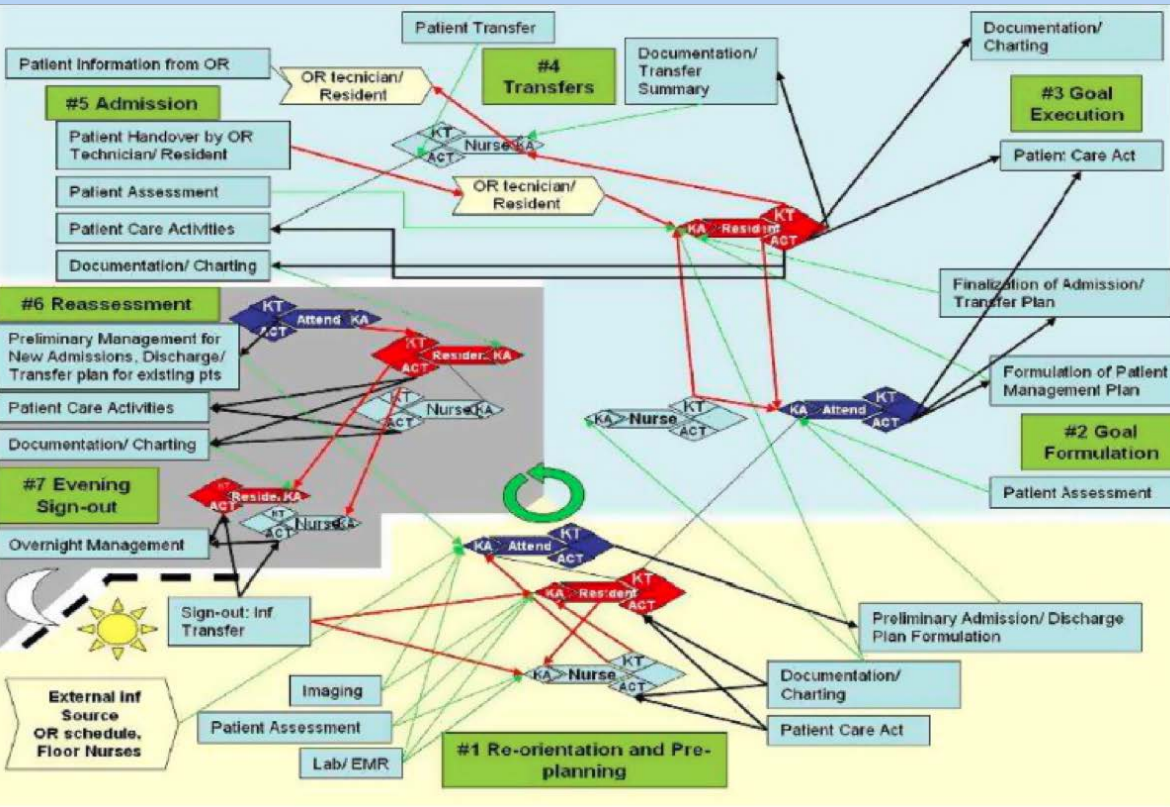


Fig. 3 The cognitive workflow model for inpatient care (from Malhotra et al. [92]; Reprinted with permission from Copyright Elsevier Limited 2007). The workflow moves in a counter-clockwise fashion, with the sun...

