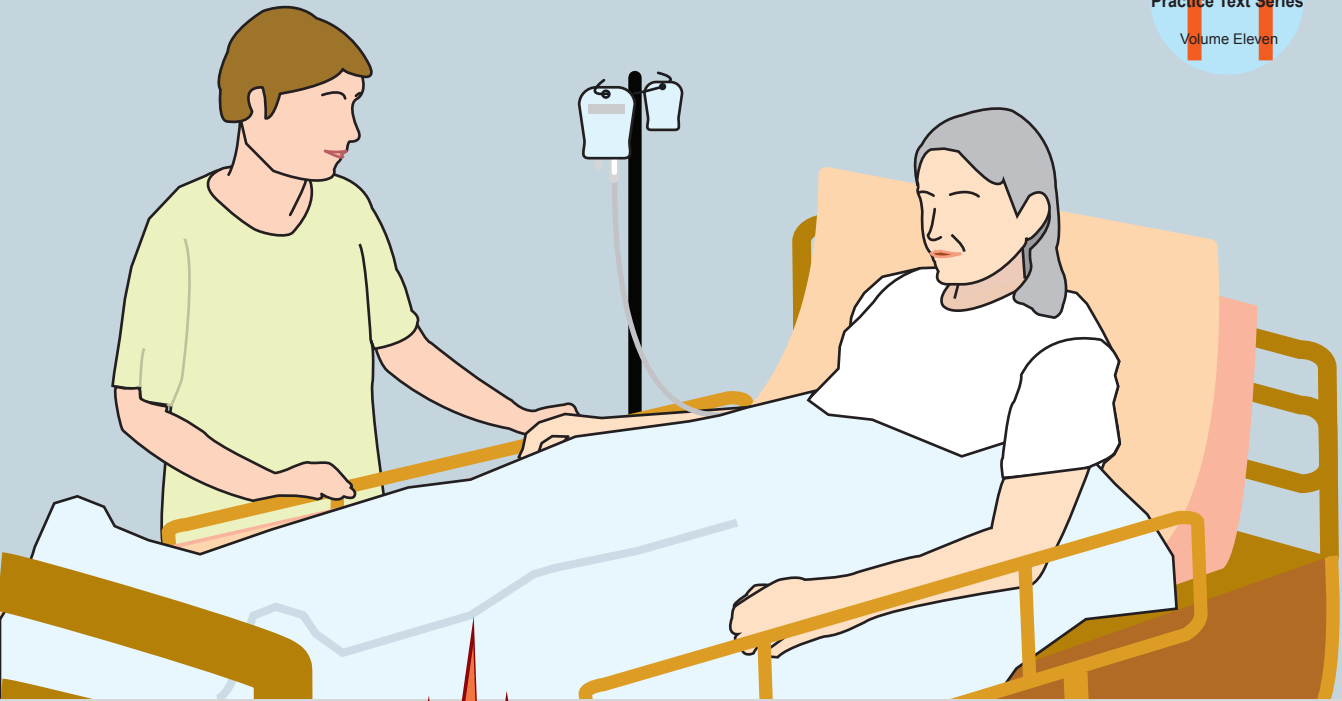


# Ethics in Health Care Social Work Practice: Issues and Directions

The Exemplars in  
Practice Text Series  
Volume Eleven



Editor:  
William J. Spitzer, PhD/DCSW



National Society for Social Work Leadership in Healthcare

*The Select Practice Series:*

*ETHICS IN HEALTH CARE SOCIAL WORK PRACTICE:  
ISSUES AND DIRECTIONS*

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*ETHICS IN HEALTH CARE SOCIAL WORK PRACTICE:  
ISSUES AND DIRECTIONS*

***The Exemplars in Practice Series***

National Society for Social Work Leadership in Health Care

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## Preface

This is the first text in the second decade of the *Exemplars in Health Care Social Work Practice Series*. Like the first series edition appearing in 2004, it focuses on ethical issues prevalent in health care delivery and examines how these issues impact decision-making by patients, providers and other involved parties. New technologies, life-style changes and the success of increasingly sophisticated interventions have altered the length and quality of life. At the same time, the broadening sociocultural diversity of our population brings greater challenges to the access and appropriate use of health care services. Differences in values, beliefs and preferences among cultures and religions pose an expanding array of dilemmas for intervening health care professionals.

Politics, economics and business decisions influence the service delivery landscape and ethics of practice. Increasing awareness of inequitable care coupled with concerns with ever-escalating health care costs precipitated passage of the landmark *Patient Protection and Affordable Care Act of 2010 (PPACA)*. The Act emphasized patient self-determination and care coordination while companion measures expanding Medicaid eligibility guaranteed increased health care access to large numbers of previously non- and underserved populations. To enhance effectiveness while reducing expense the PPACA encouraged evolutionary changes in delivery methodologies including transdisciplinary models, preventative care, tele-health technologies and home-based or clinic services. These changes affected not only the nature of interventions, but an increase in the frequency and complexity of ethical decisions about applying such care.

In this volume, six distinguished authors examine the factors affecting contemporary health care and highlight the ethical implications for social work practice. *Dr. Frederic Reamer* discusses the concept of risk management, contributes a detailed description of the key ethical challenges to the profession and then identifies the steps in implementing comprehensive risk management strategies designed to mitigate these challenges. *Dr. Patricia O'Donnell* provides an in-depth, thought-provoking examination of proactive intervention in cases of futility, while *Judy Shipman* reveals the ethical and legal issues associated with clinical practice in a memory disorder clinic. *Drs. Adrienne Farrar and O'Donnell* offer a review of practice and research associated with biomedical issues and social work. These range from end of life concerns to privacy and confidentiality issues, patient autonomy and administrative considerations related to delivery of clinical care. They review social work ethical obligations and conflicts as well as models of ethical decision-making. *Subha Addy* examines the pervasive influence of culture on health access and use, including the importance of establishing culturally competent professional practice. Rounding out our eleventh Exemplars edition, *Dr. Michael Reisch* reveals the myriad of ethical implications of the Patient Protection and Affordable Care Act of 2010 on health care delivery.

Readers will find this volume to be particularly valuable in its contribution of perspective and knowledge about sensitively providing health care services in an ever-challenging practice environment. The future unquestionably holds the prospect that such expertise will be required.

*Dr. William J. Spitzer, DCSW*

Editor – National Society for Social Work Leadership in Health Care

## EDITOR'S NOTE

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## *ETHICS IN HEALTH CARE SOCIAL WORK PRACTICE: ISSUES AND DIRECTIONS*

### **OVERALL DESCRIPTION:**

This text focuses on ethical issues prevalent in contemporary health care and examines how these issues impact decision-making by patients, professionals and other involved parties. It presents the challenges to determining appropriate interventions and highlights the role of social work in addressing concerns that arise among those receiving and providing care. The philosophic underpinnings and practice skills associated ethical service delivery are highlighted.

### **LEARNING OBJECTIVES:**

Upon completion of this publication, readers will be able to:

1. Identify and describe how to manage the ethical dilemmas and risks that arise in the delivery of contemporary health care services.
2. Recognize the issues and techniques associated with proactively intervening in situations of futility.
3. Understand the ethical and legal issues influencing patient service delivery in a memory disorder clinic.
4. Recognize the impacts of socio-cultural factors on the accessing and use of health care services.
5. Understand the ethical implications of the *Patient Protection and Affordable Care Act* on patients, professionals and provider organizations.

# Social Work Ethics in Health Care: Managing Dilemmas and Risk

*Frederic G. Reamer, PhD.*

## Introduction

Nearly three decades ago, I was invited to write an article for the tenth anniversary issue of *Health and Social Work*, the pioneering journal published by the National Association of Social Workers (Reamer, 1985). My charge was to discuss the relevance of bioethics to social workers in health care settings. I discussed the nature of bioethics in general and the ethical issues social workers in health care settings encounter with respect to patients' challenging medical conditions, the relationships between social workers and clients, the relationships among professional colleagues, and health care policy.

It is quite humbling to reread one's words nearly thirty years after the fact. Examined through the rearview mirror, and with the benefit of hindsight, the words take on different meaning. After all, in the early 1980s the bioethics field was still relatively young, having emerged in earnest in the 1970s. Social work's formal involvement in the bioethics world was even younger. With a handful of exceptions, social work's scholarly literature on professional ethics did not begin to appear until the early 1980s. Thus the intellectual foundation on which my Health and Social Work essay rested was remarkably thin compared to the one on which I now stand.

Without question, social workers' understanding of ethical issues in the profession and health care in particular is one of the most remarkable developments in social work's history. As a group we have traveled far. In some respects, we have headed in the direction I forecasted in 1985. In other key respects, social workers in health care are encountering ethical issues I could not have then imagined.

My aim here is to take a fresh look at the emergence and evolution of ethical issues social workers face in health care settings, the current status of social work ethics related to health care, and issues that practitioners may face in the future. I feel reasonably confident about my assessment of the historical and contemporary facts; however, I speculate about the future with some trepidation. Given my inability nearly thirty years ago to fully anticipate the bioethics issues with which today's social workers deal, I am reluctant to forecast what the next generation of social workers is likely to face.

In many important respects, social workers have always been concerned about ethics. Beginning in the 19<sup>th</sup> century, social workers were preoccupied with basic values related to client well-being and dignity, although some argue that professionals' concern during this era was tinged with paternalistic concern about clients' moral rectitude (Banks, 2012; Plant, 1970; Popple, 1992; Reamer, 2013a). Over time social workers have moved away from their focus on clients' morality and toward concern about the profession's core values, ethical dilemmas involving conflicting duties and obligations, ethical decision making and, most recently, ethical

risk management. This evolution reflects developments in the broader discipline of applied and professional ethics (also known as practical ethics) and in social work itself.

The formal discipline of applied and professional ethics, which is the intellectual home of bioethics, got its start around 1970, although there certainly were earlier expressions of interest in ethical issues facing professionals (*Beauchamp and Childress, 2012; Foster, 2008*). Seminal discussions in the 1970s addressed core ethics concepts such as patient autonomy, paternalism, beneficence, nonmaleficence, justice, informed consent, futile and end-of-life care, truth-telling, distributive justice, euthanasia, and whistle blowing. Medical schools, and eventually training programs in other health care professions, began to incorporate ethics education into their curricula (*Callahan & Bok, 1980*). Health care professionals were beginning to learn and speak the language of ethics and its unique argot; the vocabulary included philosophical terms and concepts used to analyze ethical dilemmas, such as metaethics, normative ethics, deontology, teleology, act utilitarianism, rule utilitarianism, egoism, virtue ethics, prima face duty, and moral absolutism and relativism.

During this period, a number of hospitals formed institutional ethics committees following the 1976 New Jersey Supreme Court decision in the Karen Ann Quinlan case, and a number of major teaching hospitals inaugurated ethics grand rounds (*Beauchamp & Childress, 2012*). The phenomenon of ethics consultant was invented, which led to formal employment in some hospitals for ethicists whose mission was to assist health care professionals with ethical decisions involving termination of life support, organ transplantation, reproductive rights, prenatal and genetic screening, treatment refusal, administration of neuroleptic medication, triage, informed consent, advance directives, and proxy judgment. Research centers – especially The Hastings Center in New York and the Kennedy Institute of Ethics at Georgetown University – devoted entirely to professional ethics, and especially bioethics, flourished. By the 1980s, applied and professional ethics had arrived; ethics had ventured out of the Ivory Tower and into the professions' trenches, including social work's.

## **Social Work and Bioethics**

Today's social workers in health care settings are much more attuned to ethical challenges than were their predecessors. Here are several examples of contemporary dilemmas:

### **Case Examples**

*Edgar R.* was a 94-year-old man who was admitted to a nursing home after his recent hospitalization for pneumonia. About one month after his nursing home admission, Mr. R. developed signs of congestive heart failure. The nursing home's social worker, Darlene M., looked through Mr. R.'s chart to review his advance directive and durable power of attorney for health care. Darlene was confused by apparent inconsistencies in the record; apparently Mr. R. had checked options about his preferences for life-sustaining treatment options (including his wishes concerning artificial ventilation and artificially administered fluids and nutrition) that were contradictory. Shortly thereafter



Mr. R. went into a coma. His sole surviving child insisted that the health care staff do everything possible to save Mr. R.'s life. However, Darlene felt strongly, based on her conversations with Mr. R. and some of the information on his advance directive, that he did not want life-sustaining treatment.

*Marla N.* is a 62-year-old woman with ovarian cancer who received home-based care from a local agency. Ms. N. and her social worker, Suzanne E., became quite close; at times Ms. N. referred to Suzanne as her "pretend daughter." One day Ms. N. told Suzanne that she had some gifts for her. Ms. N. then gave Suzanne two pieces of fine jewelry (a necklace and ring), an expensive sculpture, her theater subscription, and an antique lamp that Suzanne had often admired. Ms. N. told Suzanne, "I really don't need these things anymore and I know you'll love them. I really want you to have them." Suzanne initially told Ms. N. that she should not accept the gifts, but Ms. N. persisted. Eventually Suzanne accepted the gifts. About a month later Ms. N.'s estranged daughter discovered that her mother had given Suzanne the gifts. The daughter was enraged; she contacted the state social work licensing board and filed a formal complaint against Suzanne.

*Alvan B.* was a 47-year-old man who lived alone in a small, ramshackle home. He received home-health services after his discharge from a hospital following hip surgery. Luis D., the home-care agency's social worker, visited Mr. B. to speak with him about the services he would be able to offer. Mr. B. was reluctant to let Luis into his home. Eventually he opened the door. Luis was startled to see the home's condition. Luis could barely enter the home; he was surrounded by floor-to-ceiling piles of newspapers, magazines, blankets, pillows, clothing, rags, and other objects. Several cats roamed among the piles; the home reeked of cat urine. Luis D. was concerned about Mr. B.'s safety. He conducted a comprehensive assessment and shared his impressions with his clinical supervisor and the agency's consulting psychiatrist. The agency staffers agreed that Mr. B. showed clear signs of extreme hoarding behavior and obsessive compulsive disorder. Unfortunately, Mr. B. refused Luis' and the other staffers' offers of assistance: "This is how I live," he said. "Just leave me be." Luis and the agency staffers discussed the risks facing Mr. B. but disagreed among themselves with respect to his right to live as he pleases and the agency's obligation to take steps to protect him.

Clearly, social workers' principal moral duty is to protect clients. However, in some instances, social workers and others may disagree about the most appropriate course of action to protect clients. To what extent should clients' autonomy and right to self-determination be respected? Are there times when social workers should interfere with clients' rights paternalistically, in order to protect them from self-harm? Under what circumstances is it appropriate for social workers to disclose confidential information about clients, without their permission, to clients' family members to protect clients from harm? What is the social worker's role when a terminally client wants the social worker to gather information about physician-assisted suicide? Is it permissible for social workers to accept gifts or social invitations from

clients and if so, under what circumstances? Do parents have the right to refuse medical treatment for their children, on religious grounds?

Competent social workers need to know a great deal about the nature of ethical dilemmas and ethical decision-making protocols designed to manage risk. In addition to protecting clients – which is always social workers’ principal duty – practitioners should also be aware of risks they incur when they make professional judgments (*Healy, 1998; Holstein & Mitzen, 2001; Johnson, 1999; Moody, 1996*). In order to protect clients and related third parties, and minimize risk to themselves and their employers, social workers need to be informed about ethical decision-making protocols, including the application of ethical theories and concepts (known as normative ethics and metaethics), and understanding the role of ethics consultation and agency-based ethics committees.

In addition, social workers should understand prevailing standards to prevent ethics complaints and ethics-related lawsuits. Ethics complaints – filed with social work licensing boards or with professional organizations such as the National Association of Social Workers (NASW) – typically allege that social workers violated widely accepted ethical standards in their relationships with clients, colleagues, employers, or other parties. Ethics-related lawsuits typically claim that social workers were negligent, in the strict legal sense, by virtue of their mishandling of some phenomenon, such as the proper management of confidential information or informed consent, maintenance of professional boundaries, use of controversial treatment techniques, conflicts of interest, undue influence, or termination of services (*Reamer, 2003, 2006, 2009, 2013a*).

## **The Concept of Risk Management**

Social workers expose themselves to risk when they practice in a manner that is inconsistent with prevailing professional standards (*Houston-Vega, Nuehring, & Daguio, 1997; Reamer, 2003; Strom-Gottfried, 2000, 2003*). Some ethics complaints arise out of social workers’ mistakes and oversights. Examples include social workers who inadvertently disclose confidential information in a hallway conversation in a pediatric nursing home or fail to protect confidential information transmitted via a Facebook posting, hospital fax machine, or email message. Other ethics complaints and lawsuits arise from social workers’ deliberate ethical decisions – for example, when social workers engage in dual relationships with clients’ family members, disclose confidential information without clients’ consent to protective services officials, or override a hoarding client’s expressed wish to be left alone and right to self-determination. In addition, some complaints and lawsuits are the result of practitioners’ ethical misconduct, for example, when a social worker exploits her or his relationship with a client for the social worker’s own financial or other benefit (for example, when a social worker bills for services that were not provided or uses what lawyers call undue influence to convince a cognitively impaired client to include the social worker in her will).

Social workers can be held accountable for negligence and ethical violations in several ways. In addition to filing lawsuits, parties can file ethics complaints with the NASW or with state licensing and regulatory boards. In some instances, social workers are also subject to

review by other professional organizations to which they belong, such as the American Board of Examiners in Clinical Social Work and the Clinical Social Work Association. In exceptional circumstances, criminal charges may be filed against social workers (for example, based on allegations of sexual misconduct with a client, embezzlement or misappropriation of a client's funds, failure to comply with a mandatory reporting requirement, or fraudulent billing of an insurance company or government funding agency).

State legislatures also empower social work licensing boards to process ethics complaints filed against social workers who hold a license. Ordinarily these boards appoint a panel of colleagues to review the complaint and, when warranted, conduct a formal investigation and hearing (some state boards include public members in addition to professional colleagues). Some licensing boards are interdisciplinary and have jurisdiction over different helping professions in addition to social work, such as counseling and marriage and family therapy.

Negligence claims or lawsuits filed against social workers typically allege that social workers engaged in malpractice in that the practitioners failed to adhere to specific standards of care. The standard of care is based on what ordinary, reasonable, and prudent practitioners with the same or similar training would have done under the same or similar circumstances (*Madden, 1998; Reamer, 2003; Woody, 1996*). Departures from the profession's standards of care may result from a social worker's acts of commission or acts of omission. Acts of commission can occur as a result of misfeasance (the commission of a proper act in a wrongful or injurious manner or the improper performance of an act that might have been performed lawfully) or malfeasance (the commission of a wrongful or unlawful act). For example, a social worker who discloses confidential information about a client inappropriately, and perhaps inadvertently, may be liable for misfeasance. In contrast, a social worker who exploits a client financially for personal benefit may be liable for malfeasance. An act of omission, or nonfeasance, occurs when a social worker fails to perform certain duties that ought to have been performed. For example, a social worker who fails to obtain a client's informed consent before releasing sensitive confidential information may be liable for nonfeasance. Another example is failing to report suspected child or elder abuse as required by law.

Lawsuits and liability claims that allege malpractice are civil suits, in contrast to criminal proceedings. Ordinarily, civil suits are based on tort or contract law, with plaintiffs (the party bringing the lawsuit) seeking some sort of compensation for injuries they claim to have incurred as a result of the practitioner's negligence. These injuries may be economic (for example, the daughter of an elderly client claims that she was deprived of property that the social worker improperly accepted from her mother); physical (for example, a psychiatric hospital patient who claims that a social worker mistreated him physically); or emotional (for example, depression suffered by a client who did not receive competent care from a practitioner or who was involved in an improper dual relationship with a social worker).

As in criminal trials, defendants in civil lawsuits are presumed to be innocent until proved otherwise. In ordinary civil suits, defendants will be found liable for their actions based on the legal standard of preponderance of the evidence, as opposed to the stricter standard of proof beyond a reasonable doubt used in criminal trials. In some civil cases – for example, those involving contract disputes between a home health agency and a client or the client's family –

the court may expect clear and convincing evidence, a standard of proof that is greater than preponderance of the evidence but less than proof beyond a reasonable doubt.

In general, malpractice occurs when evidence exists that (1) at the time of the alleged malpractice a legal duty existed between the social worker and the client; (2) the social worker was derelict in that duty or breached the duty, either by commission (misfeasance or malfeasance) or omission (nonfeasance); (3) the client suffered some harm or injury; and (4) the harm or injury was directly and proximately caused by the social worker's dereliction or breach of duty.

In some cases, prevailing standards of care are relatively easy to establish, through citations of the profession's literature, expert testimony, statutory or regulatory language, or relevant code of ethics standards. Examples include standards concerning sexual relationships with current clients, disclosing confidential information to protect clients who may have been abused or neglected, fraudulent billing, or falsified clinical records.

In other cases, however, social workers disagree about standards of care (*Austin, Moline, & Williams, 1990; Haas & Malouf, 2005; Reamer, 2003*). This may occur in cases involving controversial treatment methods or ambiguous clinical or administrative circumstances (*Reamer, 2013*). For example, social workers and others involved in the case of Alvan B. (above) may disagree about his right to live in his home given the risky conditions arising from his extreme hoarding behaviors and other mental health issues. Social workers encounter many situations where thoughtful, reasonable, and principled colleagues disagree about the limits of clients' right to self-determination, to privacy and confidentiality, to refuse treatment, to truthful information, management of dual relationships, termination of services to noncompliant clients, and so on.