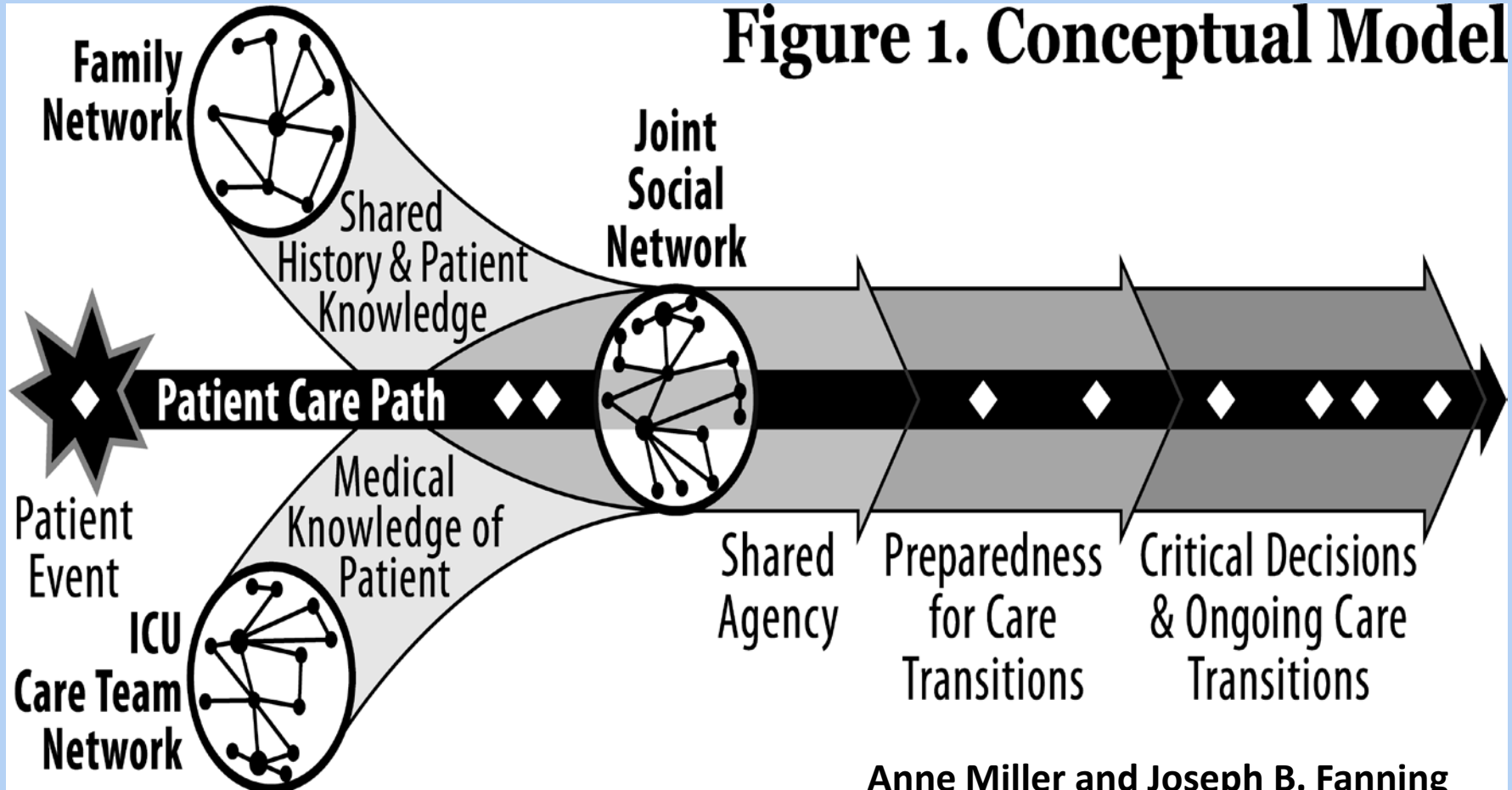
Vimla L. Patel, Jiajie Zhang, Nicole A. Yoskowitz, Robert Green, Osman R. Sayan

Translational cognition for decision support in critical care environments: A review

Journal of Biomedical Informatics Volume 41, Issue 3 2008 413 - 431

What is shared decision making?

Figure 1. Conceptual Model



Anne Miller and Joseph B. Fanning

“patients and providers have different – but equally valuable – perspectives and roles in the medical encounter” – Gregory Makoul

Health Care Ethics

Everyday Healthcare Ethics

Habits and skills used everyday.

- Collaborating to improve the patient's health
- Showing compassion in the presence of vulnerability
- Developing trust with patients/surrogates
- Discerning how to make a patient's life or death better

Exceptional Healthcare Ethics

Key principles in question or conflict

- Respecting **autonomy**
- Discerning **benefit**
- Avoiding or minimize **harm**
- Distributing healthcare goods **justly**

Everyday Health Care Ethics



Carol Gilligan, Ph.D.
University Professor
New York University
School of Law

This conception of morality as concerned with the **activity of care** centers moral development around **the understanding of responsibility of relationships**, just as the conception of morality as fairness ties moral development to the understanding of rights and rules.