### **Key Ethical Challenges in Social Work**

Social workers in health care settings should focus on a number of practical ethical issues and risk areas (*Reamer, 2001b, 2006b*). These include:

**Client rights.** Especially since the 1960s, social workers have developed a keen understanding of a wide range of clients' rights, many of which were established by legislation or court ruling. These include rights related to confidentiality and privacy, release of information, informed consent, access to services, use of the least restrictive alternative, refusal of treatment, options for alternative services, access to records, termination of services, and grievance procedures.

**Confidentiality, privileged communication, and privacy.** Social workers must understand the nature of clients' right to confidentiality and exceptions to these rights. More specifically, social workers should have sound policies and procedures in place related to:

- solicitation of private information from clients;
- disclosure of confidential information to protect clients from self-harm and to protect third parties from harm inflicted by clients; release of confidential information pertaining to alcohol and substance abuse assessment or treatment;
- disclosure of information about deceased clients;
- release of information to guardians or conservators of elderly clients;
- sharing of confidential information among family members;
- disclosure of confidential information to media representatives, law enforcement officials, protective service agencies, other social service organizations, and collection agencies; protection of confidential written and electronic records, information transmitted to other parties through the use of electronic mail, social networking sites, fax machines, telephones, and other electronic technology;
- transfer or disposal of clients' records; protection of client confidentiality in the event of a social worker's death, disability, or employment termination;
- precautions to prevent social workers' discussion of confidential information in public or semipublic areas such as hospital or nursing home hallways, waiting rooms, elevators, and restaurants;
- disclosure of confidential information to third-party payers; disclosure of confidential information to consultants;
- disclosure of confidential information for teaching or training purposes, and;
- protection of confidential and privileged information during legal proceedings (such as termination of parental rights, probate, guardianship, conservatorship proceedings and negligence lawsuits).

To protect clients and minimize risk, social workers should discuss with clients and other interested parties (such as guardians) the nature of confidentiality and limitations of clients' right to confidentiality (*Dickson, 1998; Polowy & Gorenberg, 1997*). Depending on the setting, these topics can include:

- the importance of confidentiality in the social worker-client relationship (a brief statement of why the social worker treats the subject of confidentiality so seriously);
- laws, ethical standards, and regulations pertaining to confidentiality (relevant federal, state, and local laws and regulations);
- ethical standards in social work);
- measures the social worker will take to protect clients' confidentiality (storing records in a secure location, limiting colleagues' and outside parties' access to records);
- circumstances in which the social worker would be obligated to disclose confidential information (for example, to comply with mandatory reporting laws related to abuse or neglect, comply with a court order, or protect a third party from harm or the client from self-injury);
- procedures that will be used to obtain clients' informed consent for the release of confidential information and any exceptions to this (a summary of the purpose and importance of and the steps involved in informed consent);

- the procedures for sharing information with colleagues for consultation, supervision, and coordination of services (a summary of the roles of consultation and supervision, and coordination of services and why confidential information might be shared);
- access that third-party payers (insurers or healthcare officials) or employers will have to clients' records (social workers' policy for sharing information with managed care organizations, insurance companies, insurance company representatives, utilization review personnel, supervisors, and regulatory agencies);
- disclosure of confidential information by telephone, computer, fax machine, email, and the Internet;
- access to agency facilities and clients by outside parties (for example, people who come to the agency to attend meetings or participate in a tour), and;
- audiotaping and videotaping of clients.

Social workers should be aware that different ethnic and cultural groups view the concepts of privacy and confidentiality differently; some people are more likely than others to place a high premium on privacy and confidentiality and to insist on strong protections regarding disclosure (*Cortese, 1999*).

**Informed consent.** Informed consent is required in a variety of circumstances when working with clients in health care settings, including release of confidential information, program admission, service delivery and treatment, videotaping, and audiotaping (*Berg, et al., 2001; Miller & Wertheimer, 2010*). Although various courts, state legislatures, and agencies have somewhat different interpretations and applications of informed consent standards, there is considerable agreement about the key elements that social workers and agencies should incorporate into consent procedures: clients should be given specific details about the purposes of the consent, a verbal explanation, information about their rights to refuse consent and withdraw consent, information about alternative treatment options, and an opportunity to ask questions about the consent process. Social workers need to be assured that clients are competent to provide informed consent (*Moody, 1992*). Social workers should be aware that different ethnic and cultural groups view the concept of informed consent differently; some people are more likely to defer to professional authority while others may be more insistent on client's involvement in treatment and other services-related decisions (*Cortese, 1999*).

**Service delivery.** Social workers must provide services to clients and represent themselves as competent only within the boundaries of their education, training, license, certification, consultation received, supervised experience, or other relevant professional experience. Thus, for example, social workers should conduct competency assessments of elderly clients or treat clinical depression only when they have pertinent expertise. They should provide services in substantive areas and use practice approaches and techniques that are new to them only after engaging in appropriate study, training, consultation, and supervision from people who are competent in those practice approaches, interventions, and techniques. Social workers who use practice approaches and interventions for which there are no generally recognized standards should obtain appropriate education, training, consultation, and supervision.

**Boundary issues, dual relationships, and conflicts of interest.** Social workers should establish clear policies, practices, and procedures to ensure proper boundaries in their relationships with current and former clients; relationships with clients' relatives or acquaintances; relationships with supervisees, trainees, students, and colleagues; physical contact with clients; friendships with current and former clients; encounters with clients in public settings; attending clients' social, religious, or lifecycle events; gifts to and from clients; performing favors for clients; the delivery of services in clients' homes; financial conflicts of interest; delivery of services to two or more people who have a relationship with each other (such as clients' family members); bartering with clients for goods and services; managing relationships in small or rural communities; and self-disclosure to clients (*Golden & Sonneborn, 2001; Reamer, 2012*). Social workers who provide home-based or home-health services face unique challenges because of the informal setting, frequent lack of privacy, and ambiguous boundaries. Also, social workers should pay close attention to boundary issues that can emerge associated with their use of digital technology to communicate with clients and family members (for example, social networking sites, text messages, and email).

**Documentation.** Careful documentation and comprehensive records are necessary to assess clients' circumstances; plan and deliver services appropriately; facilitate supervision; provide proper accountability to clients, other service providers, funding agencies, insurers, utilization review staff, regulatory agencies, and the courts; evaluate services provided; and ensure continuity in the delivery of future services (*Kagle and Kopels, 2008; Reamer, 2005; Sidell, 2011; Wiger, 2005*). Thorough documentation also helps to ensure quality care if a client's primary social worker becomes unavailable because of illness, incapacitation, vacation, or employment termination. In addition, thorough documentation can help social workers who are named in ethics complaints or lawsuits (for example, when evidence is needed to demonstrate that a social worker obtained a client's informed consent before releasing confidential information, assessed for suicide risk properly, consulted with knowledgeable experts about a client's clinical issues or a potential conflict of interest, consulted the NASW Code of Ethics in order to make a difficult ethical decision, or referred a client to other service providers when services were terminated).

**Defamation of character.** Social workers should ensure that their written and oral communications about clients, their family members, and others are not defamatory. Libel is the written form of defamation of character; slander is the oral form. Defamation occurs when a social worker says or writes something about a client or another party that is untrue, the social worker knew or should have known that the statement was untrue, and the communication caused some injury to the client or third party (for example, a client with major mental illness was terminated from a day services program because of noncompliant behavior or an elderly client's adult child's reputation was damaged because of a social worker's allegations that the adult child abused the elder).

**Client records.** Social workers should maintain and store records for the number of years required by state statutes or relevant contracts. Practitioners should make special provisions for proper access to their records in the event of their disability, incapacitation, termination of practice, or death. This may include entering into agreements with colleagues

who would be willing to assume responsibility for social workers' records if they are unavailable for any reason.

**Supervision.** In principle, social workers can be named in ethics complaints and lawsuits alleging ethical breaches or negligence by those under their supervision. Social work supervisors in health care settings should ensure that they meet with supervisees regularly, address appropriate issues (for example, protective services, treatment and intervention plans, case recording, correction of errors in all phases of client contact, dual relationships, protection of third parties), and document the supervision provided.

**Consultation and referral.** Health care social workers should be clear about when consultation with colleagues is appropriate and necessary and the procedures they should use to locate competent consultants. Also, social workers have a responsibility to refer clients to colleagues when social workers do not have the expertise or time to assist clients in need. Practitioners should know when to refer clients to other professionals and how to locate competent colleagues.

**Fraud.** Social workers should have strict procedures in place to prevent fraud related to, for example, documentation in case records, billing for clinical services provided to clients, and employment applications.

**Digital technology and social media.** Digital, online, and other electronic technology has transformed the nature of social work practice in health care settings. For example, contemporary social workers can provide mental health services to clients by using online counseling, telephone counseling, video counseling, cybertherapy (avatar therapy), self-guided Web-based interventions, electronic social networks, e-mail, and text messages. The introduction of diverse digital, online, and other forms of electronic social services has created a wide range of complex ethical and related risk management issues concerning practitioner competence, client privacy and confidentiality, informed consent, conflicts of interest, boundaries and dual relationships, consultation and client referral, termination and interruption of services, documentation (*Reamer, 2013b*). This is a compelling example of contemporary ethical challenges in health care settings that were unimaginable until recently.

**Termination of services.** Social workers expose themselves to risk when they terminate services improperly – for example, when a social worker leaves a mental health, home care, or hospice agency suddenly without adequately referring a vulnerable client to another practitioner – or terminates clinical services to a very vulnerable client who has missed appointments or who has not paid an outstanding bill. Practitioners should develop thorough and comprehensive termination protocols to prevent client abandonment.

**Practitioner impairment, misconduct, and incompetence.** A significant percentage of ethics complaints and negligence claims are filed against social workers who meet the definition of impaired professional (impairment that may be due to factors such as substance abuse, mental illness, extraordinary personal stress, or legal difficulties). Social workers in health care settings should understand the nature of professional impairment and possible causes, be alert to warning



signs, and have procedures in place to prevent, identify, and respond appropriately to impairment in their own lives or colleagues' lives (*Reamer, 1992, 2003, 2012; Strom-Gottfried, 2000, 2003*).

In addition, social workers occasionally encounter colleagues who have engaged in ethical misconduct or are incompetent. Examples include social workers who learn that a colleague is exploiting a vulnerable client financially or sexually, stealing a client's narcotic medication, falsifying travel expense vouchers or client records, or providing services outside his or her areas of expertise.

In some instances, social workers can address these situations satisfactorily by approaching their colleague, raising their concerns, and helping the colleague devise an earnest, constructive, and comprehensive plan to stop the unethical behavior, minimize harm to affected parties, seek appropriate supervision and consultation, and develop any necessary competencies. When these measures fail or are not feasible – perhaps because of the seriousness of the ethical misconduct, impairment, or incompetence – social workers must consider “blowing the whistle” on their colleague. Whistle-blowing entails taking action through appropriate channels – such as notifying administrators, supervisors, professional organizations, and licensing and regulatory bodies – in an effort to address the problem.

Before deciding to blow the whistle, social workers should carefully consider the severity of the harm and misconduct involved; the quality of the evidence of wrongdoing (one should avoid blowing the whistle without clear and convincing evidence); the effect of the decision on colleagues and one's agency; the whistle-blower's motives (that is, whether the whistle-blowing is motivated primarily by a wish for revenge); and the viability of alternative, intermediate courses of action (whether other, less drastic means might address the problem). Social work administrators need to formulate and enforce agency policies and procedures that support and protect staffers who disclose impairment, misconduct, and incompetence conscientiously and in good faith.

**Management practices.** Periodically, social work administrators should assess the appropriateness or adequacy of the agency's risk-management guidelines and ethical standards; ethical decision-making protocols (for example, staffers' use of supervision and agency-based ethics committees); staff training on risk management; government licenses; the agency's papers of incorporation and bylaws; the state licenses and current registrations of all professional staff; protocols for emergency action; insurance policies; staff evaluation procedures; and financial management practices (*Chase, 2008; Fireman, Dornberg-Lee, & Moss, 2001*).

### **Implementing a Comprehensive Risk Management Strategy**

Social workers who serve can prevent ethics complaints and ethics-related lawsuits by conducting a comprehensive ethics audit (*Reamer, 2001*). An ethics audit entails thorough examination of major risks associated with one's practice setting (whether independent or agency-based practice). The audit involves several steps designed to identify ethics-related risks and minimize harm to clients, social workers, and social service agencies:

- (1) appoint a committee or task force of concerned and informed staff or colleagues;
- (2) gather the information necessary to assess the level of risk associated with each ethics-related phenomenon (i.e., clients' rights; confidentiality and privacy; informed consent; service delivery; boundary issues and conflicts of interest; documentation; defamation of character; client records; supervision; staff development and training; consultation; client referral; fraud; termination of services; practitioner impairment, misconduct, or incompetence; management practices) from sources such as agency documents, data gathered from interviews with agency staff, and national accreditation standards;
- (3) review all available information;
- (4) determine whether there is no risk, minimal risk, moderate risk, or high risk for each risk area, and;
- (5) prepare an action plan to address each risk area that warrants attention, paying particular attention to the steps required to reduce risk, the resources required, the personnel who will oversee implementation of the action plan, the timetable for completion of the action plan, the indicators of progress toward reducing risk, and plans to monitor implementation of the action plan.

Social workers have become much more cognizant of, and informed about, ethical issues in health care settings. During the course of the profession's history, social workers have moved away from their preoccupation with clients' values to rich conceptual analysis of ethical dilemmas and the application of decision-making protocols. Most recently, social workers have been paying close attention to ethics risk management.

## **Summary**

Health care social workers have been more involved in ethics-related activities than most other social workers because of their direct exposure to developments related to bioethics. Thus, social workers in health care settings are in a unique position to provide ethics-related leadership in the profession. These practitioners can promote ethics education, expand social workers' contributions as ethics consultants and members of agency-based ethics committees, and strengthen ethics risk-management efforts. This comprehensive agenda can have simultaneous benefits of intensifying social workers' commitment to professional ethics and extending social work's values and the profession's reach into allied health professions.

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# **Futility: Proactive Intervention**

*Patricia O'Donnell, PhD, ACSW*

## **Introduction**

It is 4:30PM Friday and you are a member of the on-call consult team for the Ethics Committee. The following urgent referral is received for a “futility” case:

A widowed seventy-five year old African-American woman is diagnosed with breast cancer metastatic to the lung, bone and brain. She also has a history of diabetes and End Stage Renal Disease. Her symptoms include bone pain, extensive skin decubiti, dyspnea, and depression. Hospitalized for six weeks, she has had all the standard chemotherapies and is being considered for an experimental protocol. She remains on a three times weekly schedule of dialysis.

The nurses report the patient is intermittently confused, complains of being uncomfortable, and asks to be left alone. They also state that because of her confusion, the physicians and family are not including her in all the treatment decisions. The nurses feel the patient is suffering, receiving no benefit from aggressive treatment, and should be referred for [supportive](#) comfort care. There are multiple consultants but none of the physicians, including the attending physician, seems to have a working relationship with the family. The consultants do not appear to be coordinating care planning with the attending physician. There is no apparent consensus on the overall goals of care and conflicting goals are being presented to the family.

Family members are refusing to consider withdrawal of any treatment, as they believe their prayers will be answered and the patient will be cured. They also believe God will take her when he is ready. They have agreed to a modified Do Not Resuscitate (DNAR) order, but only to the extent that cardiopulmonary resuscitation (CPR) is not used if the patient has cardiac or respiratory failure. The nurses report extensive disagreement among the immediate and extended family members about what to do and the patient's preferences. The patient's primary decision-makers are her five children. They refer often to the death of their father a few years ago and vow “it won't happen again to their mother”. The request comes for the Ethics Consultation team to “make” the physicians and family agree to a full DNAR order and withdrawal of all aggressive treatment as the patient is failing.

A number of common myths associated with futility cases are evident in this case. First, the urgency conveyed in this referral is unlikely as acute as portrayed. The patient has been in the hospital for weeks, the referral is made on late Friday afternoon, and the phrase “the patient

is failing” is ambiguous in relation to time and other criteria. Second, the factors contributing to the referral for futility are not as black and white as presented. We know there is a communication issue, but is it the only contributing factor in the impaired family-physician relationship? Third, a belief may exist among family members, staff and physicians that once a treatment is begun, it cannot be discontinued for any reason (*Meisel, Synder, and Quill, 2001*).

In addition to the concern for futility, the problems inherent in this not untypical referral involve issues of patient autonomy and capacity, the patient’s best interests, withholding and withdrawal of treatments and the moral well being of the professional caregivers. Increases in the success of technology, the aging population and hospital costs are generating more concern about futile treatment (*Schneiderman, Jecker, and Jonsen, 1990*). In particular, concerns have increased regarding the use and utility of extensive and expensive technology to support patients in the intensive care unit. A prospective study of five ICUs in a recent study found nearly 20% of patients were perceived as receiving futile treatment by critical care specialists after chart review as the patient died before hospital discharge or within six months of ICU care (*Hunyh, Klerup, Wiley, Savitsky, Guse, Garber, & Wenger, 2013*).

This chapter reviews the ethical aspects of futility, frameworks for resolution of futility issues, and the role of social work in helping care teams recognize and intervene before futility becomes an issue.

## **Defining and Determining Futility**

Orr (2000) observes that ethics committees often experience a sense of wariness when they receive a referral for futility. The chief complaint of ethics consultants in relation to futility is that there is no standard definition of the concept of futility. One individual’s perception of futile treatment is another’s life-saving treatment or, as with pornography – it cannot be defined, but you recognize it when you see it. At the heart of the issue is the relief of patient suffering and avoidance of secondary costs to the family and care team as well as the pursuit of institutional mandates that futility cases be resolved. Rubin (1998) identifies a number of conflicts associated with the definition and establishment of criteria for futility. Questions persist as to who has requisite expertise, whether health care professionals, the patient and/or family should select the goals of treatment that may be judged futile, and how to choose criteria for determining futility.

The lack of uniform criteria to define futility leaves room for confusion and for the focus of the ethics consultation to shift from quality patient care to that of financial costs and social prejudice (*Lantos, 1994*). Schneiderman, et al (1990) adapt a science based approach to set quantitative and qualitative measures for criteria defining futility. The quantitative criteria are derived from empiric data or clinical experience where the physician notes that in 100 cases, the treatment brought no physical improvement. The qualitative criteria that define futility include treatment that merely preserves unconsciousness or fails to end total dependence on intensive medical care. They recommend that any treatments that meet either quantitative or qualitative criteria should be regarded as non-beneficial and therefore futile. Rubin (1998) notes that, even

when conflicts of definition and criteria are resolved, conflict may arise as to when the criteria apply to particular treatments for a particular patient.

The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Bioethical Research (1983) suggests that consideration of the burdens that treatment imposes on the patient is reasonable criteria for evaluating the futility of treatments. Pellegrino (2000) utilizes the concepts of benefit and burden of treatment to develop a moral algorithm for withdrawing treatment. He describes a collaborative decision-making process between physician and patient for withdrawing treatment. The algorithm considers the physician's clinical evaluation of the probability of beneficial outcomes of treatment in conjunction with the patient's estimations of the physical, social, and financial burdens associated with treatment.

Younger (1994) proposes that evaluation of the worth of treatment goals serves as the measure for defining futility. He identifies the use of life-sustaining treatments for patients diagnosed as in Persistent Vegetative State (PVS) or use of chemotherapy for patients with end stage metastatic cancer as two examples of futile treatment. In these instances the ultimate course of the patient's illness will not be reversed as a result of treatment. Others may argue the goals of gaining time for the family to reach closure or for the patient to receive palliation from pain through chemotherapy would exempt the treatments from Younger's definition of futility.

The ultimate question to be answered is, whose values and goals are given priority – the patient, the family, the care provider, the physician – and why. This is especially critical in our current pluralistic society where the values of individual parties may be in absolute conflict with each other and thereby weaken the fit between medical practice and public values (Callahan, 1994). Such conflict can lead to difficult interpersonal relationships among the patient, family, care team, and physician. It can also contribute to increased complexity to decision-making regarding the best interests of the patient. Truog, Brett and Frader (1992) argue the best interest of the patient, and not rules and standards, may be the best approach to resolve futility issues. Conflict may still arise, however, as to whether the physician, staff, patient and/or family should determine the best interests of the patient.

## **Who Determines?**

The second principal controversy associated with futility is that of who determines that treatment is futile and should be withdrawn. How do we balance patient autonomy with the moral rights of care providers? Concerns related to the physician or other care providers serving as the determiners of futility include several unacceptable results. Should the patient's status as an individual be diminished, will the determiner substitute their values for the patient's, and will the best interests of society replace the best interests of the patient? In their review of futility, Swanson and McCrary (1994) found both physicians and non-physicians were concerned that if physicians unilaterally decided that a treatment was futile, there could be many consequences. Examples of such consequences include: whether patients' rights to make decisions are violated; whether futility would become a tool for cost control denying critical care for some patients; whether futility could be applied to patients for social rather than medical reasons; whether

criteria for futility could ever be established and agreed upon across a variety of practitioners and settings, and; whether physicians would advance their own values over patients' values.

The importance of preserving patient trust in the physician based on the power imbalance inherent in their relationship is key to the patient-provider relationship (*Lantos, 1994*). Physicians who offer ineffective treatments or misrepresent expected outcomes of treatments diminish their integrity (*Brody, 1994*). *Asch (1995)* reported that 14% of physicians in sampled adult intensive care units had withheld or withdrawn treatment they considered futile without informing the patient's family. More than 80% had withdrawn treatment over the family's objection. *Smith (2001)* believes futility policies are being developed to ration treatments and not to promote quality care.

*Helft, Siegler, & Lantos (2000)* suggest in their review of the "futility" movement that the physician's judgment that further treatment is futile is not a prompt to stop treatment but rather a prompt to begin the difficult task of talking with and helping the family understand the realities of the patient's condition. There is often a natural reluctance to engage the family in discussions that may harm the relationship the physician has worked to build with the family, as the physician is now saying no to treatments the physician, and not the family, has deemed as futile in that the treatments are unlikely to meet goals of care and may harm the patient (*O'Reilly, 2011*). *Truog (2010)* suggests that administering futile CardioPulmonary Resuscitation (CPR) is not always wrong if doing so supports a family's belief that "everything" was done to extend the life of their family member and is an act of professional compassion for that family. However, *Meltzer and Huckabay (2004)* found that futile treatment not only harms the patient but contributes to the moral distress and emotional exhaustion of members of the critical care team.

If the patient and family solely determine futility, the result may be a decrease in the role of involved professionals with both a violation of the professionals' ethical obligations to the patient and increased disadvantage to others as a result of the patient's choices. *Veatch and Spicer (1992)* argue that any competent patient should have access to any available treatment if the treatment is funded and is so desired. *Troug (2000)* believes that in pediatric cases, priority should be given to parental wishes. He justifies this course based on the contractual relationship between the patient, family and physician; the priority of value judgments of the family, and; the fact that the family will live with the memory of their decisions for the balance of their lives. He adds that clearly established goals of care will promote cooperation and understanding in the treatment process and when difficult decisions must be made.

Each case merits an individual assessment that includes an overview of the patient's overall health status and their ability to achieve meaningful life goals. *Rubin (1998)* offers that, if treatment will not further the patient's goals, then the treatment should be considered futile. The best interests of the patient are met when the intent of withholding or withdrawal of any treatment is to allow the natural course of the illness to continue, not to hasten death. Patients, families and care providers want reassurance that the goal of care remains on comfort and palliation throughout the final stages of the illness. *Alpers and Lo (1999)* suggest physicians may refuse to continue treatments considered futile but have a moral obligation to negotiate decisions with families and surrogates, while maintaining a focus on the patient's best interests. Physicians also have an obligation to be culturally sensitive and compromise as appropriate.



They may apply the ethical principles of beneficence and non-maleficence to justify not providing treatments that will harm patients without a corresponding benefit.

## **Legal Resolutions**

In 1999 the Texas legislature amended the Texas Advance Directive Act (TADA) to allow a physician to ask for an ethics committee review of a patient or their designated decision maker receiving treatment that the physician deemed “inappropriate” but that the patient or designated decision maker insists continue (*Luce, 2007*). The patient is given written notice and information on the process and invited to participate in the deliberations. If the hospital cannot come to a resolution then the hospital must locate another facility that will accept the patient in transfer within 10 days. If no other facility can be found and the physician’s opinion was affirmed by the committee, treatment can be withdrawn with immunity from civil or legal prosecution. A judge may extend the search period if there is a reasonable expectation of arranging a transfer. A 2004 review of 409 hospitals by the Texas Hospital Association found 149 had developed a written policy and 40 had used the policy for conflict resolution in 256 cases. In 70% of the cases the committee agreed with the physician’s recommendation. 44% of the patients died before final resolution, 40% agreed to discontinue treatment, 17% were transferred to other facilities, and .05% improved and were discharged (*Smith, Gremillion, Slomka, & Warneke, 2007*). A review by Fine & Mayo (2003) of the implementation of the law at Baylor University in the first 2 years resulted in an increased use of the ethics committee and an increase in futility consult requests, while no family asked the courts to intervene in the process. The greatest benefits were improved communication and time limits imposed on negotiation. A second state wide survey resulted in similar results (*Smith, Gremillion, Slomka, & Warneke, 2007*). The study showed a drop in the original numbers and that cases tended to occur in urban, non teaching, non-specialty facilities with greater than 150 beds. Particularly difficult cases have involved children and, at the base of the cases, there has been a deep distrust of the medical community by the family as well as a severe breakdown in communication (*Truog, 2007*).

## **Ethical Problem-Solving**

The Education for Physicians in Education of Life Care curriculum developed by the American medical Association (1999) offers the following paradigm for a due-process approach to futility situations. The process addresses both prevention and resolution of conflicts related to futile treatment.

1. Attempt to negotiate an understanding between patient, surrogate, and healthcare team as to what constitutes futile treatment in advance of the actual conflict.
2. Establish joint decision-making as the goal. Use the assistance of consultants as appropriate.

3. If disagreements persist, suggest use of other consultants, colleagues and the institution's ethics committee. This provides the maximum possible place for patient autonomy.
4. If institutional review supports the patient's position and the physician is uncomfortable with the decision made, transfer of care may be arranged.
5. If review supports the healthcare team's position and the patient/surrogate disagrees with the decision, transfer to another institution/provider can be arranged if both parties agree and if possible.
6. If no receiving institution can be found, the problem remains unsolved and further discussion must continue.

The first step of this process often clarifies and addresses communication failures, poor understanding of facts and outcomes related to the diagnosis and treatment, and unrealistic expectations. It provides an opportunity to implement partnering among the physician, staff, patient and family directed toward the best interests of the patient. The social worker is the key professional in establishing common ground and gaining commitment from all parties to resolve the conflict. This requires that social workers not only have advanced clinical practice skills, but a thorough grounding in ethical problem solving.

It is crucial that social workers understand the delineation and context of ethical problems and the application of ethical perspectives and principles. They must have knowledge of legal precedents and regulations, be able to realize the obligations and duties mandated in various professionals' Codes of Ethics, understand the influence of values and biases in decision-making, and possess skill in presenting and defending options for problem resolution based on an ethical assessment (*Joseph, 1983*). *Joseph and Conrad (1989)* found that social workers who had a discrete course in ethics were better prepared to participate as presenters of psychosocial content related to ethics cases and to serve as interpreters of ethical information to patients and families. *Foster and his colleagues (1993)* found that discussing futile treatment of the irreversibly ill was identified by social workers as an area for further ethical training. The respondents specifically noted their training needs were in bioethics, not psychosocial practice skills.

An additional source of ethical related stress for social workers arises from conflicts involving multiple obligations and duties (*Proctor, Morrow-Howell and Lott, 1993*). Conflicts concerning issues of patient self-determination versus their best interest are common in health care practice (*Abramson, 1988*). Social workers may also be challenged to weigh their commitment to the patient versus their obligations to the family, health care team and the institution.

*Csikai and Bass (2000)* determined that specific professional activities related to the social work role in end-of-life decisions include promotion of self-determination; serving as liaison between providers and patient/family, and; providing help in identifying options for the patient and family. Futility was not identified as a specific issue. The most common issues were

confusion or conflict because there were no advance directives and questions related to patient competency. In most cases, there had been little or no discussion of patient wishes. If a family cannot voice the patient's treatment preferences, they will likely have a difficult time with subsequent decisions related to withholding and withdrawing treatment.

## **Communication Training and Protocols**

Communication gaps and lapses are most often noted in discussions of “managing” communication issues and resulting conflict (*Shuman, Montas, Barnosky, Smith, Fins, & McCabe, 2013*). The literature on enhanced communication skills includes directives for when to communicate, how to communicate, what to communicate, and how often to communicate as well as step by step processes to insure success. A relationship built on trust that the physician has the best interests of the patient as the primary focus serves as the anchor for the physician/patient and family mutual decision making. The physician must begin with demonstrated respect for the patient/family perspective by eliciting information, recognizing and addressing attendant feelings, and providing further information toward the common goal of deciding what is best for the patient and why (*Gallagher & Holmes, 2012, Pollack, Arnold, Jeffreys, Alexander, Olsen, Abernathy, Skinner, Rodriguez, & Tulsky, 2007, Tulsky, 2005, & Weaver, 2012*). If a patient or family member feels dismissed or is denied information, that trust is broken and may never be repaired. Galushko, Romotzky, & Voltz (2012) note that all parties in the discussion, including members of the health care team, bring their own perspectives, experiences, and values which may be similar but have differing influences and priorities which are often the source of conflict.

Lo, Quill, & Tulsky (1999) and Tulsky (2005a) suggest that, in recognizing feelings and emotional responses that are common to difficult situations, those feelings are validated and refocused on what is best for the patient. A simple statement like “other families have found” normalizes what a family may be experiencing. Patients and families often offer emotional cues via complaints that then may trigger negativity in the professional resulting in the use of labels (unrealistic, demanding, unreasonable) that dismiss the reality of the feelings voiced. This also reinforces the necessity of listening without interrupting and allowing the patient/family to fully describe what is the source of their anxiety (*Tulsky, 2005b*). In responding the use of language can guide or distract from the discussion. Negative words like meaningless, futile, hopeless or phrases like “stop the machines” and “nothing to do” distance the patient/family from the discussion (*Lofmark & Nilstun, 2002 & Pantilat, 2009*). Quill, Arnold, and Platt (2001) suggest using phrases such as “I wish that were possible” or “It must be hard” personalized to the patient's situations builds on the trust relationship without supporting demands for futile treatment. Exploring what is meant by “doing everything” by the patient/family provides an opportunity for the physician to clarify the patient's status and offer recommendations that continue to offer care that promotes the patient's comfort and support (*Quill, Arnold, & Back, 2009*). These skills can be taught and modeled by the social worker.

## **The Role of the Social Worker**

In addition to initiating, prompting, and teaching communication skills as described in the above section; the social worker brings a perspective that always includes environmental and contextual factors associated with the patient and family.

### *Motivation for Treatment Requests*

Younger (1994) suggests the ethics of prevention may be the most effective way to avoid futility issues. A thorough exploration and understanding of both the motivation of patients and families asking for futile treatment and physicians and other care providers offering futile treatment is essential to avoid futility issues. As previously noted, Joseph and Conrad (1989) identified social workers as primary presenters of the psychosocial factors relevant to a case and as the advocates for patient and family perspectives. Communication and culture are the most common psychosocial factors associated with futility cases (Younger, 1994). As the number of physicians involved with any one case increases, consistency in communication becomes more difficult. Patients and families often receive contradictory information, adding to the complexity of their decision-making. Physicians and other care providers may attempt to soften the blow of difficult information by focusing on the positives of the patient's condition. Unfortunately, this may reinforce patient and family denial of the realities of the patient's condition. In other cases, the language used to present information may be sufficiently technical and complex as to defy the patient's and family's understandings. They may not raise questions or ask for clarification out of fear of appearing ignorant. Patient and families may turn to the social worker for help in understanding what information has been presented and what decisions need to be made. Early intervention directed toward improving communication patterns and assuring patient/family understanding can prevent the miscommunication that fosters futility issues.

### *Listening and Support: The Patient and Family Story*

It is important that social workers explore the patient and family story and then share it with involved physicians and other care team members. Such stories must be inclusive of all parties in a case, including extended family members and significant others. Unresolved conflicts and losses may generate requests for treatment that others judge as lacking benefit to the patient. This may be an effort of the family to buy some time for resolution and/or reconciliation. Members of minority cultures may have experienced prior denial of access to care or unequal care for themselves and/or their extended family. There may be a distrust of the care team, institution and health care system based on perceptions of neglect and discrimination. Recent immigrants from disadvantaged populations who now have access to state-of-the-art medical care may harbor unrealistic expectations of what such care can accomplish.

Attentive listening, clarification of perceptions and beliefs, and offering unconditional support on the part of the social worker serve to reassure the patient and family that their stories are heard and understood. The social worker can help the patient and family share their feelings, concerns and cares with physicians and other care team members. The physician and care team can present information in such a way that it is inclusive and addresses their needs.

Understanding the meaning attached to a treatment can shape acceptance of information by the patient and family. In a retrospective study of family members, Jacob (1998) found positive interactions with physicians and the care team helped family members find peace in decisions made during their loved ones' terminal care.

### *The Significance of Values*

Values are based on judgments and preferences. In ethical consultation, one of the goals is to achieve an understanding, not a victory or win for one party over the other. In ethical analysis, the values of all parties, including the physician, care team, patient and family, are given equal weight and respect (Nelson, 1994). The values of the physician and care team include both personal and professional values. Values common to, and expected of, health care professionals include compassion, truthfulness, integrity, service to others, competence and knowledge, and equal treatment of all patients. Personal values arise from factors such as family beliefs and traditions, religious doctrines, ethnicity and racial background, education, view of the world, meaning of health and suffering, and the environment. Values are individualized even among family members.

Understanding how past experience influences values is fundamental to managing personal biases that may influence care decisions. Social workers are trained early in their careers in self-awareness and its influence in practice. The social worker presenting the patient family values to the physician and care team will model how to examine the influence of their values in understanding the patient/family perspectives and choices. This serves to clarify common ground for the work of the physician and care team.

## **CASE STUDY**

A sixty-year old Sudanese woman was admitted to the hospital Intensive Care Unit for treatment of advanced leukemia. The patient experienced a great deal of pain and required almost daily blood transfusions. She was in the United States on a visitor's visa to see her three grown children who had immigrated to the United States over the last fifteen years.

The patient's physicians recommended that aggressive treatment be discontinued and suggested hospice inpatient placement for palliative care would be the most appropriate plan of care. The patient's sons reacted angrily, accusing the physicians and care team of not being compassionate and the hospital of wanting the patient discharged because she had no insurance. The physicians felt insulted and misunderstood, the nurses felt angry that they were being forced to provide painful treatment for the patient, and the family felt unheard and unattended.

A futility referral was made to the hospital Ethics Consultation team. The Ethics Consultation team included a physician, chaplain, and social worker not involved with the patient or family. With the family's permission, the team reviewed the patient's medical record and interviewed the physicians and care team members. The Ethics Consult team recommended a joint meeting with the attending physician, the social worker who had been working with the

family on planning, the charge nurse and any family members who wished to participate. Two sons agreed to the meeting.

The attending physician and the charge nurse started the meeting with a review of the patient's condition and their reasons for recommending withdrawal of aggressive treatment. The sons interrupted the nurse, disagreeing that their mother was suffering. They shared their perspective and detailed their family story, including their mother's sacrifices to help with their education and immigration to the United States. They made a clear statement of the importance of honoring their parents and how much they had missed being with their mother. They had known of her diagnosis and arranged for the "visit" with the intention of getting her medical care not available in the Sudan.

The unit social worker shifted the focus from clinical facts and the sons' complaints by commending the sons for their devotion and ended with the statement – "It must be terrible for you to think about losing your mother". Both sons immediately welled up with tears and poured out their grief about her situation. The nurse on the unit noted that due to restricted visiting hours in the unit, the sons saw the patient only intermittently during the day and never at night. When they visited, she sat up in a chair and never complained of pain. They never witnessed her in pain or asking why the nurses were doing all these things to her. The sons agreed that their mother would not want them to know she was suffering and would do everything possible to reassure them.

As the discussion continued, the focus shifted to those treatments considered in the best interests of the patient. Throughout the conversation, unconditional support was offered to the sons. The social worker and nurse volunteered to be with the family during a talk with their mother and the sons agreed to a hospice referral. Two days later, the patient was transferred to an inpatient hospice unit where she died with her family present. Bereavement services provided to the family through hospice helped them resolve their guilt about not being able to secure a cure for their mother.

Resolution of this case was based on clarification of the ethical and psychosocial aspects of the case, exploration and understanding of the patient/family story, voiced respect for the values of all parties and a focus on finding common ground to formulate a care plan that met the patient's best interests. This case reflected an investment of time and care. The care team was willing to expose themselves to the sons' grief and anger to achieve a resolution. Physicians and care team members benefited from the social worker's ongoing support and reinforcement of the value of their participation.

## **Summary**

Referrals for futility are often reported as the most difficult for Ethics Consultation teams. These cases are fraught with communication problems and misunderstanding of medical details. There is an overall sense of frustration marked by displaced emotions and potentially unrealistic expectations held of patients and families by physicians and care teams. At the same time, patients and families may harbor unrealistic expectations of physicians and care teams. For the

consultation team, the initial difficulty lies in a uniform definition of futility supported by the medical professionals, ethics scholars and the community at large. If there is agreement on the definition, the question becomes whether it applies to this particular patient in these circumstances.

A second controversy arises as to who should set the criteria and make decisions. Are these the prerogative of the physician, care team, patient or family? What are the risks associated with one party making the decisions? Physicians and non-physicians have suggested a better alternative may be for all parties to make collaborative decisions in the best interests of patients. The process can disintegrate, however, when disagreement exists about what constitutes the best interests of the patient.

Beyond their advanced clinical expertise, social workers providing direct services and/or serving on ethics consultation teams require ethics education to ground them in ethical analysis and ethical problem solving. Competence and comfort in addressing ethical issues contributes to the issues being appropriately recognized and addressed. Facilitating communication among all involved parties, attending to process and generating options are interventions social workers can employ to help resolve ethical dilemmas. They can also be utilized to identify ethical concerns before they develop into intractable, time-consuming, and alienating problems for the physician, care team, patient and family. By using proactive intervention, social workers can enhance and secure their traditional liaison role between physicians and the health care team as well as the patient and family in ethical problems, especially the most difficult – futility.

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# Clinical Practice in a Memory Disorder Clinic: Ethical and Legal Issues

*Judy Shipman, LCSW*

## Introduction

The State of Florida has a large and growing older adult population. Florida has the highest proportion of residents age 60 and older in the nation, comprising 23.6 percent of the state population. The state also has the highest median age (40.7) and the highest old-age dependency ratio, which measures the number of elderly as a share of those of working age. Growth among elder Floridians is expected to continue, with those age 60 and older comprising 41 percent of the state population by 2030” (*Florida State Plan on Aging 2013-2016, p.2*). The Alzheimer’s Association report projects that in 2014 Florida will have 480,000 residents aged 65 years or older with Alzheimer’s disease (AD). By 2025 this figure is projected to grow to 720,000. This chapter discusses the particular efforts of Tallahassee Memorial Hospital in addressing the needs of those patients with Alzheimer’s disease.

The Florida Legislature established the Alzheimer’s Disease Initiative (ADI) in 1985 as a way to address the needs of some of these elderly and their caregivers. The Florida Department of Elder Affairs (2007) referred to the ADI as “one of the most comprehensive programs in the nation addressing Alzheimer’s disease and related dementia” (p. 3). The Memory Disorder Clinics (MDCs) are important components of the ADI. Currently Florida has 15 state designated MDCs, 13 of which receive state funding. Clinics are directed to pursue three goals:

- Encourage early diagnosis and treatment through screenings and medical evaluations;
- Provide education, resources and information to professionals, caregivers and the general public;
- Pursue basic medical and applied research to discover the causes and improve the understanding of these diseases.  
(*Florida Department of Elder Affairs, 2008*).

In FY2010-2011, the 13 funded clinics provided diagnostic and counseling services to over 7,000 individuals (see: <http://elderaffairs.state.fl.us/index.php>). The MDC at Tallahassee Memorial Hospital was founded as a state designated center in July, 1998. During the first year the clinic was open, 56 people were evaluated; 332 people were served in the fiscal year ending June 20, 2008. Even though Tallahassee is one of the younger areas of the state demographically, continued growth is expected as the population ages. The Tallahassee MDC is one of several clinics in the state in that employ a master’s level social worker as Clinic Coordinator. The clinic benefits from the placement of social work interns from Florida State University for most of the academic year. Social work expertise available to the Tallahassee MDC is invaluable when ethical and legal issues arise.

The treatment team includes a neurologist/medical director, a neuropsychologist, pharmacist, social worker and an administrative assistant. Of these, only the administrative assistant and social worker (who also is Clinic Coordinator) are full-time employees. Evaluations include clinic visits with the appropriate medical professionals. Neurological assessments are performed to rule out other conditions that can cause memory loss such as stroke or seizures. The neuropsychologist administers a battery of cognitive tests to determine areas of strength and weakness in functioning. Since many seniors are prescribed multiple medications by multiple physicians, a pharmacy evaluation can focus on those medications that may be cognitively impairing and problematic medication interactions. The social worker meets with family members to assess their situation, resources and coping skills. Interdisciplinary case staffing and discussion assists diagnosis and the creation of a detailed summary report and recommendations that are provided to the patient, his/her family and the referring physician. Potential ethical and legal concerns may arise at any point in this evaluation process and influence practice decisions.

### **Ethical Base for Practice**

There is no single accepted definition of clinical ethics. The Social Work Dictionary defines ethics as “a system of moral principles and perceptions about right versus wrong and the resulting philosophy of conduct that is practiced by an individual, group, profession or culture” (*Barker, 1995, p. 124*). Ahronheim, Moreno and Zukerman (2000) note three commonly cited principles that underlie ethical decision making: patient self determination (autonomy), justice, and beneficence. *Self-determination, or autonomy*, asserts that the patient is the ultimate authority on what is best for his or her well-being. Beauchamp and Childress (2001) further define the principle as respect for autonomy asserting that respect involves respectful action not just a respectful attitude. The professional obligations that flow from autonomy include truth telling, respect for privacy, protecting confidential information, obtaining consent for interventions with patients and when asked, helping others make important decisions. The principle of *justice* mandates equal treatment to all members of society, including those who are most disadvantaged, and a fair distribution and purposeful stewardship of healthcare resources. *Beneficence* instructs the clinician to act in the patient’s best interest by protecting and defending their rights, helping people with disabilities and rescuing people in danger.