--*In a Different Voice*, 1982

Exceptional Health Care Ethics

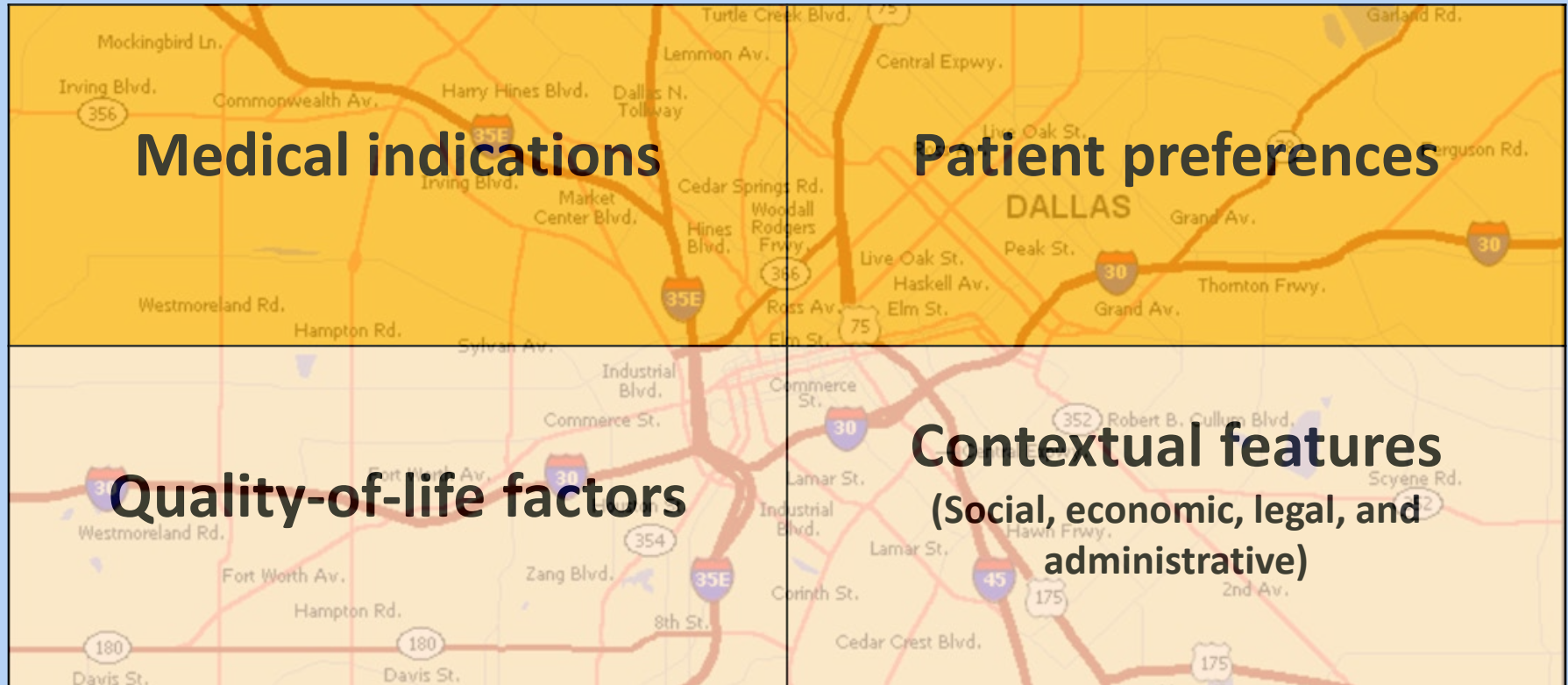
“Many disputes in biomedical ethics are largely disputes about **normative principles** – which principles, if any, are applicable, how much weight they have, especially if they are in conflict and what they imply for particular cases.”



James F. Childress

“The Normative Principles of Medical Ethics” in Robert Veatch’s *Medical Ethics*

Clinical Ethics: Four Topics Method



Jonsen, Siegler, & Winslade, *Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine*, 7th Edition, McGraw Hill Medical.

Medical Indications

- What is the patient's medical problem? History, diagnosis, and prognosis?
- Is the problem acute? Chronic? Critical? Emergent? Reversible?
- What is (are) the goal(s) of treatment?
- What are the probabilities of success?
- What are the plans in the event of failure?
- How can medical care benefit this patient and how can harms be avoided?

Quality of Life

- What are the patient's prospects for meaningful recovery?
 - What deficits is the patient likely to experience if the treatment succeeds?
 - Are there biases that might affect the view of the patient's quality of life?
 - If patient's current/future life is viewed as unacceptable, why?
- If plan is to forego treatment, then why?
- Are there plans for comfort care?