These principles are echoed in the Social Work Code of Ethics (1999). The Code defines the purpose of the profession particularly its duty to vulnerable populations. The Preamble states, “The mission of the social work profession is rooted in a set of core values. These core values, embraced by social workers throughout the profession’s history, are the foundation of social work’s unique purpose and perspective:

- service
- social justice
- dignity and worth of the person
- importance of human relationships

- integrity
- competence (NASW, 1999)

A set of ethical principles evolve from these values that guide practice. These include duties and obligations to clients, colleagues and practice settings as professionals, the profession and the broader society.

Standard 1.02 specifically addresses the issue of self-determination. “Social workers respect and promote the right of clients to self-determination and assist clients in their efforts to identify and clarify their goals. Social workers may limit clients' right to self-determination when, in the social workers' professional judgment, clients' actions or potential actions pose a serious, foreseeable, and imminent risk to themselves or others” (NASW, 1999).

Standard 2.03, Interdisciplinary Collaboration, is particularly applicable to the Memory Disorder Model: “(a) Social workers who are members of an interdisciplinary team should participate in and contribute to decisions that affect the wellbeing of clients by drawing on the perspectives, values, and experiences of the social work profession. Professional and ethical obligations of the interdisciplinary team as a whole and of its individual members should be clearly established.” Team collaboration and mutual respect are essential to arriving at an appropriate diagnosis and treatment plan. This enables the social worker to have the best possible information with which to assist the family with coping skills and future planning. The skills of the social worker are essential to the treatment team in providing appropriate communication, counseling and resource acquisition. As the population ages, the responsibility of social workers to the broader society will mandate increased services to this vulnerable population.

## **Diagnosis**

Early diagnosis of dementia is recommended for a number of reasons including initiating treatment when it may be most effective and allowing sufficient time for patient input into advance care planning. However, even the decision to diagnosis can have ethical implications. Kapp (2006) notes the “Catch 22” nature of the dilemma: how can we be sure that the person who we want to diagnosis is cognitively and emotionally competent to consent to diagnosis or treatment? For practical reasons medical practitioners often rely on surrogate consent, but this may prove questionable without the existence of a valid durable power of attorney or healthcare proxy.

Newer methods of diagnosis including analysis of spinal cord fluid, Positive Emission Tomography (PET) scans, Magnetic Resonance Imagery (MRI) and even blood tests are continually being developed. Some of these tests purport to diagnose disease even before symptoms are evident. It is now possible to detect beta-amyloid in the human brain by using radioactive tracers and positron emission tomography (PET). Beta amyloid is found in the brain plaques associated with Alzheimer's disease and so is considered to play a part in the disease (see: <http://alzfdn.org/>). Although this testing is

currently available in only research facilities, as it becomes more available the question is raised as to the value and ethical appropriateness of performing an expensive and non-insurance covered diagnostic test which does not yield a definitive diagnosis when preventative treatment is not available.

Similarly, many people want to know if it is possible to predict Alzheimer's by genetic testing. Less than 1 % of AD cases develop as a result of genetic mutations. Again, the question is raised as to the ethics and efficacy of performing such testing in the absence of treatments that prevent, stop or slow the disease. The potential emotional consequences of these test options, neither of which provide definitive diagnosis, must be considered.

### **Truth Telling: Communicating Diagnoses**

The ethical decision-making process begins with diagnosis. Despite recent advances, it is not possible to make an absolute diagnosis of Alzheimer's disease before autopsy; it remains a "rule out" diagnosis, a presumptive diagnosis of "possible" or "probable" Alzheimer's after other causes for the symptoms have been ruled out. As many people are afraid of the word "Alzheimer's" and the mental pictures it evokes, it is common to hear something like, "my mother doesn't have Alzheimer's disease; she just has dementia." Dementia in fact is an "umbrella" term encompassing many types of conditions, of which Alzheimer's is by far the most common.

### **Case Example**

*A 70 yearold man comes to the MDC for a baseline diagnosis and is found to have normal memory for age. He returns every two years. On his third visit, testing indicates the beginnings of cognitive decline. The man comes to the clinic without a family member, and the social worker knows from previous visits that he and his wife do not get along well. At each visit, he has described in detail how he will kill himself (he has been saving medications) if the diagnosis of Alzheimer's is ever made.*

In the culture of western medicine, the common belief is that people have the right to know their diagnosis and prognosis in order to make the most informed choices. However, many family members come into the MDC asking specifically that the word "Alzheimer's" not be mentioned. Often, the patient has had prior experience with the disease and its most difficult aspects, such as taking care of a parent or spouse. One has to wonder, however, whether it is the patient or the caregiver who needs protection from the diagnosis.

It is crucial to be aware of cultural considerations in communicating a diagnosis. Not all cultures adhere to the western dictum that the patient must be told, and for some cultures, including many Asian cultures, this is quite inappropriate (*Galanti, p. 143*). In

any event, communicating a diagnosis should be completed in a quiet place and delivered sensitively with sufficient time allowed for questions and discussion. The insight of the patient should never be underestimated. It is not unusual for a professional to try to soften a diagnosis using terms such as “memory problems” or “dementia” and to have the patient look directly at him/her and ask, “Do I have Alzheimer’s disease?” While one can state it is not known in an absolute sense, honesty with sensitive candor is the best policy. Of note, families will occasionally demand that a patient be told the diagnosis in the belief that he/she will be more agreeable to the limitations imposed by the disease if they are aware of the condition. This rarely works. Even if there is an initial understanding, the combination of memory loss and lack of insight usually make such a tactic useless and unnecessarily harsh.

## **Driving**

Whether a person should drive is one of the most difficult topics discussed at a MDC. At the Tallahassee MDC, which serves nine very rural counties in addition to the Tallahassee/Leon County area, the discussion is intensified because for many patients there are simply no good alternatives to driving. In addition to the symbolic meaning in our culture where a car equals independence, as a practical matter not having a car can mean not being able to leave home.

To further complicate the issue, a diagnosis of Alzheimer’s disease does not necessarily mean that a person is not competent to safely drive a car. Driving is a complex skill, and for most of us it is a skill embedded in our long-term memory. Alzheimer’s disease first attacks the short term memory; for otherwise healthy adults limited driving may still be safe for a time. However, eventually the disease will make driving unsafe. In this instance the principles of autonomy and beneficence collide, and responsibility to others plays a part as well. Ahronheim et. al. (2000, p. 19) note the choice of the patient and his own best interest, not to mention the best interests of others, may be in conflict. The patient’s decision to continue driving may very well put them as well as others at significant risk.

Reactions to a recommendation to stop driving vary greatly. Some patients have already made a decision to stop, perhaps following an accident or an incident of becoming confused or lost. Other patients simply refuse, sometimes quite vehemently. Family reactions vary as well, from a desire that the MDC somehow enforce the directive to a desire to keep their loved one independent by allowing them to drive perhaps within a restricted area. There are, in fact, several actions that can be taken. First, if the person is still able to drive, conversation about what will happen when they are no longer able is critical. When available, a formal driving evaluation by a Certified Occupational Therapist (OTR) can be helpful in further clarifying circumstances.

Written directives are helpful since patients may truly not remember being told that driving is unsafe. A physician may write “no driving” on a prescription form, which can be used as a reminder. The written MDC report can also be used for this purpose.

The State of Florida Department of Highway Safety website includes a downloadable anonymous reporting form to report concerns and trigger further evaluation.

Regardless of the involved professionals' skills, much of the burden for stopping the patient from driving will fall on the caregiver(s). They may be encouraged to shift "blame" to the professionals, but they are the ones on the front lines. Suggestions may include removing keys or removing or disabling the car. It should be kept in mind, however, that persons with dementia may be quite capable of calling a locksmith or even buying another car. It is crucial that every effort be made to transport the person with dementia to wherever they need to go – church, senior center, club meetings, outings with friends – so as to maintain that individual's quality of life.

### **Autonomy and choice**

This principle is at the crux of many practical and ethical dilemmas facing professional and family caregivers. Kitwood (1997) asserts "men and women who have dementia have emerged from the places where they were hidden away; they have walked on to the stage of history and begun to be regarded as persons in the full sense" (p. 133). One can only hope that this is true, and that we never deny the person with dementia his/her personhood. "People with dementia should be allowed to exercise their remaining capacities for specific tasks and choices; denying these choices challenges their independence and dignity" (Post and Whitehouse, 1995, p. 3). As the Canadian Guidelines state, "a diagnosis of Alzheimer's disease, in itself, does not mean that a person is immediately incapable of making decisions. However, as the disease progresses, a person's decision-making abilities will change." (see: <http://www.alzheimer.ca/en>).

The concept of a person with a diagnosis of AD or dementia making informed decisions can be a surprising one for those who do not realize the variations of impairment at different stages of the disease. Particularly in the early stage of the disease, although impairments in short term memory are present, many choices can still be made. Although a person may not be able to make sophisticated financial decisions or even manage their checkbook, they may still be able to name a Power of Attorney or make the decisions needed for a Living Will. Indeed, if it has not been done previously, it is at this stage when such choices and documentation should be completed to avoid the potential for later conflict and confusion.

It is often extremely difficult, however, to determine what choices a person is safely able to make. Should they remain at home, living alone? Should they drive? What level of supervision is necessary? What about spending money? What about intimate relationships, sex or marriage? The dilemma is complicated by the inability of the patient to recognize their own limitations, which is characteristic of the disease. Thus, attempts by caring professionals or loving family members to limit freedom and activities are frequently seen as unnecessary, even cruel. Since suspicion and paranoia

are also common symptoms, caregivers will not be thanked and may suffer anger and even verbal or physical abuse in response to their attempted interventions.

The question of capacity often leads to issues of guardianship. If advance care decisions are not made early in the dementia process, the family may be faced with the need to later take legal action to assume guardianship. In Florida, a three person examining committee is appointed to advise the Court on the person's abilities. Such decisions are not made in the MDC although the MDC report is often submitted as part of the process.

## **Behavioral Control**

### *Living alone*

#### **Case Example**

*A woman is brought to the MDC by her daughter. The daughter has been living with her mother, but is planning to move to New York City in two weeks to start graduate school. The plan is for the mother to continue to live at home alone. The mother is still driving. Examination indicates that the mother is entering middle stage dementia, probably AD. Alternatives suggested to daughter include an assisted living facility or hiring a case manager, however none are received favorably.*

Safety is a primary concern for a person with Alzheimer's disease and living alone can certainly pose risks. On the other hand, many people in the earlier stages of the disease function well in familiar surroundings and with a well-known routine. This is why the disease is occasionally not diagnosed until the individual is removed from their environment, perhaps during a trip or a hospitalization. Again, diagnosis does not indicate a clear direction.

Evaluation of supports and safety concerns can help with decision making. Clinic staffs attempt to determine the level of available family and community support. How often are family and friends coming to visit? Are there regular checks such as Meals on Wheels? The notion is that the more eyes on a situation, the better. As for safety, indicators such as forgetting to turn off appliances, such as the stove, forgetting to take medications or not taking them correctly may be warning signs. The individual may be forgetting to pay bills or has had the power or telephone disconnected. People who live alone may also be vulnerable as targets for unscrupulous businesses or may open the door to strangers when it is not safe to do so.

Adjustments can be made to keep the person in the home as long as possible, ranging from a pill box organized by a family member to a personal caregiver. At some point, however, living alone may no longer be viable. The sooner the family starts to



discuss and plan for this eventuality, the less likely it is that decisions will have to be made at a time of crisis.

The case cited above was the subject of intense discussion. After the daughter moved, the woman returned for a follow up appointment with no idea why she was there and no memory of past visits. At this time the decision was made to call in a report of elder neglect. Although the investigation did not lead to any changes because the woman was not judged to be at imminent risk, staff agreed that this action was warranted.

### *Personal life, intimacy and sexuality*

#### **Case Example**

*A patient was brought in by her daughter with whom she was living. She was diagnosed with probable Alzheimer's disease, early stage. Several weeks later the daughter called to say that her mother was planning to marry a man she had met at the local Senior Center. The daughter did not feel that this was in her mother's best interest; she felt that the man was after her mother's money and would not take good care of her. She asked how to stop this marriage from taking place.*

When is it appropriate to extend control into the most private aspects of life? This is a difficult topic for many, especially for adult children. In this case, the clinic social worker did not have enough information to accurately evaluate the merits of the situation other than knowing that the disease does affect decision making and judgment. A diagnosis of probable Alzheimer's disease, however, does not automatically affect legal capacity or rights. The daughter was advised to seek legal assistance.

### *Financial Affairs*

#### **Case Example**

*A prominent and quite wealthy member of the community had been diagnosed with Parkinson's disease and Lewy Body Dementia. He never completed a Power of Attorney and there was a disagreement about who should be in charge of his affairs – his (second) wife or his children. The children wished to prove that he was not competent when he married her.*

Issues of money and financial control emerge frequently. Many families are genuinely concerned and wish to preserve resources to ensure good future care. At other times, relatives may have different motives. For whatever reason, family members may ask the MDC to make a determination as to whether a patient is competent to handle financial affairs. Again, adults are presumed to have capacity until determined otherwise. Such determination is a legal action. While memory may be a component of capacity, it

is not the only component. Capacity is a determination best left to trained evaluators and the legal system.

### *Quality of Life.*

As Alzheimer's disease progresses, a person loses many of the skills and abilities that considered important to quality of life. The Alzheimers Society of Canada (*see: <http://www.alzheimer.ca/en>*) emphasizes that:

“those who participate in the lives of people with Alzheimer's disease should know or learn that, despite changes and loss of abilities, people with Alzheimer's disease are able to find pleasure and experience satisfaction. The disease does not remove a person's ability to appreciate, respond to and experience feelings such as anger, fear, joy, love or sadness. Recognizing an individual's abilities, interests and life-long skills helps to maintain and enhance that person's quality of life.”

It is part of the job of a MDC to educate family and professional caregivers on the ability as well as the disability of the person with AD. Professional staffs work with family members to plan for a good quality of life for the patient. At the same time, the quality of life of the caregiver cannot be ignored. Caregivers commonly neglect their own health and wellbeing. The Family Caregiver Alliance notes that a “substantial body of research shows that family members who provide care to individuals with chronic or disabling conditions are themselves at risk. Emotional, mental, and physical health problems arise from complex caregiving situations and the strains of caring for frail or disabled relatives.” (*see: <https://www.caregiver.org/national-center-caregiving>*).

Maintaining caregiver well-being is essential to maintaining patient well-being. It can, however, bring the wishes of the patient and the needs of the caregiver into opposition. The caregiver may have promised never to place the parent or spouse into a nursing home and then find that promise to be untenable when that person becomes belligerent, or incontinent. Caring professional social workers can negotiate between the differing wants and needs of the patient and the caregiver while attempting to find a “good enough” solution.

Autonomy, beneficence, safety and quality of life are all important considerations when working with patients with AD and their caregivers. As indicated, these important values can be in conflict. Although not all of Florida's MDCs employ social workers, the profession is an ideal one to help negotiate between these values and concerns. Working with patients and families, assessing and accessing strengths, support systems, community resources, taking time to learn family and cultural values, is the optimal path to ensure acceptable, ethical outcomes.

## Death and Dying

While most patients seen at a Memory Disorder Clinic are in relatively good health, the issue of advance planning is frequently addressed. When a diagnosis is made in the earlier stages of the disease, the patient is still able to understand the purpose of advance directive options and plan accordingly. It becomes the responsibility of the social worker to educate the patient and family about options and planning tools and to refer to legal counsel when appropriate (*Alzheimer's Association – South Central Wisconsin, 2002*)

## Summary

Alzheimer's disease and other conditions affecting the cognitive and functional abilities of older adults represent potential threats to emotional well-being, safety, physical health and quality of life for the patient, involved caregivers and/or family members. The changes in competency and functioning caused by these conditions frequently lead to ethical and legal dilemmas.

The growth in numbers of individuals affected by Alzheimer's makes effective intervention crucial, not just for the patients and their families, but for communities at large. Memory Disorder Clinics represent a valuable treatment team approach that addresses such circumstances and provide a model on how professionals can collaborate effectively and ethically with elder patients with Alzheimer's or related health concerns.

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## **Biomedical Ethical Issues and Social Work: The State of Practice and Research**

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### **Introduction**

There has been an increased involvement of social workers in the identification and resolution of biomedical ethical issues (Reamer, 1985). Reamer noted that as social work is a values based profession, it is particularly suited to address the often value laden decisions that patients and families commonly face in modern health care. These decisions include the use and allocation of technology, the right to live, the right to die, the limits of intervention, and quality of life. As patients and families struggle to understand the parameters of care and accept limitations of intervention, they turn to social workers to help them resolve these difficult issues and manage their consequences. Social workers are integral members of Ethics Committees in all healthcare settings. The American Society for Bioethics and Humanities (ASBH) whose members include ethicists, philosophers, physicians, and members of healthcare teams including nurses and social workers created a separate affinity group for social workers. The group maintains a list server and meets at the annual ASBH conference.

This article will identify common bioethical issues confronting social workers and explores how conflicting social work values and obligations lead to ethical dilemmas. It will present models of ethical problem solving in social work, review the use of and barriers to ethical consultation, and offer recommendations for enhanced social work participation in biomedical ethical problem solving.

### **Common Ethical Issues in Health Care Social Work**

#### *End of Life Issues*

Researchers identify end-of-life issues as the most common basis for ethical dilemmas faced by social workers. Other health care professionals from clergy to dietitians as well as physicians and nurses also identify end-of-life issues as their most difficult bioethical dilemmas. The most frequently cited end-of-life issues include: Do Not Attempt Resuscitation (DNAR) orders; confusion or conflict about advance directives; withdrawal or withholding of treatments such as artificial nutrition and hydration, dialysis, and mechanical ventilation; physician assisted suicide; and futility.(Csikai & Bass, 2000; Edelstein & Anderson, 1991; Foster, et al, 1993; Manetta & Wells, 2001; Miller, Hedlund & Murphy, 1998; Yen & Schneiderman, 1999). The key concern in many of these cases involves the patient's capacity for decision-making and the patient's best interests (Egan & Kadushin, 2001). A commonly cited barrier to resolution of end-of life ethical issues is poor or the lack of clear communication between and among professionals, families, and patients. This has resulted in an increased presence in the medical and nursing literature related to end-of- life care communication tools and offering protocols for

interventions to engage team members and the patient and their families in decision making related to goals of care. The literature includes guidelines on why and when to have a family conference, how often to meet, and what content to include; on effective ways to share information including samples of clinically empathetic phrasing and what wording to avoid; and step by step toolkits to promote collaboration and avoid conflict (*Back, Arnold, & Tulsky, 2009; Billings, 2011; Coulehan, et al, 2001; Curtis, et al, 2012; Lilly, et al, 2000; Lo, Quill, & Tulsky, 1999; Galushko, Romotzky & Voltz, 2012; Pantilat, 2009; Shannon, Long-Suthehall, & Coombs, 2011; Tulsky, 2005; Weaver, Bradley, & Brasel, 2012; Tulsky, 2005*).

Black's (2011) review of issues for patients facing the end of life include 1) understanding and accepting their changing health status, 2) the need to hold on to some normality in life, 3) the need to be supported by family and friends and to know they will be taken care of after the death, and 4) the need to have good and trusting relationships with health professionals. These needs can be prioritized and addressed in the social work care plan for the patient and family.

The Supreme Court established that patients with decisional capacity have the right to refuse any treatment including life-sustaining treatment (*Burt, 1997*). Beauchamp & Childress (2001) define decisional capacity as the ability to understand the information presented and discern decisions to be made as well as all associated risks, benefits, and alternatives of the all of the options for treatment including no treatment. The second feature of capacity is whether or not the person can make the decision free from undue or interfering influence (*Beauchamp & Childress, 2001*). If a patient does not have decisional capacity, a surrogate decision-maker may act on the patient's behalf. Controversy may arise, however, on the status and capacity of the surrogate and whether he/she is acting in the best interests of the patient. Advance Directives, a written statement of the patient's designation of a surrogate decision maker and statement of preferences for treatment, may not serve as an adequate guide for care providers if the statements are too broad or too narrow (*AMA, 1999*). Initiatives directed to institutions and care providers have been developed to increase the "conversation" and documentation of patient's goals of care at the end of life. The Institute for Healthcare Improvement (IHI) launched collaboration with The Conversation Project that educates healthcare systems and providers can encourage patients to establish goals of care and share them with the families so that their wishes will be respected and actively promoted. Active participation by the institution and its support to staff education and community engagement has the potential to promote a shift the way end of life is faced in their community (*Gunther-Murphy & Adams, 2013*). Another initiative involved a quality improvement program at a teaching hospital that financially incentivized resident physicians to elicit and document in the patient's record the patient's advance care planning wishes. At the end of the project documentation of advance care planning rose from 22.2% to 90% in a review of 1474 patient records over a 10 month period. In comparison patient records for patients on attending only units contained on 11.7% documentation of patient advance care goals (*Lakin, et al, 2013*).

Decisions at the end of life often involve issues related to prolongation of life versus quality of life. The patient or family may be asked to withhold or withdraw treatments or interventions such as mechanical ventilation, cardiopulmonary resuscitation, dialysis, and/or artificial nutrition and hydration. The decision to withhold or withdraw may be prompted by

issues related to patient's stated preferences, undesirable quality of life, perceived burden of treatment, and wish for a natural death free of extraordinary care. Such decisions are made in collaboration with the care team, the patient or surrogate, and the family. Difficulty arises when disagreement or different perceptions exist about the patient's wishes, what constitutes quality of life, the acceptable burden level of treatment, and a belief that life must be preserved at all costs including physical, emotional, and social costs (*Meisel, Snyder & Quill, 2001*). These concerns have become more complex over the decades with the increased availability of technology that provides life support well beyond the natural course of disease. Many deaths in the Intensive Care Unit are the result of withdrawing life support as the patient's disease status cannot be reversed (*USA TODAY, 2005*). Families need information and assurance that their decision mirrors the patient's goals of care. A movement to change the terminology of DO NOT ATTEMPT RESUSCITATION (DNAR) to ALLOW A NATURAL DEATH (AND) has been embraced by healthcare providers as it emphasizes what will be done to support the patient through the end of their life and not what will not be done. The AND order supports mutual decision making and provides both the care providers and families with a certainty of attention and care to the end (*Meyer, 2008; Vennerman, Narnor-Harris, Perish, and Hamilton, 2008*). The order can be customized to reflect the patient care needs based on their status and needed supports.

Physician assisted suicide (PAS) was originated in Oregon in 1998. Currently PAS is legal in the states of Oregon, Washington, Vermont, Montana, and New Mexico. The laws allow physicians to provide patients, who meet the state requirements, with a prescription for a lethal dose of medications that will end their lives when they wish. This continues to be a difficult ethical issue for care providers, legislators, patients and families, and the general population. In a 2013 Gallup Poll, public support for PAS has dropped from a high of 70% in the mid 1990s to 50% in 2013 (*Eckholm, New York Times, 2014*). The Washington State Department of Health 2011 Report and Oregon State Public Health Department reported that 63.7% in Oregon and 65.1% of patients who received prescriptions died after ingesting the medication (*O'Reilly, 2013*).

When patients ask their social worker about PAS, the question should be addressed directly beginning with an assessment of the patient's concerns. These concerns may include fears of dying in pain, being a burden to family, and of losing personal dignity. *Tulsky, Clampa, & Elliott (2000)* recommend that assessment also include comprehensive screening for depression. Depression is not an expected feature of terminal illness and requires pharmacological and social intervention (*Block, 2000*). In 1999, the Association of Oncology Social Work (AOSW) suggested the social worker's obligation to the patient in relation to PAS requests is not to facilitate or judge requests but rather to seek to understand the patient and their difficulties, and to assist them in their search for meaning and solutions. AOSW stated that the majority of the requests reflect a failure of the health system to respond to the needs of dying patients. The National Association of Social Workers (NASW) policy statement on patient autonomy and choice declared that social workers may support the self-determination of terminally ill patients including the request for PAS. However, they cautioned that decisions should be weighed in terms of patient capacity. The AOSW 2012 position on Palliative and End of Life Care developed and published jointly with the Oncology Nursing Society (ONS) states that a proactive approach to palliative care that includes assessment and management of physical,

spiritual, psychological, and social pain and suffering is integral to oncology. This includes addressing requests for PAS. The 2013 NASW Issue Statement on End of Life Decision Making and Care supports full participation by the patient and /or their designated decision maker in decisions about how they will be cared for and what interventions will be utilized. Social workers in the advocacy and caring roles are directed to support the patient's wishes and requests and speak for the patient when those wishes and requests conflict with care providers' and family members' beliefs and directions. The social worker assumes the mediator role helping clarify the source of conflict and possible resolutions. This is grounded in the social work value of client self-determination directing the social worker to protect the interests of the vulnerable (NASW, 2011).

Medical futility is a common referral for ethical consult referral and often is identified as most difficult to resolve because the question of who defines futility remains a topic of debate among philosophers, physicians, care team members, and patients and their families (Orr, 2000; Shuman, et al, 2013). Futile treatment is commonly defined as treatment that will not alter the natural course of the disease and, in fact, may be adding additional physical, social, and/or emotional burdens to the patient (Schneiderman, Jecker, & Jonsen, 1990). Care team members may also experience the burden of providing futile treatment in instances where they feel they are harming and/or not benefiting the patient and family. Protocols for approaching resolution of futile treatment issues recommend the inclusion of other support staff, including social workers, on the ethics consultation team (AMA, 1999). A consultation includes clarifying the patient's, family's or physician's reason for continuing treatment in contrast to the patient goals of care if they are known; exploring and offering alternatives, including time-limited treatment; and unraveling myths or resolving unrealistic wishes in relation to the patient's condition. To reassure the patient, family and staff regarding the purpose of the consultation, focus should be maintained on the comfort and care of the patient and not on social or financial imperatives and the voluntary nature of ethics consultations (Tarzian, 2013). (See P.O'Donnell chapter in this book for more extensive discussion of medical futility.)

### *Privacy and Confidentiality Issues*

Issues related to privacy and confidentiality rank as the second most common source of ethical dilemmas for social workers and include information disclosure, the privacy of patient records, and the importance of documentation (Egan & Kadushin, 1999; Foster, et al, 1993; Landau, 2000a). The majority of concern is generated over how, why and when information is shared among care team members, patients, families and third parties. Social work documentation must be concise but inclusive, timely but relevant, and thorough but appropriate to the situation (Reamer, 2000).

### *Patient Autonomy*

Patient autonomy issues such as self-determination, truth-telling, and informed consent represent the third most common source of ethical dilemmas (Jansson & Dodd, 1998; Foster et al, 1993; Proctor, Morrow-Howell & Lott, 1993). These dilemmas arise when family members request that information be withheld from the patient. The social worker's practice insight into the family's reasons for withholding information can be helpful to the care team's understanding



and approach to the family. The assessment of the family's patterns of communication and understanding of the illness may also suggest clinical interventions that the social worker may utilize to resolve the issue.

Ethical dilemmas may also be prompted by decisions regarding the accurate and full sharing of information with the patient (*Gordon, Turner & Bourret, 2000; Landau, 2000a*). Based on their interaction, social workers may perceive a patient as having limited understanding of their own diagnosis and treatment. They may also recognize the patient as unwilling or embarrassed to share the limits of their understanding with their physician or other care team members. Patient self-determination, especially in relation to discharge planning, can generate team conflict related to the patient's right to make sometimes questionable plans for discharge care (*Abramson, 1981; Abramson, 1989; and Proctor, et al, 1993*). The social worker may take the lead in helping the team members to understand the patient's point of view and accommodate both parties' needs in planning for a safe discharge to the community.

The Hastings Center publication reflecting on the controversial end-of-life cases brought to court by families seeking control of the patient's care often sensationalizes the social aspects of these cases in the popular press without clarifying the differences between the ethical, moral, and legal tenets that can provide the guidance needed to find the best solution for the patient (*Meisel, 2008*). Examples include the 2005 Schiavo case, the Cruzan case in 1990, and the Quinlan case in 1976. Early and documented decision making by these patients in an Advance Directive may have avoided the conflicts. These cases have had an effect on current care for patients receiving Left Ventricular Assistive Devices (LVAD). The LVAD was originally developed to provide a destination bridge to cardiac transplant for patients in total heart failure. As its use became more common and available, cardiologists began implanting the LVAD in patients with no prospect of heart transplant as a palliative comfort measure. Ethical issues developed around when to discontinue the use of the LVAD in these patients. Whose choice was it? What if the patient and care team disagreed? Many LVAD programs now require that the physician have an extensive informed consent discussion on goals of care and end-of-life care preferences with the patient and family documented in an Advance Directive documented in the medical record to avoid these conflicts. Physicians and family members agree to follow the patients documented wishes if the patient cannot participate in the final decision (*Rizzeri, et al, 2008*).

#### *Administrative Issues Related to Clinical Care*

Loyalty to the best interest of the client directs social workers to prioritize the interests of their clients. Stewardship of resources and loyalty to an employer would suggest that strict adherence to policy despite the client's situation is the right course. The ethical principle of justice as outlined in the NASW Code of Ethics (*1999*) requires that social workers challenge social injustice particularly in cases involving vulnerable, oppressed, and deprived clients. Restrictions mandated by insurers, state Medicaid programs, and charity services to services such as mental health, home health, and access to certain medications may be challenged by social workers on the basis of social injustice. In fact, the values and mission of the social worker's institution may be better served by advocating for the patient based on the moral imperatives of

social justice (*Emanuel, 2000*). The institution, meanwhile, may be dependent on compliance with the contract to maintain it and the overall fiscal solvency of the institution.

## **Social Work Ethical Obligations and Conflicts**

Social work is a values based and driven profession. The National Association of Social Workers (NASW) Code of Ethics (*1999*) outlines the values that direct social work practice. These values include: honoring the worth and dignity of the individual, promoting social justice, recognizing the importance of human relationships, practicing with integrity, maintaining competence, and working in service to the client (*NASW, 1999*). These values also support the mission of social work to enhance human well-being and help meet the basic human needs of all people, with particular attention to the needs and empowerment of people who are vulnerable, oppressed, and living in poverty.

Jennings, Callahan, and Wolf (*1987*) note that society has entrusted the professions including social work to protect our most basic values such as knowledge, health, procedural justice and the rule of law, civil liberties, freedom of information, economic prosperity, and equity in the distribution of social benefits and burdens. The professions have obligations to support the public interest, that is, the coming together of individuals to secure interests of mutual advantage but more particularly to promote the common good, that is, the general well being of the community. The authors designate the public duty of social work is to make the invisible visible in concert with the profession's stated values of altruism, mutual aid, and social justice. Reamer (*1987*) identifies social work as a vocation, not just a position, as it involves a "calling" that is driven by the social work values noted above and obligation to promote the public good above self-interest.

Beauchamp and Childress (*2001*) define ethical dilemmas as circumstances in which moral obligations demand or appear to demand that a person adopt each of two (or more) alternative actions. Dilemmas arise from the inability of the person to perform all the required alternatives. Each alternative is justifiable by ethical perspectives, principles, values, and the Code of Ethics. In social work practice, the conflicting duties and obligations that social workers have to clients, agencies, colleagues, other professionals, the social work profession, and the community often generate ethical dilemmas. Timely discharge to promote fiscal solvency for the institution, for example, may conflict with the patient's preferences for care and the health care professional's ability to support patient interest versus the need to support team relationships.

## **Models of Ethical Decision Making**

To help social workers identify, examine, and resolve the ethical issues and conflicts that are the source of ethical dilemmas in social work practice in health care settings, social work scholars have developed several models for ethical decision-making. The models have much in common, but do include some variation in guiding the process. Joseph (*1983*), building from the biomedical models, begins with the need to clearly define the dilemma. At times, social workers may approach ethical dilemmas from a practice perspective that blocks full exploration of the

dilemma and its context. The definition process includes a describing the setting and identifying involved parties, and details of the problem that have given rise to the dilemma. Review of the social work and ethics literature can reveal precedents established in similar cases, provide a complete range of the ethical issues involved, and propose why particular resolutions were selected. The second advantage of the literature review is that previous reviews will inform future deliberations.

Grounding in bioethical principles such of autonomy, beneficence, nonmaleficence, and social justice as well as understanding of the ethical perspectives such as deontological, teleological, and utilitarian will help the social worker reflect on the ethical factors of the dilemma and its resolution. Professional codes of ethics, such as the NASW Code of Ethics (1999), provide guidance on expectations of the profession for ethical practice. It is important to also consider the codes of ethics of other professionals involved in a given case. There are occasions when the guidelines provided in other professional's codes, differ from those outlined in the NASW Code of Ethics. A review of the values of all parties, including the institution and community, will help establish a hierarchy to measure the impact of each option for resolution of the dilemma.

The Joseph (1983) model serves as a model for social work ethical decision-making with other social work ethics scholars adding further refinements to the model. The following provides a case example in which the Joseph model may be employed:

### **CASE EXAMPLE HERE I COME TO SAVE THE DAY**

Mrs. B has been resident of local nursing home for the past year. She had a stroke three years ago and has a history of diabetes. She did not achieve any return of function after her stroke moving into a "locked in" syndrome. She remained on mechanical ventilation and had a PEG tube placed for nutrition. Her condition has deteriorated. She is no longer alert or able to respond in any way to her husband. She was admitted to the hospital with a UTI and fever. After the UTI was treated, her fever remained leading to diagnosis of metastatic cancer. Her physicians have recommended she be terminally weaned from the ventilator and allowed to die a natural death.

Her husband despite his own health problems visits his wife daily in the nursing home and hospital. He is gentle and caring – talking with her but telling the nurses she never really responds to what he says. He has talked with his pastor and the hospital chaplain and agrees that the patient should be terminally weaned. A call is received from the patient's son in California. He insists that his father is incapable of making decisions and demands that nothing be done until he can get to the hospital. HE IS A LAWYER. Physicians want to proceed but concerned about antagonizing the son. All agree that waiting another day or so is reasonable.

Son arrives with his wife who is seven months pregnant. He insists that the patient be maintained as is so she can see her grandchild. The husband looks at the son as if he has lost his mind as Mrs. B has not seen anything for a long time.

### *Questions and Issues to Consider*

Where does one intervene in this situation?

Who has decision-making authority?

What should be done to prepare the family for weaning the patient from support?

(*see*: Joseph, M.V. (1983). Ethical decision-making in clinical services: A model for ethical problem solving. In C.B. Germain (Ed.). *Advances in Clinical Practice*. Silver Spring, Maryland: National Association of Social Workers, pp. 207–217.)

In addition to the factors proposed by Joseph and NASW, Reamer (2006) includes reviewing appropriate social work theory and principles, consultation with colleagues and other appropriate experts. Reamer goes further by encompassing documenting, monitoring and evaluating the decision as important components of the ethical decision making process. NASW (2014), adds determining professional ethics and standards, legal and regulatory requirements and agency policies to the ethical decision making process. The case example below pertains to the Reamer model:

### **CASE EXAMPLE DEFINING THE DIFFICULT**

Mrs. F, a woman in her early forties, has recurrent pancreatitis. Previously admitted for several surgeries, including a colostomy, ileostomy, and PEG tube placement, she was admitted to the hospital with serious nutritional depletion and an infection thought to derive from an abdominal abscess. However, Mrs. F refused a CT scan to determine the cause of her infection.

Her non-adherence to medical advice included refusals of blood draws and medications and pulling out IVs, which she continued to do during her hospital stay. She also refused placement of a PICC line and Hickman catheter, necessary for antibiotics and long-term nutrition.

Mrs. F also has behavior problems. Her disposition ranges from being withdrawn and sullen to being nasty, lashing out and spitting at nurses, and dumping urine containers on the floor. Since she was admitted from a nursing facility, MRSA and VRE screenings were done in the Emergency Department. The MRSA test was positive and isolation measures were instituted. She refused to observe the protocol and left her room at will to visit the cafeteria, gift shop, etc.

Mrs. F has been diagnosed with borderline personality disorder, but psychiatrists repeatedly concluded that Mrs. F. was capable of making her own medical decisions. She has few visitors but does talk on the phone daily with a former

neighbor. The neighbor has called the unit and administration to voice the patient's complaints about her care and staff response. However, she refuses to visit the patient and voices her fears about medical care.

After several weeks in the hospital, during which Mrs. F. refused numerous procedures, she has become critically ill with VRE and sepsis. She continues to refuse all diagnostic procedures that might have ascertained the source of her infections and the cause of her increasing respiratory distress. Simultaneously, she insists that, when necessary, she be transferred to the ICU, and demands that "everything be done". She has refused to complete any Advance Directives or name a Durable Power of Attorney for Health Care Decisions.

### ***Questions and Issues to Consider***

What are the various ethical dilemmas arising in this example?

Where would one initiate intervention?

What plan of action would you initiate?

(see: Reamer, F. (2006). *Social Work Values and Ethics, 3<sup>rd</sup> Ed.* New York, NY: Columbia University Press)

McAuliffe and Chenoweth (2008) are other advocates for a decision making model in ethical deliberations. They support an inclusive model that includes many of the steps proposed by Joseph and Conrad (1989) as well as Reamer (2006) with regards to defining the dilemma, gathering information, and reviewing alternative approaches and actions. They propose that an inclusive model provides an action oriented foundation for deliberations which includes Accountability, Critical Reflection, Cultural Sensitivity and Consultation. These platforms are considered interlinked and crucial to strengthening the core of ethical decision making.

### **Ethical Consultation**

Ethical consultation is a commonly used approach to address difficult ethical dilemmas and issues in health care institutions. The consultation process generally involves a team of two or more professionals from a variety of disciplines with formal or informal training in ethics who evaluate the problem and offer options for resolution (ASBH, 1998) in an open and safe environment (Reamer, 2006). As previously described, social workers encounter and confront a variety of ethical dilemmas in health care including such issues as end of life care, do not resuscitate orders, advanced directives, withholding and withdrawing life support, futility, informed consent and self-determination to name a few (O'Donnell et al, 2008). These issues often result in what is called moral distress. As defined by Andrew Jameton, moral distress is the inability of an individual to act according to core values and obligations due to external or internal constraints (Ulrich, C.M, Hamric, A. B. & Grady, C. 2010). Manning (1997) describes the moral citizenship responsibilities of social workers as the obligation to fully live by social work values and to participate in ethical action. In the presence of ethical stress or moral distress

ethics consultation is one of the resources available to health care social workers to engage in discussion and ethical decision making.

Danis, et al (2007) examined ethics consultation and fear of retaliation among nurses and social workers and found that 40% of those with access to ethics consultation personally experienced or observed colleagues experiencing retaliation when seeing ethics consultation. This study also found that social workers seek consultation more frequently than nurses and that a more favorable ethical climate promoted the use of ethics consultation and fostered less fear of retaliation. Although fear of retaliation is considered a realistic and an actual fear, it is not associated with reduced requests for ethics consultation.

Even though studies demonstrate that allied health professionals including social workers utilize ethics consultations less frequently than physicians (Landau, 2000a; Olson, et al, 1994). The major reasons cited for not seeking ethics consultations are related to the professionals' perceptions about power, communication failures and distrust among professionals and the individual's knowledge and understanding of ethics. These are described more fully below.

#### *Power*

Power is a broad topic that includes a number of concepts dealing with perceived power and how to empower members of the medical team. In their research, Joseph and Conrad (1989) found that influence on ethical decision-making correlates directly with one's ability to contribute to those decisions. According to Joseph and Conrad, to effectively take part in an ethics consultation, one needs to have role clarity, role satisfaction, skill in information exchange, a collaborative style, and preparation in understanding ethics.

In some medical systems, the social workers state that physicians have the actual ethical responsibility because they are responsible for the medical interventions, thus transferring the power solely to the physicians (Landau, 2000a). According to O'Donnell et al (2008), perceptions of power are perhaps a function of role and the locus of decision making authority in medical teams. Social workers may view themselves as less powerful members of the team in the medical hierarchy. To foster an environment where social workers and other allied health professionals participate in the ethical deliberations, there is a need to have a sense of shared power among the medical team members.

#### *Communication*

The essential first step in accessing an ethics consultation is communication between the members of the medical team, patient and families (Csikai & Bass, 2000; Homenko, 1997; Thiel & Robinson, 1997). Lack of accessibility to, and mutual trust among, colleagues can create weak relationships between team members and become obstacles to positive communication (Grochowski & Blacksher, 2000; Kerridge et al., 1995; Landau, 2000b; Thiel & Robinson). Ulrick, Hamric, & Grady (2010) report that repeated situations of moral distress are indicative of systemic poor communication, problems with collaboration and perceived feelings of powerlessness. These must all be addressed to minimize moral distress in the clinical setting.

Positive communication is characterized by mutuality, openness, clarity, and understanding. It is fostered by listening, respect and tolerance for differing viewpoints, with a focus on mutual goals. Social workers' training and skills in communication places them as natural leaders and educators on the health care team.

### *Knowledge of Ethics*

Joseph and Conrad (1989) found that social workers who had a discreet course in ethics in their graduate curriculum participate more fully in multidisciplinary ethical decision-making. Among social workers with little or no training in ethics, there was general acknowledgement that they lacked confidence in properly identifying an ethical dilemma and seeking an ethics consultation. Edelstein & Anderson (1991), Foster et al. (1993) and Landau (2000a) agree that knowledge of ethical rules, principles, and theories and their clinical application is essential in order to fully participate in ethical decision-making. In a national study of the relationship between ethics education and training and use and usefulness of ethics resources and moral action of nurses and social workers, Grady, et al (2008) found that social workers more often than nurses reported having basic or advanced ethics, training during their professional program. Social workers also reported taking more continuing education programs in ethics than nurses. Other research suggests that institutions can create an environment that fosters increased ethical consultations with social workers and other allied health professionals by providing education on the topic of ethics (Homenko, 1997; Landau, 2000b; Thiel & Robinson, 1997).