Patient/Family Preferences

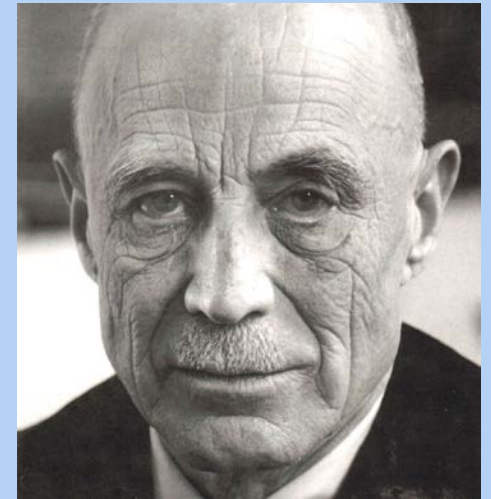
- Does patient have capacity for medical decision making?
- If capacitated, what does the patient state about his or her preferences for treatment?
- Has the patient been informed about risks and benefits of treatment, understood them, and consented?
- If incapacitated has the patient expressed prior preferences?
- If surrogate appointed, is the surrogate using appropriate standards for decision making?

Contextual features

- Are there family issues that might influence treatment decisions?
- Are there financial and economic factors?
- Are there religious or cultural factors?
- Are there limits on confidentiality?
- Are there problems with access to care or allocation of resources?
- How does the law affect treatment decisions?

Interpreting Narratives

“In our responsibility we attempt to answer the question of “What shall I do?” by raising as the prior question, “What is going on?”



H. Richard Niebuhr
in
The Responsible Self

Stigma

- “Undesired differentness” that sets individuals apart from “normal” society [Goffman, *Stigma: Notes on the Management of Spoiled Identity*, 1963]
- Stigma is a fundamental cause of health inequalities because it contributes to the unequal distribution of resources and power through multiple pathways. [Hatzenbuehler, M.L., Phelan, J.C., Link, B.G., 2013. Stigma as a fundamental cause of population health inequalities. *Am. J. Public Health* 103 (5), 813e821.]

STIGMA and HIV/AIDS

- In 1981, the Center for Disease Control (CDC) published a report that five gay men in the United States had been treated for a rare pneumonia, which seemed to be associated with a “homosexual lifestyle.” This pneumonia was later identified as a late manifestation of AIDS. Living with AIDS immediately became associated with gay men (Epstein, 1996) and, later, drug users and sex workers (Brown et al., 2003; Deacon, 2006) **groups stigmatized for engaging in risky and immoral behaviors.** Perceived to be communicable, AIDS has been stigmatized for instrumental reasons as well, given the **fear of and misconceptions surrounding contagion** (Herek, 1999).

M. Clair et al. / “**Destigmatization and health**: Cultural constructions and the long-term reduction of stigma.” Social Science & Medicine xxx (2016) 1e10 5

MR. SMITH

A 55-year-old man was recently diagnosed with an aggressive lymphoma and HIV/AIDS.

At hospital admission, the physician learns that the patient's spouse does not know that the patient has AIDS. The spouse has late stage Huntington's disease.

Should this information be disclosed to the spouse?

Indications for Medical Intervention

- What is the patient's medical problem? History? Diagnosis? Prognosis?
- Is the problem acute? Chronic? Critical? Emergent? Reversible?
- What is(are) the goal(s) of treatment?
- What are the probabilities of success?
- What are the plans in the event of failure?
- How can medical care benefit this patient and how can harms be avoided?

Patient Preferences

- Does the patient have capacity for medical decision making?
- If capacitated, what does the patient state about his or her preferences for treatment?
- Has the patient been informed about risks and benefits of treatment, understood them, and consented?
- If the patient is incapacitated,
 - Has the patient expressed prior preferences? (e.g., through an advance directive)?
 - Has a surrogate decision maker been appointed? Is the surrogate using appropriate standards for decision making?
- Are the patient's rights being respected?

MR. SMITH

Patient does not want this information disclosed to his spouse for three reasons.

1. He thinks it will do psychological harm to her because her mental status is altered.
2. He has not put her at risk because they have not had sexual intercourse since being infected.
3. He is her primary caregiver and she could reject his care after disclosure

Should this information be disclosed to the spouse?

Quality of Life

- What are the patient's prospects, with and without treatment, for meaningful recovery?
- What physical, mental, and social deficits is the patient likely to experience if the treatment succeeds?
- Are there biases that might affect the providers' and others' view of the patient's quality of life?
- Is the patient's present or future condition such that his or her continued life might be judged unacceptable?
- Is there any plan to forego treatment? If so, with what rationale?
- Are there plans for comfort and/or palliative care?

Contextual Features

- Are there family issues that might influence treatment decisions?
- Are there financial and economic factors?
- Are there religious or cultural factors?
- Are there limits on confidentiality?
- Are there problems with access to care or allocation of resources?
- How does the law affect treatment decisions?
- Is clinical research or teaching involved?
- Is there any conflict of interest for the provider or institution?

Tennessee Code on Disclosure

68-10-101. Reports of physicians and health officers.