Ethics training prepares health care team members by providing the theory base, technical language and confidence needed to discuss ethical dilemmas. Ethics education additionally enhances social workers' and others' sensitivity to, and understanding of, different ethical issues and provides a framework for ethical analysis (Homenko, 1997; Gordon et al., 2000). The use of ethics rounds to regularly discuss cases can increase one's understanding of ethical issues and provide practical experience when discussing sensitive topics (Gordon et al., 2000). Such discussion and use of consultation are thought to increase as social workers enhance their understanding of the ethical policies and procedures of an institution. With enhanced understanding comes a sense of teamwork and collegiality. Ulrich, C. et al (2007) report that an organizational ethical climate that fosters open communication and provides ethical resources and sustainable work related interventions to allay ethical stress are important components of job satisfaction and the decision to remain in the profession. In addition, since ethics stress is influenced by the climate and resources available to engage in ethical deliberations, it is important that organizations support Ethics Committees, consultation teams, continuing education and ongoing discussion of complex ethical issues (O'Donnell, et al 2008).

### **Recommendations for Social Work**

There are numerous implications for practice, education, supervision, and research in enhancing the role and involvement of social workers in the bioethical consultation process (Kadushin & Egan, 2001; Foster et al., 1993; Silverman, 1992). This suggests that social workers have a significant role in biomedical ethics deliberations and problem solving.

## *Practice*

Social workers bring a variety of professional practice skills, values, and ethics to the bioethical decision-making arena. Training and experience in mediation, problem solving, family conferencing and communication are particularly valuable in working with families. The goal of such intervention is to foster autonomy and self-determination and to identify and resolve psychosocial issues. These skills also benefit interdisciplinary deliberations on treatment and end of life decisions. According to Silverman (1992), practice skills are valuable in facilitating the group process because they elicit input from all disciplines and balance professional egos. The ability to gather psychosocial information is crucial in understanding the functioning levels of patients and families, their communication patterns, coping styles, and nature of financial resources.

## *Education*

The immediate context and practice skills contribute to shaping practice decisions, but prove insufficient in the biomedical ethics arena where specific skills in ethical inquiry are crucial (Foster et al., 1993). In addition to the ethical decision making model developed by Joseph (1983) and later refined by Reamer (1990), Kadushin & Egan (2001) recommend specific course content in graduate and continuing education programs emphasizing ethical principles and skills development, ethical conflict analysis and ethical skills development. These authors promote the use of case studies and courses with content focusing on interests of the stakeholders as well as on competing ethical principles and ethical analysis. Silverman (1992) supports this point, noting that social workers in health care have a sense of the political atmosphere within the institution which, when coupled with group work skills, provides an advantage in leadership.

Twenty-three (23) states require three to six hours of continuing education in ethics every two years and another four states require one to two hours of continuing education hours every two years (Groshong, L. (2009). While these requirements address the issue of training in social work ethics and how to practice ethically, medical ethics deliberation or decision making is not a common focus of this education. Bioethics training can provide social workers with the skills to systematically address ethical problems in health care, (McCormick, A., et al, 2014). For healthcare social workers, bioethics training in fundamental ethical principles, understanding standards of ethical decision making, with real world examples or case studies of complex issues in health care is particularly important.

## *Supervision*

While education is important in preparing social workers for engaging in ethical deliberations, the contribution of social work supervisors in health care settings must also be considered. Social work leadership has a critical role to play in empowering staff through education and support to work with the care team in addressing ethical issues faced by patients and families. Supervisors are often the first to apprise staff of the power centers and stakeholders as well as the mission and vision of an organization. Supervisors are helpful in analyzing the interests of stakeholders (Kadushin and Egan, 2001). Such information in most social work departments in host settings, but is even more pivotal in managed care environments



where there may be an inherent conflict between managing financial pressures and complex ethical issues.

The attentive listening skills of the supervisor are needed to help staff identify their own values and biases and to support clinicians as they negotiate the challenges of service provision in managed care (*Silverman, 1992; Riffe, 1998*). The supervisor can help staff to identify the ethical issues to support and direct social workers in taking concerns to the appropriate forum for ethical consultation in the institution. Recent research points to the conclusion that the more supportive the ethical climate and the more ethical resources provided by the employer contributes to less ethical stress in health care social workers (*O'Donnell, 2008*). This in turn leads to a greater ease and willingness to take moral action. Supervisors are crucial in fostering this kind of receptive environment

## **Research**

Another major area where social workers can contribute to the development of knowledge is in research. It is recognized that social work has been involved in bioethics research only since 1980. Proctor et al. (1993) note that research has the potential to increase social workers' understanding of ethical dilemmas and can facilitate the revelation of specific principles and issues in conflict. Such revelation can lead to identification of avenues for problem-solving.

In 1998, Jansson and Dodd examined the scant contribution of social work to bioethics research and created a theoretical framework they believed could assist social workers identify gaps in ethical research, expand conceptual horizons and generate a range of empirical studies. Since then, there has been increasing research conducted by social workers and about the involvement of the profession in bioethics. A regional study conducted by Jansson & Dodd (2002) examined the extent to which medical social workers engage in ethical activism. Csikai (2004), in a study of the resolution of ethical dilemmas in hospice care, found that social workers were mostly involved in providing information about community resources, psychosocial histories, and in promoting self determination. As previously mentioned, O'Donnell, et al (2008) looked at ethical stress, moral action, and job satisfaction among in medical social work. Others have compared nurses' and social workers' responses to ethical stress (*Ulrich et al., 2007*) and looked at the impact of ethics education and continuing education in ethics on moral action and role of the social worker in ethical decision making (*Grady, et al, 2008* and *McCormick, et al 2014*). More research is needed perhaps applying the methodology proposed by Jansson and Dodd (1998) which includes studies of ethical deliberations, contextual factors, and ethical outcomes. In addition, this methodology should be supplemented by studies examining complex emerging bioethical issues confronting social workers such as the use of information technology in practice, e-medicine and ethical issues arising from pandemic or disasters to name a few.

## Summary

Social workers have an important, expanding role in the identification and resolution of bioethical issues. The literature identifies the most common ethical dilemmas for social workers as end-of-life issues, privacy and confidentiality concerns, and autonomy issues. While social work ethics leaders have developed models for ethical problem solving, social workers' lack of familiarity with ethical knowledge and lack of training in ethical analysis continues to deter social workers from fully recognizing and referring ethical issues for consultation and resolution. Our review finds that social workers seek fewer ethics consultations than physicians because of a perceived lack of power, lack of clear communication related to ethical issues and lack of ethical training. Suggested remedies included discrete ethics graduate and continuing education programs, increased supervisory content specifically related to ethical issues in clinical practice, and directed research in aspects of social work ethical challenges including deliberations, context and outcomes.

The literature review raises a number of questions for further research. Does the practice setting impact social workers' identification of ethical dilemmas? What are the barriers to the use of ethics consultation in various settings? What would make social workers more open to using ethics consultation? How are their dilemmas addressed if ethics consultations are not sought? Further understanding is needed on how medical institutions can promote medical collaboration and teamwork, along with research on effective approaches to ethical education for all allied health professionals.

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# Culture, Health Care and Ethics

*Subha Addy, MA, LMSW-ACP*

## Introduction

Since the initial 2003 discussion of this topic in the Exemplars in Practice series, cultural knowledge and the importance of cultural competence have gained considerable recognition. New theories and research findings on the cultural influence on health care beliefs have prompted a fresh approach to implementing cross cultural healthcare practices. This chapter will illustrate the existing and the changing trends of cultural movement and the extent to which culture powerfully influences the social system and our everyday lives.

Diversity has been noted as one of the defining trends of our time...one that has influenced the changing landscape of America (*USA Today, 2007*). Cooper (2012) speculated that the term “minority,” at least as used to describe racial and ethnic groups in the United States, may need to be retired or rethought as the US Census Bureau projects that *by the end of this decade no single racial or ethnic group will constitute a majority of children under 18*.

We live in a continuously changing world and cultural competence becomes imperative to meet the needs of an increasingly diverse patient population. This chapter introduces health care personnel to the global nature of culture and the cultural processes that impact beliefs, customs, rituals, religion, values, morals, socio-ethical concepts and institutions. It explores the influence of culture on human behavior and how culture impacts the manner in which patients experience an illness, how they respond to diagnosis and treatment, deal with crises and make decisions. As cultural beings, we need to be conscious of how culture influences our own attitudes towards others and how cultural learning enhances our competence by augmenting awareness, knowledge and skills.

## Historical Perspective:

Exchange between culturally diverse groups is not a new concept. History takes us from ancient times to the recent past, when individuals raised in one culture travelled the world as explorers, fortune-hunters, traders, teachers, students, religious messengers, conquerors, immigrants, tourists or settlers and had cultural contact with others of differing backgrounds. These individuals, however, were exceptions to the common people who lived in mono-cultural societies and maintained values and norms provided by their specific social structure. In contrast, America has always been and is presently a culturally diverse nation in every sense. While diversity was once regarded as a dilemma to be managed and quickly assimilated into a larger societal mainstream, advancing globalization now prompts diversity to be viewed not as a problem but appreciated as an asset. Disappearing global margins and technological advances including instantaneous communications and rapid transportation systems not only created exciting opportunities for international economic and business enterprises but rocked the “business as usual” concept in the form of conflicts around cross-cultural issues.

Like their multinational business counterparts, health professionals have also witnessed demographic and behavior changing trends in patient populations. Social workers face the challenge of caring for patients who display innumerable cultural variables, including distinctive ways of comprehending, illness, disease and health care depending on their sociocultural context. The biomedical model evolving from Louis Pasteur's germ theory of disease that has been the established force in Western medicine is not necessarily embraced by the rest of the world. Growing awareness of the significant role and meaning of behavior has promoted the use of patient-centered care delivered by interdisciplinary provider teams. Experiencing illness, seeking and responding to treatment and accepting or rejecting help, all depend on the cultural learning in the context of a cultural environment (*US Surgeon General, 2001*).

### **Impact of Culture in Healthcare**

Culture is both a major influence on how patients respond to health care information and impacts medical compliance. Medical professionals in the Western countries such as the United States typically regard disease as a result of natural scientific phenomena, promote medical treatments that fight microorganisms and use sophisticated technology to diagnose and treat disease. Other societies however, even within Western countries, have beliefs that illness is the result of supernatural occurrence and support prayer or other spiritual or religious interventions that offset the presumed condemnation of powerful forces. Cultural disapproval plays a major role in patient compliance. A Chinese adult patient with minimal formal education may make effort to comply with offered medical therapy but continue using herbal medicines prevalent in their culture and in which he/she had great faith.

Cultural generalization, a prospective stereotypical process that tends to put individuals of a certain culture to a set of specific characteristics, can fail to notice the significance of social factors that can play a considerable role on cross cultural encounters. Problems often arise from failing to recognize variations in health beliefs and cultural expectations. These problems in turn threaten both patient satisfaction and desired clinical outcome. Groper (1996) notes that compliance with recommendations and patient satisfaction is interrelated and depends upon patient-provider relationship and effective communication between the two.

### **Importance of Cultural Competency:**

O'Hara-Devereaux & Johanson (1994) envisioned "cross cultural, well-designed cultural competency and knowledge of cultural variable such as language, context, time etc. will be some of most highly valued resources of the 21<sup>st</sup> century work arena." Cultural sensitivity and cultural competency play important roles in social work practice. It is particularly important to balance the vibrant diversity of cultural variables and sensitivity to the forceful array of cultural influences that permeate the encounter between the service provider and the client during the clinical process. NASW (2000) "supports and encourages the development of standards for culturally competent social work practice, a definition of expertise, and the advancement of practice models that have relevance for the range of needs and services represented by diverse client populations" (p. 61).



Contemporary patient populations are comprised not only of individuals from a boundless array of countries, ethnicities, races, and religions, but also differ by age, class, disabilities, education, gender, socioeconomic status and sexual orientation. Each encounter may convey diverse cultural values and expectations. Migrating clients are inclined to maintain their cultural identity while learning the ways of their adopted culture. These individuals may bring distinctly different issues to the counseling sessions, needing special awareness and attention. Contradictory expectations can lead to conflict and unacceptable outcomes. Lack of information on the part of the healthcare professional regarding the profound influence of culture on human understanding, outlook and behavior can negatively influence the ability to make ethical decisions and offer optimal services. Of further concern is the price paid from impaired relationships, missed opportunities and reduced output of efficient services.

Cultivating cultural fluency begins with awareness and education. Health care institution staffs of physicians, nurses, therapists, and social workers have their own cultural systems, language and ethical perspectives. These can result in conflicts and frustrating management predicaments as such cultural differences can create significant barriers to effective teamwork. Social workers can make important contributions that serve to minimize strife by recognizing the underlying cultural causes of conflict. Through education and mediation they can get the concerned parties back on tract and empower staff to deal with future challenges. Sensitivity to one's own self and others' worldviews are crucial to interacting with multicultural populations and successfully rendering needed assistance.

### **Definition of Cultural Competence**

Campinha-Bacote (2014) defines cultural competence in health care as "the process in which the healthcare professional continually strives to achieve the ability and availability to effectively work within the cultural context of a client" (*p.1*). NASW (June 2001) similarly regards it as "the process by which individuals and systems respond respectfully and effectively to people of all cultures, language, classes, races, ethnic backgrounds, religions and other diversity factors in a manner that recognizes, affirms and values the worth of individuals, families and communities and protects and preserves the dignity of each." Agencies need to incorporate cultural knowledge into policymaking and practices to develop organization wide cultural competence.

Doman Lum (1999) noted the four basic components of cultural competence:

**Awareness:** This is the initial point of the cultural journey, a pre-competence stage in which clinicians examine and strive to become aware of their personal and professional worldview and that of others, consisting of identity, perceptions, biases, values, and other elements of their culture and those of cultures different from their own.

**Knowledge:** Based on awareness of one's own culture, cultural knowledge establishes the ability to examine in depth one's own psychological framework, and opens the way to learn about cultural differences, and general and specific

attributes of cultural rules of communication. This knowledge of other cultures enables the participant, not only identify how to deal with any specific cultural encounter but also to focus on how to be effective in a cross cultural environment.

**Skill:** This corresponds to an application level, in which clinicians effectively use their cultural awareness and knowledge during interviewing, assessment, and treatment, education and advocacy. A culturally skilled clinician efficiently performs culturally competent practice and gets involved in training others in cultural competence, and conducts research that adds to the knowledge base of communication and differences in diverse populations.

**Inductive learning:** Continuous education that offers contemporary and enhanced information and insights relating to multicultural practice.

## Definition of Culture

Appreciation of the concept of culture is the key to understanding cultural competence. Race and ethnicity are often applied to define culture however they constitute an incomplete description of the term. Culture is an adaptable, evolving and continuous process through which individuals and groups interpret their world and design their social order of institutions, values and beliefs and base their life practices.

Culture has been defined in distinctive ways. Cecil Helman (1997) quotes the famous anthropologist Taylor's (1871) definition of culture as, "that complex whole which includes knowledge, belief, art, law, morals, custom, and any other capabilities and habits acquired by man as a member of society." Helman further explains, "Culture is a set of guidelines (both explicit and implicit) which individuals inherit as members of a particular society, and which tells them how to *view* the world, how to experience it emotionally, and how to behave in it in relation to other people, supernatural forces or gods, and to the natural environment. It also provides them with a way of transmitting these guidelines to the next generation- by the use of symbols, language, art and ritual." (pp. 2-3)

Cultural definitions essentially denote that human identity is indistinguishable from his or her culture. Culture can be regarded as an overall assortment of expressions, language, behavior patterns, conditioning, traditions and ideology. Culture is learned, shared and passed down from one generation to the next. Culture symbolizes collected values and expectations that transpire from society's basic assumptions and principles. It provides for its members, ways to behave and to infer the behavior of others. O'Hara-Deveourex & Johansen (1994) also note that one of the basic purposes of culture is as a vehicle of reliable communication. They explain, that to avoid misunderstandings five common cultural characteristics may be kept in mind:

**Logic:** Cultures are based on reason. All cultures develop with logical integrity and offer the basis for harmonious and meaningful interaction of all components and forces within their environment. Understanding the law of cultural logic is the key to finding the rationality between beliefs and behavior. The challenge is to

learn to accept the logic of other cultures without judging them in contrast to the different logic of one's own culture.

**Communication:** Communication is more than words in a message; it is both verbal and non-verbal. Non-verbal communication, such as style of greeting, eye contact and gestures, accounts for about 80% of a communication and holds a certain culturally-based meaning to the member. Culture is the vehicle of communication. It reveals the essential patterns of thinking, experiencing, acting and interacting in a life situation. These can easily be misinterpreted and give way to misunderstanding. Giggling, for example, is a common response to embarrassment in Southeast Asian culture but can be mistaken for callousness by western cultures. Communication is not possible without some system of mutually shared meaning.

**Self- identity:** Cultural identity keeps us oriented to a particular milieu, providing roots and a sense of belonging. Self-identity provides us with individuality, values and beliefs, assisting us to function and maintain a sense of rootedness and continuity. In complex societies, individuals constantly reshape identities through choice of cultural overlays added to the original culture.

**Conduct:** The manners and practices of a particular culture are generally observable to members of other cultures. Commonly, cultures are equated with the things that are visible, such as art and artifacts, music, food, costume and language. But the deeper connotations of behavior, including the concepts of beauty, justice, modesty, sin and shame, body language, patterns of handling information, range of social stratification, and method of decision making remain apparently invisible. Just as the larger portion of an iceberg submerged under water poses the gravest danger to a ship, the invisible dimensions of culture can be the cause of serious misunderstanding, confusion and clash.

**Adaptability:** Culture is a process in a constant dynamic exchange that can transform over time when major external forces influence thoughts and actions. This process of acculturation can be seen among migrant population and over generations of other groups. (pp. 47-48).

### **Cultural Lenses:**

Cultural variables are lenses through which people perceive their world. To understand how multiple cultural variables control individuals' actions and reactions to their environment and to understand their behavior, it is vital to recognize that their world-view is predisposed by a number of significant cultural cues. All of the variables exist in an active relationship to each other creating a total cultural pattern. O'Hara-Devereaux and Johansen (1994) identify the following variables: *Language, Context, Time, Power/equality, and Information Flow.*

**Language:** All cultures have some language structure. Within a primary culture, sub-cultures develop their own specialized dialect and expressions. Language and thoughts are closely interrelated and provide a vital understanding of a cultural process. Greater range of understanding a language undoubtedly facilitates the development of a meaningful relationship and presents a distinct working advantage. Familiarity with the language of a culture provides cues otherwise missed for getting information, making evaluations and offering advantageous assistance. Using jargon or special terminology (such as medical terms) can be a barrier to effective communication. As individuals are most comfortable in their original language, the use of an expert interpreter may be warranted when, language barriers are an issue.

### **Case Example: Lost in Translation**

Mr. Bok, an 85 year old, Indonesian gentleman was brought to a modern urban clinic accompanied by his son, complaining of extreme shortness of breath. The patient had been in the United States for just over a year and had not been exposed to western medical system prior to this. He spoke in Bhasa Indonesia, his native tongue, but seemed to follow simple instructions in English. His son's command of English was better but not fluent. Mr. B, a chronic smoker, was diagnosed with exacerbation of chronic obstructive lung disease and as his oxygenation was severely decreased. He was admitted to the hospital for three days and discharged with maintenance medications and detailed instructions by the nurse in charge. A week later, his son brought him back to the clinic as his condition had seriously deteriorated. This was perplexing because on reviewing the hospital notes it seemed that he had been doing very well at discharge. On reviewing his medications it was established that one of his maintenance medications, SPIRIVA, dispensed in capsules, needed to be inserted in a "Handihaler" (inhaler) and used via the inhalation route. On further investigation it was found out that instead of using an inhaler, the patient was cutting up the capsules and ingesting the powder inside the capsule with honey. Needless to say this was the reason for his worsening symptoms and the result could potentially have been disastrous. At the time of discharge, the patient or his son did not have any questions for the instructor and it was taken for granted that they followed the directions provided to them.

During the follow up interview the staff used the services of an interpreter who was able to explain to them that Mr. B, who had used herbal medicines for treatment of ailments in his country, used similar means to take the capsules received from the hospital. Further, Mr. B thought that the "machine" given to him was a keepsake from the hospital and did not realize that he was supposed to use it at home. Both he and his son refrained from asking questions due to respect for authority.

Among Asian cultures, keeping harmony is of central value; thus, there is a compelling emphasis on avoiding conflict and direct confrontation. Disagreement with the recommendations of health care professionals is avoided

out of respect for authority, but, agreement does not indicate that the patient and family fully comprehend, concur with or will follow treatment recommendations. Lack of grasp is also an acknowledgement of being ignorant and thus inexcusable. “Loss of face” in Indonesian and most Asian cultures is negatively valued and must be avoided at any cost. Communication, verbal or unvoiced, carries important cultural implication. Factors such as context, personality, and disposition interact with variety of cultural influences that persuade choices during an interactive encounter.

**Context:** Context is possibly the most essential cultural dimension and also the most complicated to explain. Context provides the overall framework within which humans learn to systematize and express their thoughts, emotions, and behaviors in relation to their environment. Hall (1976) distinguishes between “*high-context*” and contrasting “*low-context*” cultures:

*High Context* cultural communication contains a minimum amount of explanation and specifics, as the contributor and the recipient are both familiar with the information shared. High context are deeply rooted in the past through a strong and effective network of customs and rituals. Relationships are close and committed to conformity and interdependence. Members of high context cultures rely heavily on traditions as background for communication and interpreting messages. The meaning of all verbal and non-verbal communication is derived from the surrounding context and the communication style is subtle and implicit. Key high context values include group approval, maintenance of harmony, respect for hierarchy and authority and regard for family honor and obligations. Circuitous communication style calls for longer discussions and negotiating time. Hurried communication without the establishment of a trusting relationship is considered rude and suspicious. Change comes slowly.

*Low context* communication must be objective, overt, detailed, explicit, and precise. Words convey the bulk of the message and written communication is preferred. Communication style is direct and subtleness and non verbal communication is rarely included in low context messages. Mostly present and future oriented, progress and new initiative and inventions are greatly prized in low context cultures. Protective of individual space, members of low context cultures, tend to maintain distance in personal relationships, and community. Equality, individual freedom of choice, self reliance, assertiveness, competition, and drive for improvement are highly valued in low context cultures.

Since context is a form of cultural pattern, most cultures can be placed in a high or low scale. Not only primary cultures but also professional cultures demonstrate high or low cultural context. To illustrate, the context orientation of social workers is one motivated by rapport building and high value is placed on personal relationships. By comparison, physicists tend to value precision, work within rigid analytical guidelines and place less emphasis on personal relationships. Sexes and genders also exhibit different cultural contextual inclination. When focus shifts to examining countries, high context countries include Japan, Asian, Arab, African, and Latin American countries, rooted deeply in their past, history, social structure, relationships and community. In contrast, most western countries can be regarded as low context cultures valuing individualism, equality, freedom, individual success, future orientation and a direct precise communication process. Some of the high context professions are medicine, law, social

work, human resources, education and sales/marketing. Some low context professions include engineering, science, research and development, Information technology and finance.

**Time:** Concept and management of time differs by culture and it has intense effect on all aspects of our lives and actions. Cultural time variations can be classified as monochronic or polychronic times. Cultural anthropology (Munn, 1992) has been a major contributor to the study of temporal orientations. Most of the literature in anthropology considers time perceptions as cultural artifacts. Numerous anthropological observations highlight that it is impossible to assume that men were born with any type of innate “temporal sense”. Our concept of time is always “culture-bound” (Hallowell, 1955). Time orientation is vital for healthcare issues because time impacts on a number of important concerns such as behavior with respect to time, planning, and commitments.

*Monochronic time:* In a monochronic time system things are done in sequence, and individually. Time is scheduled, arranged and managed. Monochronic time is linear, single tract, tangible and a scant item for consumption. Monochronic time is evident in low context cultures such as the western cultures. Monochronic cultures place a supreme value on schedules, tasks and completing a mission on time. Being loyal to regimented agenda may find those who do not subscribe to the same sensitivity of time as impertinent.

*Polychronic time:* Polychronic time is circular, multi-tract, flexible, and abundant. In a polychronic time system several things can be done at once, and a relaxed approach is taken to scheduling time. High context cultures such a Latin American, African, Asian and Arab cultures use the polychronic time system. These cultures pay less attention on the preciseness of keeping time and instead focus on relationships. As a result, loyal to relationships and with a sense of unlimited time, they are comfortable multitasking and carrying on several conversations at once. Being late for a reason is not considered to be rude. Monochronic and polychronic cultural members have the same problems adjusting to one another as the high and low context people.

### **Case Example: Impact on Organizational Behavior**

Rural Eastern Texas parents of an infant appeared at a busy urban pediatric clinic an hour late for an appointment for a well baby check, and were extremely upset to learn that the physician had no other openings that day to see their baby. They were offered alternate appointments and an opportunity to see the nurse practitioner but angrily refused both. Their primary concern was seeing the original physician and did not seem to understand that due to scheduling constraints this was not an option. They accused the clinic staff of being unconcerned about the baby’s welfare and also the time they spent in travelling and away from their daily chores at the farm. The social worker tried to offer support and arrange for an appointment to see an available health professional but to no avail. They left the clinic enraged, after bitterly complaining to the manager and promising to report their mistreatment to the media and seek the assistance of a lawyer to sue the physician and the clinic.

Considering the aspects of monochronic and polychronic times, we can sense how they impact the behavior of those seeking healthcare and organizational staff. In our case example we are dealing with cultures possessing two entirely opposing viewpoints of time and work. The unfortunate outcome of the case arose from conflicting viewpoints as they relate to time. Obviously, the clinic viewed the utilization of structure and dealing with time precisely as valuable; (*monochronic*) to say the least. On the other hand, the baby's parents looked at it as their work/life balance and did not understand schedules could not be altered considering their hardship of bringing the baby to the clinic; (*polychronic*) blending personal time and formal time as one. They were hurt and angered to learn the physician who they trusted and revered did not find the time to see them.

To manage a diverse clientele it is important for health professionals to understand cultural differences so as to avoid situations as described above. Patient education regarding how clinics work within time constraints may be one approach to adopt for all incoming new patients to minimize misunderstandings. What one person might view as a strict schedule, another would look at as part of their work/life balance and not take as seriously. A manager with a diverse workforce would need to understand these concepts and manage the cultures that are present.

**Information Flow:** Information is a tool for making decisions and cultures differ in decision-making choices and style. Closely linked to context, power dimension and time, this cultural variable can become a serious obstruction in the cross cultural work arena. It is important to get an understanding of how information flows in a given situation and the rules that regulate decision-making. Such knowledge is beneficial if communication problems arise. Cultural rules direct the flow of information.

**“Getting straight to the point”** *Low context* cultures or most western cultures are inclined to consider information as articles to receive, pass on and apply to make decisions. Typically information is transmitted up or down in a straight, short line. Efficiency in the process, path and swiftness of information flow is highly valued and reaching a target at any cost is the ultimate goal. Dependent on firmly programmed activities, people of low context who hold fast to monochronic time concept, may cringe at broken chain of actions as they value strict adherence to time. In the rather flattened social structure of a low context culture, rank may not be important in the flow pattern.

**What's the point of getting straight to the point?** By comparison, *high context* cultures tend to regard information as a blend of perceptions, relationships and remarks looped through several consents and analysis. Information must pass through the power structure before acceptance for a final decision. High context cultures may resist strong reliance on objective information ignoring vital interpersonal relationships. Polychronic/high context cultures are comfortable with flexible time schedule. Power dimension also plays an important role in message flow pattern. In the hierarchical high context culture information or messages, flow from top to bottom.

For example, “the American way” is one of meeting the objective in the most direct way, following the shortest path may meet with resistance from a client from South America, who is

used the need to establish comfortable working relationship before deciding on a path to solve a problem.

### **Power Dimensions of National Cultures:**

Hofstede, Gert Jan Hofstede and Minkov (2010) developed an enhanced framework for cross cultural communication, describing the effects of a society's culture on the values and behaviors of its members. Hofstede and Minkov explain that cultures differ along the following indicators:

- **Individualism vs. collectivism (IDV).** Individualistic societies emphasize personal achievements and individual rights. People are expected to stand up for themselves and their immediate family, and to choose their own membership. In contrast, in collectivist societies, individuals act primarily as members of a lifelong and unified group or organization. Extended families are used as a protection in exchange for absolute fidelity.
- **Power Distance Index (PDI)** addresses the distribution of power between people in a culture. It measures a culture's social hierarchy, or the extent to which power influences the behavior of its members and to what extent people submit to authority. The PDI is lower in cultures in which equality is valued and higher in cultures that value a more authoritarian chain of command.
- **Uncertainty avoidance index (UAI).** People in cultures with high uncertainty avoidance tend to minimize the occurrence of unknown circumstances and to proceed with cautious planning and by applying rules, laws and regulations. In contrast, low uncertainty avoidance cultures are more tolerant of change, accept and feel comfortable in unstructured situations or changeable environments and try to have as few rules as possible.
- **Masculinity vs. femininity (MAS).** Competition, assertion, materialism, ambition and power, are masculine cultures' values and feminine cultures place more value on relationships and quality of life. In masculine cultures, the differences between gender roles are more dramatic and less fluid than in feminine cultures where men and women have the same values stressing caring and support.
- **Long term orientation vs. short term orientation (LTO).** Long term oriented societies put more importance to the future. They cultivate values leaning toward rewards. In short term oriented societies, values upheld are related to the past and the present, including respect for tradition, preservation of one's face, and fulfilling social obligations.
- **Indulgence vs. restraint (IVR).** Indulgent societies have a tendency to allow rather free fulfillment of natural personal desires related to enjoying life,



restrained societies have a belief that such gratification needs to be restricted and in kept within strict norms.

Hofstede acknowledges that these cultural dimensions are theoretical constructs and that generalizations about cultures must be regarded as only guidelines using national averages applying to a population in its entirety; Hofstede's cultural dimensions distinguish countries but are not about differences between members of societies.

### **Cultural Competence and Patient/Culture Centeredness**

Both patient/family centered healthcare and culturally competent healthcare recognize the importance of patients' and families' perceptions of disease, illness and treatment and responding with quality healthcare in the context of those perceptions. Beach, Saha & Cooper (2006) suggest that "...while not the exclusive focus of cultural competence, the general characteristics of patient centered care (e.g., building rapport, exploring patient belief, values, and the meaning of illness; finding common ground may be endorsed as aspects of cultural competence. Conversely, because cultural context is relevant to the care of all patients, not only to people of color, cultural competence has the capacity to enhance patient- centeredness and improve quality for all patients" (*executive summary, p. viii*).

#### **Case Example: 21<sup>st</sup> Century Challenges**

Mrs. Smith, a 79 year old widow came to the hospital for treatment of a rash that had been unresponsive to home remedies. Mrs. Smith was articulate and able to give her health history meticulously and chatted about current affairs easily. She saw the dermatologist and was prescribed a treatment regime and was asked to make a follow up appointment before leaving. At the checkout window, when asked if she was accompanied by any one, she proudly announced that she is able to drive and comfortable living independently. The checkout staff, a young man, gave her a form to complete with her address, home, telephone number and e-mail address. He also mentioned that the clinic contacted all patients through e-mail with appointment reminders. He added excitedly that all medical reports were now "on line" and patients could conveniently access their medical records from home. Mrs. Smith left saying that she will contact the clinic later. She never returned. When the clinic checked back Mrs. Smith mentioned that she was looking for another physician's office where she could do business face to face and not through "machines".

This example illustrates the communication gap felt by a patient from a pre-digital generation that not infrequently harbors different attitudes towards computers, technology and technical jargon. In spite of being a member of the mainstream culture and fluent in the language, Mrs. Smith's unfamiliarity with the culture of information technology that came naturally to the young man at the checkout window made her feel uncomfortable and probably out of touch. Such perceptions can threaten the self-respect of certain individuals. For the

elderly, discomfort with technology can generate feelings of frustration and incompetence. They can be a letdown to the one's values of independence, and dignity. In Mrs. Smith's case, this resulted in a negative outcome. This is not an uncommon scenario; it can be readily observed in many modern health organizations. Major changes in modern health care systems including the storage and access of medical information can prompt patients and other involved parties to become distressed and discouraged. Individuals often maintain their primary generational values and worldview despite moving from one life stage to another. Salkowitz (2008) notes that,

...“when it comes to generations and technology, one size most certainly does not fit all. Generational issues around technology are largely unspoken and unacknowledged, but they can hamstring the efforts of organizations to get most out of their investments in both people and information systems. Strategies that look good on paper may end up exposing underlying conflicts that paralyze productivity.” (p. 11) He further comments that “the problem can be solved by recognizing the importance of distinct generational attitudes as a part of the organizational approach to technology.”(p. 55)

Culture is a decisive factor in the success of any organizational agenda. Changes that go against cultural values or beliefs have a lesser acceptance rate as they solicit individuals to readjust or change their outlook. Change is possible with sensitive communication and education. Salkowitz (2008) observes that “because the largest changes associated with new collaborative information work tools are cultural not technological, the generational problems created by their implementation have less to do with the relative ease or difficulty of using new software, and more to do with the underlying changes to the patterns of authority implicit in user- created content and widespread collaboration.” (p. 226). We are in the middle of digital technology evolution and are transforming into an information-based society. A generational gap exists in this IT-based society and the gap is both individual and cultural. As such a need exists for a sensitive, interpersonal and culturally competent approach to patient care.

## **Cultural Competence and Ethics**

Paasche-Orlow (2004) observes that cultural competence has strong ethical directives to facilitate access to health care and eradicate health disparities for all who are served. The essential principles that underpin those directives are: acknowledgement of diversity; respect for disparity, and; efforts to diminish negative outcome. Globalization is generating issues that challenge us to change the way we look at human diversity, global ethics and ethical conflict. Every culture strives to establish social justice and order based on values, beliefs and reasoning. Laws are formulated on these factors and enforced to achieve desired outcomes.

Ethical issues are sufficiently complicated within one cultural milieu that holding a globally homogeneous view on ethics is literally infeasible. Ethical principles unique to each culture help us resolve ethical questions. Ethical directives are devised to guide and control behavior based on the approval and practice of individuals within a particular culture. Ethics are not static, but rather are a constantly modified and altering proposition. Although the United States has witnessed the effect of globalization on the medical system since the late 20<sup>th</sup> century,

we still tend to have constricted view of what is acceptable in terms of ethical behavior and essential moral agenda of cultural competence (Pederson, 1994). Pederson also observes that “because of implicit cultural bias in our social institutions, professionals sometimes have to choose between the prescribed ethical guidelines of their profession or being ethical in particular cultural context” (p.224).

Reamer (1998) notes that “social work entered a new phase in the early 1980’s influenced largely by the invention in the 1970’s of a new field known as applied and professional ethics. The principle feature of the applied and professional ethics field, which began especially with developments in medical ethics, or what has become known as bioethics, was the deliberate, disciplined attempt to apply principles, concepts and theories of moral philosophy, or ethics, to real life challenges faced by professionals” (p.491).

Morality is a collection of ideologies and rules that helps one distinguish right from wrong, behave in accordance with them and be rewarded for proper actions and rebuked or penalized for noncompliance. Ethics is the orderly investigation and application of the moral system. Moral principles and rules are set as standards for a group or profession. Ethical decision-making is an intricate, personal and emotional process, particularly when coping with the stress of ill health, uncertainty, unfamiliar culture and unknown rules that may seemingly complicate a situation. Health care professionals have the responsibility to balance professional and institutional ethical codes and boundaries while remaining vigilant to the cultural influences that include providers, the patient and his/her support system.

Reamer in his article *Viewing Social Work Ethics Through an International Eye* (2012) notes, “The complex challenge for all social workers, it seems, is to recognize that while some ethical issues are truly international and cross-cultural, others are unique to diverse nations and cultures. The concepts of confidentiality, privacy, boundaries, and self-determination are relevant for social workers everywhere, but their particular meaning and application vary considerably. Social workers who firmly embrace ethical standards and concepts in their own nation, language, and cultural context must be careful to avoid assuming that these standards and concepts translate well in other nations, languages, and cultural contexts. Ethical hubris—where social workers assume that their view of ethical issues fits squarely everywhere in the world—is dangerous.”

### **Case Example**

Mr. M. a 72-year-old, widowed retired engineer was admitted to the hospital in Texas for treatment of stage 4 metastatic lung cancer. After retiring from a high ranking job in India, Mr. M. a green card holder came to the States to be near his only daughter, and her young family. His daughter, a research fellow at a university was his only relative in the city. Rest of his close family lived in India. A highly educated world traveler, very articulate and pleasant gentleman, Mr. M. soon became a popular patient on the floor. He remained symptomatic despite maximum medical management and his condition steadily deteriorated. During a visit with the social worker, Mr. M in a matter of fact way told him, “I have lived a long life, now I am ready to die. I just want to be comfortable and not in pain anymore. I have made

peace with my family and God; it's time for me to go." He goes on to say that his daughter knows he wants no heroics and jokingly says to the social worker, "now you know it too!" While wrapping up the visit the social worker asks him about advanced directives and he says that he had thought about it but just never got around to filing the paperwork.

When the daughter arrived for a visit that afternoon, the social worker shared the discussion he had with Mr. M. and suggested that she have a word with her father regarding the advance directive forms. She agreed reluctantly and requested a meeting with the physician first to discuss the DNR status. She also wanted to talk to the extended family members and her husband prior to discussing the matter with her father. Just as a meeting was being set up, Mr. M. experienced cardiac arrest and was resuscitated and placed on a ventilator. The distraught daughter requested that all measures to be taken "do everything so my father lives!" A few days later the physician approached her for a hospice referral. The daughter did not want to consider it even though Mr. M. would meet the criteria. Her comment was, "it will be like throwing my father away, because he is sick! Also, we don't decide when life will be terminated; it comes as the will of God." The visiting extended family supported her strongly. The physician and the administration agreed that transferring the patient to a hospice for palliative care would be the best resolve and beneficial for all. The case was presented to the ethics hospital committee.

## **Ethical Problem Solving and Assessment**

The Preamble to the NASW Code of Ethics (*NASW, 2000a*) begins by stating:

The primary mission of the social work profession is to enhance human well-being and help meet the basic human needs of all people, with particular attention to the needs and empowerment of people who are vulnerable, oppressed, and living in poverty. It further states, "Social workers are sensitive to cultural and ethnic diversity and strive to end discrimination, oppression, poverty, and other forms of social injustice" (*p. 1*).

Reamer (*1998*) notes that ethical issues have always been a central feature in social work. Cross cultural ethics bring further complexity to the matter. Available from a discussion video between Reamer and Ann Patrick Conrad (*1995*) using a format developed by Vincentia Joseph & Ann P. Conrad, are six essential steps for engaging in ethical problem-solving:

**DETERMINE** whether there is an ethical issue or/and dilemma. Is there a conflict of values, or rights, or professional responsibilities? (For example, there may be an issue of an adolescent's self-determination versus the well-being of the family.)

**IDENTIFY** the key values and principles involved. What meanings and limitations are typically attached to these competing values? (For example, while

confidential information is rarely held in absolute secrecy, typically release of sensitive information to third parties occurs only with patient consent.)

**RANK** the values or ethical principles which in your professional judgment are most relevant to the issue or dilemma. What reasons can you provide for prioritizing one competing value/principle over another? (For example, the patient's right to choose a beneficial course of action could bring hardship or harm to others.)

**DEVELOP** an action plan consistent with the ethical priorities that have been determined as central to the dilemma. Have you conferred with clients and colleagues as appropriate about the potential risks and consequences of various courses of action? Can you support or justify an action plan with the values/principles on which the plan is based? (For example, have you conferred with all necessary individuals regarding the ethical dimensions of planning for a battered wife's quest to secure secret shelter and the implications for her teenage children?)

**IMPLEMENT** a plan utilizing the most appropriate practice skills and competencies. How will you make use of core social work skills such as sensitive communication, skillful negotiation, and cultural competence? (For example, colleague or supervisory communication and negotiation may enable an impaired colleague to see her/his impact on patients and take appropriate action.)

**REFLECT** on the outcome of the ethical decision making process. How would you evaluate the consequences of this process for those involved: patients, professionals and agencies? Increasingly, professionals have sought support, training, and consultation from ethical review committees.

Ethical assessments should be based on the clear understanding that all moral and ethical reasoning, however diverse in nature, is developed within a cultural context logical to its members. Reamer in his article, *Eye on Ethics: Viewing Social Work Ethics Through an International Lens* explains, "It is vitally important for social workers to view ethical issues through a sharply focused international lens. What constitutes an ethical challenge for social workers in one nation may not loom large elsewhere or may be managed very differently because of profoundly unique cultural norms and contexts." He further elaborates:

- In the United States, social workers in health care settings discuss with patients the situations and accessibility of Living wills, Durable power of attorney and Advance directives. In other cultures the discussions regarding end of life issues are considered mostly unmentionable.
- Client confidentiality strictly administered in USA is not a key issue in many cultures. The family unit primarily expects to make decisions about the patients care and the patient is protected from news of negative prognosis as best as possible.

- Clients' right to self determination may be secondary to the wishes of the family unit. For the social workers trained and working in western institutions this challenge is sure to bring about multifaceted questions to be addressed where social workers have to consider intervention with clients' and family's right to determine.

As we have discussed previously, all clients are blueprints of their own cultural settings and sometimes bring in complex issues to be responded to ethically. Issues can be compounded when the international clients enter the picture, bringing in with them vastly different world views and beliefs.

Reamer, raises the important question as to whether universal ethical standards can be applied across cultures? How does a social worker come to terms with professional, personal, client and family rights in considering ethical outcomes in conflicting issues? His recommendation is for the social worker to learn from the principles of cultural anthropology and value how different cultures develop and relate to ethical concepts and to refer to the NASW Code of Ethics to be able to, "demonstrate competence in the provision of services that are sensitive to clients' cultures and to differences among people and cultural groups." (*standard 1.05[b]*).