(a) Every physician or other person who makes a diagnosis of, or treats, or prescribes for a case of sexually transmitted disease and every superintendent or manager of a clinic, hospital, laboratory or penal institution, in which there is a case of sexually transmitted disease, shall report the case immediately to those persons or agencies designated as recipients of such reports by the commissioner.

Tennessee Code on Disclosure

68-10-115. Immunity from liability for informing person of potential HIV infection.

- A person who has a reasonable belief that a person has knowingly exposed another to HIV may inform the potential victim without incurring any liability. A person making such disclosure is immune from liability for making disclosure of the condition to the potential victim.
- [Acts 1993, ch. 322, § 3.]

Ethical Justifications of Confidentiality (and its Limits)

RESPECT FOR AUTONOMY

- Recognizes that patient has right to decide what is in his/her best interest.
- Recognizes that patient should determine who knows about personal health information.

BENEFICENCE

- Clinicians are expected to behave in way that results in benefit of patient.
- Trust in clinician confidence supports open and accurate reporting of health issues that promotes maximum benefit.

Ethical Justifications of Confidentiality (and its Limits)

RESPECT FOR AUTONOMY

- Patient is effectively depriving partner of critical health information that would allow partner to make informed decisions.
- Patient failure to inform partner does not obligate clinician to nondisclosure.

BENEFACTENCE

- Clinicians obligated to "desire and seek beneficial outcome of disease."
- This cannot be limited to the patient currently suffering from the disease.
- Disclosure to 3rd party does not negatively affect patient and could allow prevention of transmission

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Table 1. Legally Relevant Criteria for Decision-Making Capacity and Approaches to Assessment of the Patient.

Criterion	Patient's Task	Physician's Assessment Approach	Questions for Clinical Assessment*	Comments
Communicate a choice	Clearly indicate preferred treatment option	Ask patient to indicate a treatment choice	Have you decided whether to follow your doctor's [or my] recommendation for treatment? Can you tell me what that decision is? [If no decision] What is making it hard for you to decide?	Frequent reversals of choice because of psychiatric or neurologic conditions may indicate lack of capacity
Understand the relevant information	Grasp the fundamental meaning of information communicated by physician	Encourage patient to paraphrase disclosed information regarding medical condition and treatment	Please tell me in your own words what your doctor [or I] told you about: The problem with your health now The recommended treatment The possible benefits and risks (or discomforts) of the treatment Any alternative treatments and their risks and benefits The risks and benefits of no treatment	Information to be understood includes nature of patient's condition, nature and purpose of proposed treatment, possible benefits and risks of that treatment, and alternative approaches (including no treatment) and their benefits and risks
Appreciate the situation and its consequences	Acknowledge medical condition and likely consequences of treatment options	Ask patient to describe views of medical condition, proposed treatment, and likely outcomes	What do you believe is wrong with your health now? Do you believe that you need some kind of treatment? What is treatment likely to do for you? What makes you believe it will have that effect? What do you believe will happen if you are not treated? Why do you think your doctor has [or I have] recommended this treatment?	Courts have recognized that patients who do not acknowledge their illnesses (often referred to as "lack of insight") cannot make valid decisions about treatment Delusions or pathologic levels of distortion or denial are the most common causes of impairment
Reason about treatment options	Engage in a rational process of manipulating the relevant information	Ask patient to compare treatment options and consequences and to offer reasons for selection of option	How did you decide to accept or reject the recommended treatment? What makes [chosen option] better than [alternative option]?	This criterion focuses on the process by which a decision is reached, not the outcome of the patient's choice, since patients have

* Questions are adapted from Grisso and Appelbaum.³¹ Patients' responses to these questions need not be verbal.

THE NEW ENGLAND JOURNAL of MEDICINE

357;18 November 1, 2007

CLINICAL PRACTICE

Assessment of Patients' Competence to Consent to Treatment

Paul S. Appelbaum, M.D.

Quality of Life

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“Well, if I am able to eat chocolate ice cream and watch football on TV then I’m willing to stay alive.”

THE NEW YORKER

ANNALS OF MEDICINE

LETTING GO

What should medicine do when it can't save your life?

BY ATUL GAWANDE

AUGUST 2, 2010

Contextual Features

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“Ethics is part logic [following an argument], part leaps of imagination [stepping into someone else’s shoes], part storytelling [weaving a coherent thread through our moral motives, means and actions], and many other things.”

Larry R. Churchill, Nancy M.P. King, and David Schenck, “Ethics in Medicine: An Introduction to Moral Tools and Traditions”,
Social Medicine Reader