Mattison (2000) notes "the value system and preferences of the decision maker shape the entire assessment process and influence each step and ultimately the choice of action selected" (p. 207). She designed the following seven step assessment model to be used as an analytical guide, "to structure the ethical decision making process..." (p.209):

1. Assemble background information and case detail
2. Separate practice considerations and ethical components
3. Identify value tensions
4. Identify principles in the Code of Ethics which bear on the case
5. Identify possible courses of action, benefits/cost, projected outcome
6. Assess which priority/obligation to meet foremost; justify the choice of action
7. Seek resolution

Mattison (2000) further illustrates a process for care providers to analyze their own value preferences after an ethical decision has been made in a particular case:

- Engage in reflection and self awareness, personal ethical preferences and develop a conscious awareness of self value patterns.
- Analyze the current ethical dilemma, by isolating ethical components, practice issues and scientific, technical and ethical aspects of the case.
- Continue a process of self-reflection; acknowledge any client, personal, professional or organizational factors that may be influencing decisions.
- Follow systematic steps in the decision-making process and select a resolution.
- Reflect on choice of action: measure current ethical choices against others from the past: sharpen and modify conscious awareness of value patterning.

Our example portrays a host of concerns and raises questions. The patient's wishes of "no heroics" and a pain free end of life were disregarded by the only person he had trusted to honor his wishes. Is it the ethical obligation of the social worker to support the self-determination of this patient? The patient had expressed "no heroics" and a pain free, comfortable last days. Whose ethical concerns should be addressed, the institutions, the worker's or the patient's and his family? Realizing the seriousness of his illness, the patient had calmly prepared for his exit from the world with the expectation that his daughter, as his alternate decision maker, would honor his articulated wishes. Was he giving up without a fight? Did culture play a role in his decision making process?

Acceptance of the inevitable is a cultural philosophy that is prevalent in many eastern cultures. It is not considered as being a pessimist but being wise. The patient's decision though stemming from the cultural values also is a reflection of his personal thoughts and capability to make reasonable decisions for him. On the other hand, the East Indian belief is to depend on *God's will* and allows nature to take its course when the illness is considered terminal. The dying individual is to be cared for as best as possible, is shielded from the "bad" news out of humanistic concerns and prolonging life is not barred. The family is responsible for making care decisions and the concept of "autonomy" is not emphasized as it is in the western culture.

Though the daughter was exposed to the western culture, did her cultural roots create confusion in the decision making process or was she responding to her grief and unable to choose the "right" decision? Doing the right thing is not always painless, particularly regarding loved ones. Whether or not to accept the inevitable is a traumatic personal issue. Hospice care often misunderstood by many is considered to be, "where you go to die" without medical attention or comfort. Admitting the patient to the hospice may mean to agree to a viewpoint of that may be culturally unacceptable. It impacts on the reverence and comforting care for the elderly as a duty of the young, particularly the children. In a collectivist society like India, a duty-based moral code stressing broad and socially enforced obligation and sensitivity is upheld in contrast to the individualistic American society that stresses freedom of choice, personal rights to decide and responsibility. Human behaviors and actions occur in a cultural context, as demonstrated in this case. This case illustration highlights the significance of cultural competency and ethical decision making. Care providers may discount cultural imprints on individual behavior due to lack of knowledge, misunderstanding, and negligence or bias. It cannot be overemphasized that the ultimate aim of culturally competent ethical decision-making is to assist patients in expressing their values, fears and hopes in a non-threatening environment of unconditional support.

Based on both Reamer and Mattison the following questions need to be addressed:

- **Why?**  
Reasons for considering the proposed action (transfer to a hospice facility)? What is to be accomplished by taking the proposed action? Are there any alternative actions possible? What other values or ethical philosophy to the predicament being considered?

- **How?**  
How much of the requisite and process for the action properly comprehended by the involved parties? How actively they are involved in this decision making process? Who has the responsibility to make the decision? Who will it have an effect on and how? Is the action explained and offered in a culturally sensitive and supportive atmosphere?
- **What?**  
What is the context of the recommended proposal? Is this a clinical or an ethical issue? How much of a daughter's grief process being overshadowed by cultural issues? Would it be presented differently within a supportive socio-cultural context? The goal is to reach a possible resolution of the conflicting situation. The social workers primary obligation is to support professional values, but the need to understand and apply cultural ethics cannot be disregarded. Outcome for each alternative action must be considered carefully and identifying Code of Ethics bearing on the case. It is important to establish whether the ethical implication of choices can be worked out through clinical and educational interventions and arrive at rational solution.

### **Summary:**

The 21<sup>st</sup> century has been one of globalization and significant technological and communication advances. The concept of culture has spread beyond race, ethnicity and color and has embraced a vast arena with loose or no boundaries. Culture, on one hand provides accord among people in analogous social groups and on the other hand creates dissonance through tendency to judge others based on one's own world view. Acknowledging diversity, acquiring cultural knowledge and learning about multiple cultural dimensions/variables as they shape conduct and behavior patterns is not a choice but a requirement for successful patient intervention. The concept of an individual's health culture orientations such as help seeking, social responsibility, anticipation and execution of duty are intertwined with their general cultural values. Social workers are being challenged to provide culturally sensitive and ethically sound services to increasingly diverse patient populations. Caring for people while they contend with illness, disease, death and dying has always challenged health professionals. Cultural issues and encounters make the process even more daunting.

Insufficient or faulty cultural knowledge and lack of cultural expertise can quickly create predicaments for patients and providers alike. Cross cultural expertise acquired through education and experience prepares one to identify problems and clarify information, while promoting self-awareness and development of applicable skills. Generalizations about cultures are often biased observations leading to stereotype thinking. Culturally competent care relies on pertinent data, appropriate assessment and seeks sensitive resolve in decision-making. It is characterized by careful questioning, active listening, and compassionate communication focusing on beneficial patient care outcomes.



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# Ethical Implications of the Affordable Care Act

*Michael Reisch, Ph.D., MSW*

## Introduction

Although political and legal controversies continue to surround the Patient Protection and Affordable Care Act (ACA) of 2010, it has already produced significant consequences for the U.S. health care system and the practice of social work, particularly in hospitals (*Collins, et al, 2013; Gorin, 2011; Judd & Sheffield, 2010*). Funding for preventive and primary care, wellness programs, and school and community-based care has increased at the same time as cost control measures have created greater fiscal pressures on hospitals and health care providers (*Rivlin, 2013; Madison, et al, 2011*). The different responses of states to the legislation – from outright resistance to enthusiastic cooperation – have compounded existing disparities in access to health care, particularly among low-income Americans (*Starr, 2011*).

The ACA's future success depends, in part, on how well social workers adapt to their new roles and to the expansion of their long-standing functions such as patient education, client advocacy, and information and referral (*Gorin, 2013; Zabora, 2011*). The ACA's emphasis on cost control and community care will enhance social workers' brokerage role and require additional skills in inter-professional and inter-organizational collaboration (*Golden, 2011*). Social workers will have to demonstrate both the cost-effectiveness and the service effectiveness of their interventions. The changes in health care delivery the legislation creates provide social workers with the opportunity to serve a critical linkage and coordination function within emerging community health systems that will require a synthesis of psycho-social and medical approaches to care and greater attention to the environmental factors that affect health and well-being (*Mason & Fogel, 2013*). In addition, policy changes will intensify the ethical challenges that social workers have traditionally confronted and create new, more complex ethical dilemmas as it will for other professions like medicine (*Vecchione, 2012; Visse, Widdershoven, & Abma, 2012; Brody, 2010*).

To address these dilemmas effectively and consistently, social workers will need to be aware of how a wide range of environmental factors influence people's health and access to health care in the U.S. (*Collins, 2012*). Considerable research during the past several decades has demonstrated that different groups are differentially affected by certain health and mental health problems based on race/ethnicity, age, gender, socioeconomic status, geographic location, occupation, and sexual orientation; and that health and mental health disparities/inequities have a reciprocal relationship with inequalities in other domains, such as employment, education, housing, and the physical environment (*Braveman, et al, 2011; Woolf & Braveman, 2011*). In addition, historically marginalized groups have generally received poorer quality health services due to absence of care, poor access to care, the inequitable allocation of health care resources, the provision of inappropriate forms of care, and the unavailability of affordable care (*Byrd & Clayton, 2003*).

To some extent, the ACA is attempting to address these problems, but its impact, to date, has been unevenly distributed. The ACA has expanded coverage to such vulnerable populations as elderly persons of color, immigrants, low-income persons who are living with HIV/AIDS, young adults, uninsured working age adults (19-64), and ex-offenders (*Cantor, et al, 2012; Berenson & Holahan, 2010; Kenney & Pelletier, 2010; Kenney, Pelletier, & Blumberg, 2010*). Yet, even under optimal circumstances, it will take years before longstanding problems regarding access and outcomes are corrected. In a “best case scenario” the policy will still leave approximately 20 million Americans without access to insurance coverage by the end of the decade (*Moniz & Gorin, 2013*). The refusal by over half the states to expand Medicaid further dampens future prospects. Working with both newly covered populations and those who remain without health insurance will create additional ethical dilemmas for social workers in the years ahead (*Gorin, 2013*).

### **Implications for Social Work Practice**

In the new healthcare landscape, social workers will have to place greater emphasis on the influence of socio-cultural factors and socio-economic on clients’ health and mental health. Due to the ACA’s extensive accountability requirements, there will be greater emphasis on their gatekeeper role. As a consequence of the shift from institutional to community-based care and from acute care to ambulatory care, inter-professional and inter-disciplinary collaboration will be increasingly important and social workers will need to create new treatment protocols and outcome measures that combine psycho-social and medical approaches to care. The educational, care coordination, brokerage, and bridging functions of social workers will acquire greater prominence, for example as members of home-based primary care teams. With the expansion of care to the elderly and impending demographic shifts as the baby boom generation retires, there will be a growing need for geriatric social workers. Because of the focus on prevention and primary care and the failure of the ACA to cover all vulnerable populations adequately, social workers’ roles as advocates and health educators will become increasingly significant. This will require social workers to develop more sophisticated interpersonal communication skills, particularly in the use of social media (*Reisch, 2012*).

### **Emerging Ethical Issues**

Many of the emerging ethical issues that social workers will confront in the health care field are direct consequences of the tensions generated by recent and impending policy changes. These tensions can be summarized as follows:

- ▶ Between the Medical and Bio-Psychosocial Models Emphasized by Different Health Care Professionals, with their Different Underlying Value Systems
- ▶ Between Cost Containment and the Enhancement of Service Quality
- ▶ Between Administration Regulations and Client’s Self-Management
- ▶ Between the Growing Environment of Interdisciplinary Practice and the Maintenance of Professional Hierarchies and Boundaries

- ▶ Between the Pressure to Enhance Institutional Efficiency and the Importance of Providing Patients with Necessary Health Information
- ▶ Between the Universal Attributes of the Legislation and the Growing Demand to Address Long-Standing Racial and Ethnic Health Disparities

These tensions will be most powerfully felt within the following traditional sources of ethical dilemmas: client confidentiality; paternalism vs. self-determination; the allocation of scarce resources; social workers' conflict of duties; and the conflict between legal and ethical obligations (*Reamer, 2014*).

In determining how to resolve these recurring dilemmas, it would be useful to recall the different ways in which social work ethics have been defined. One definition (*Lewis, 1982*) regards ethics as propositions derived from values and morals that form the basis of actions to achieve their ends. Ethics are the basis of rules of conduct that link our fundamental morals and values, our sense of right and wrong, and what is preferable in our individual behavior and as societal goal. As the *NASW Code of Ethics* (1999) implies, ethics also connote an obligation or fiduciary duty – to clients, constituents, colleagues, employers, and the society as a whole. While they are often interpreted to mean what is customary or socially acceptable in a group, community, organization, profession, or society, it is important to note that what is “customary” is not always ethical in a broader sense. Ethics is not equivalent to one's personal feelings about right and wrong, nor is ethical practice merely competent practice. In today's complex environment, it is perhaps best to regard ethics as a systematic framework which enables us to examine the underlying assumptions of our practice and to establish a consistent basis for resolving value differences or moral dilemmas.

Particularly in systems in which the interests of diverse parties are often in conflict, ethical dilemmas often arise under the following circumstances:

1. When a practitioner must choose between two equally compelling ethical principles that cannot be reconciled;
2. When the reasons to take act or defer action are unclear due to a lack of sufficient information\_or the presence of ambiguous guidelines – as frequently happens during periods of rapid and wide-ranging policy change;
3. Where practitioners do not have sufficient time to make a reasoned ethical judgment, for example in crisis or emergency care situations;
4. When social workers are compelled to choose between equally good or equally bad options, as often occurs when practitioners attempt to satisfy several conflicting imperatives; and
5. When social work's ethical principles conflict with legal or organizational obligations. This conflict could arise over such issues as what constitutes reasonable standards of care or best practices for a specific client populations; the demands of disclosure resulting from accountability pressures or new technology and the need to establish clients' trust through the maintenance of confidentiality; and the need to inform people of the costs and risks of treatment and the desire to

encourage them to seek health care services as promptly as possible (*Reamer, 2014*).

Two of the most compelling potential ethical dilemmas in the emerging environment of health care are updated versions of the question over the limits of confidentiality and the conflict between benevolent paternalism and the promotion of clients' self-determination.

The social work literature has identified four approaches to the resolution of ethical dilemmas. One approach maintains that clients' interests are primary. Although this approach would appear to be consistent with the ethical guidelines in the *NASW Code*, particularly in the health care there is often a problem of determining what exactly constitutes a client's "best interest." A second approach recommends the use of a "prime directive" in which the values of a profession or an organization (or the policies it is obligated to follow) are imposed on the situation. While this approach could be interpreted to be consistent with social workers' ethical duty to their employers and would enable social workers to comply with shifting agency and policy guidelines, it is contrary to the profession's long-standing emphasis on client self-determination and the concern during the past several decades about client empowerment.

Most ethicists, however, including those in the social work field, identify two prominent approaches to resolving ethical dilemmas. One (a deontological approach, from the Greek for "first principles") requires the construction of a hierarchical or lexical order of values which is then applied (consistently, one hopes) to every practice situation. For example, this hierarchy could establish the promotion of client's self-determination as a higher value than the protection of client's well-being, or vice versa (*Levy, 1973*). This approach might be particularly useful for social workers in the health care field where the conflict between client choice and client well-being often occurs. It might, however, be insufficiently flexible to address all the diverse situations that confront social workers in health care settings, particularly in a rapidly changing health care environment.

Finally, a teleological or consequentialist approach, such as utilitarianism, often summarized, somewhat inaccurately, as "the greatest good for the greatest number," requires the construction of a utilitarian "calculus" or balance scale which measures the potential impact of various choices a practitioner could make. There are several difficulties with this approach. One is determining how much "weight" to be applied to the consequences of each choice. Another is determining the importance of short-term and long-term consequences, such as the immediate satisfaction of a client's need for services vs. its future impact on a client's ability to control her/his surroundings. A third challenge is measuring the impact of different choices on third parties, including the society as a whole, of different decisions. Finally, many ethical dilemmas involve the need to make "forced choices" between competing "goods" that are difficult, even subjective, to quantify or of such a different nature that a comparison between them is impossible (*Rawls, 1999*).

Without dictating which of these approaches to use, *Reisch and Lowe (2000)* propose a synthetic 7-step framework to assist practitioners in resolving the ethical dilemmas they confront. The steps are:

1. Identify the ethical principles that apply to situation;
2. Collect additional information needed to examine the ethical dilemma in question;
3. Identify the relevant ethical values and/or rules that apply to the ethical problem;
4. Identify any potential conflicts of interest and those likely to benefit from or be harmed by such conflicts;
5. Rank order the appropriate ethical rules in terms of their importance in this situation;
6. Determine the consequences of applying different ethical rules or ranking these rules differently;
7. Determine who needs to resolve the dilemma.

### **CASE STUDY**

#### **Self-Determination vs. Paternalism in Health Care**

One of your clients is a retired taxi driver, Mr. A., who lives alone and has no family since his partner/caregiver recently died. He is frequently admitted to the hospital where you work because he forgets to take his many medications and cannot care for himself. Under the ACA, the hospital is subject to financial penalties if its readmission rates exceed the policy guidelines. In the hospital, Mr. A. confesses that he likes to be there because the hospital gives him what he needs most — people who care for him and about him.

This case encapsulates a classical ethical dilemma with the added twist arising from the stipulations of the ACA. One of the principal forms of paternalism in social work practice is physical interference with a client's intentions or actions, against his/her wishes, ostensibly for his/her own good (e.g., coerced medical or mental health treatment). Gerald Dworkin (1972) defined paternalism as coercive interference with an individual's freedom rationalized solely by references to the well-being welfare, benefits, interests, or values of who is being coerced. This definition would clearly apply to the above case.

Paternalistic treatment of clients under such circumstances has been justified for several reasons. One standard rationale is that a client lacks information that, if available, would lead her/him to consent to the social worker's interference. A related justification is that the clients is incapable of understanding relevant information, either temporarily (due to age or condition), or permanently. Given the increase in elderly clients forecast for the future, this situation is more likely to arise in the years ahead. Other justifications are based either on the client's consent to the paternalistic intervention prior to the interference or the belief that the client would likely consent after the interference when presented with all the facts.

The conflicting value, client self-determination, has historically been regarded by social workers as a universal right which is particularly significant for those receiving help. One of the foremost social work scholars in the field of ethics, Charles Levy (1976), argued there is no rationale to deny clients any rights that they would have if they had not sought, or been required

to undergo any health or mental health treatment. Self-determination is considered, therefore, both an end and a means – a pre-condition to the fulfillment of one’s personal goals, and the key to the maintenance of personal dignity and worth. The emphasis on self-determination also assumes people’s ability to make decisions if given the opportunity.

The primacy of self-determination and its limitations are reflected in the NASW *Code of Ethics* (1.01):

Social workers’ primary responsibility is to promote the well-being of clients... However, social workers’ responsibility to the larger society or specific legal obligations may on limited occasions supersede the loyalty owed clients, and clients should be so advised.

The next provision in the NASW *Code* (1.02) may be particularly applicable to this case:

[Although] social workers respect promote and the right of clients to self-determination, [they] may limit clients’ right to self-determination when, in the social worker’s professional judgment, clients’ actions or potential actions pose a serious, foreseeable, and imminent risk to themselves or others.

The resolution of this and similar ethical dilemmas is further complicated by the unequal distribution of resources and power that exist between workers and clients and between clients and powerful institutions (whose power is reinforced by government policy), which the provisions of the ACA will not fundamentally alter (*Emanuel & Pearson, 2012*). Other complications include the involuntary or quasi-involuntary situation of many clients, such as Mr. A., and the conflict between the client’s rights (in this case to care and well-being) and society’s need to control service costs (*Galston & Rogers, 2012*).

In this case, in addition to maintain the client’s self-determination, the social worker must also consider the extent of the client’s competence and comprehension of his situation; the importance of preserving the client’s trust, especially if it is likely he will need further care in the future; protecting the social worker and the hospital against legal risks, either in the form of a malpractice suit by the client or in the form of fiscal sanctions imposed by the government; and the importance of preserving the social worker’s professional integrity. Particularly with clients who may be impaired, s/he must assess if the harmful consequences that are likely to occur without interference are irreversible and if a wider range of freedom for the client can be preserved only by restricting it temporarily (*Sexton, 2012*).

## Summary

While most of the current debate over the ACA has focused on its long-term fiscal impact, its constitutionality, and its administrative feasibility, the ethical dimensions of this dramatic policy shift cannot be overlooked. This is particularly important for social workers,



who as the “value-based profession” have an obligation to balance the competing demands of the people, the organizations, and the society we serve.

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# Glossary

## *Ethics in Health Care Social Work Practice: Issues and Directions*

**Defamation** - occurs when a social worker says or writes something about a client or another party that is untrue, the social worker knew or should have known that the statement was untrue, and the communication caused some injury to the client or third party.

**Beneficence** - instructs the clinician to act in the patient's best interest by protecting and defending their rights, helping people with disabilities and rescuing people in danger.

**Ethics** - a system of moral principles and perceptions about right versus wrong and the resulting philosophy of conduct that is practiced by an individual, group, profession or culture" (Barker, 1995, p. 124).

**Ethics Audit** - entails thorough examination of major risks associated with one's practice setting (whether independent or agency-based practice). An audit involves multiple steps designed to identify ethics-related risks and minimize harm to clients, social workers, and social service agencies.

**Ethics Consultation** - commonly used approach to address difficult ethical dilemmas and issues in health care institutions, the consultation process generally involves a team of two or more professionals from a variety of disciplines with formal or informal training in ethics who evaluate a problem and offer options for resolution (ASBH, 1998) in an open and safe environment (Reamer, 2006).

**Futility** – There is no standard definition of this term. Futile treatment is commonly defined as treatment that will not alter the natural course of the disease and, in fact, may be adding additional physical, social, and/or emotional burdens to the patient (Schneiderman, Jecker, & Jonsen, 1990). The qualitative criteria that define futility include treatment that merely preserves unconsciousness or fails to end total dependence on intensive medical care. Schneiderman, et al (1990) recommend that any treatments that meet either quantitative or qualitative criteria should be regarded as non-beneficial and therefore futile. A physician's judgment that further treatment is futile is not a prompt to stop treatment but rather a prompt to begin the difficult task of talking with and helping the family understand the realities of the patient's condition (Helft, Siegler, & Lantos, 2000)

***Informed Consent*** - required in a variety of circumstances when working with clients in health care settings, including release of confidential information, program admission, service delivery and treatment, videotaping, and audiotaping (*Berg, et al., 2001; Miller & Wertheimer, 2010*).

***Libel*** - the written form of defamation of character; slander is the oral form.

***Malpractice*** - in general, this occurs when evidence exists that (1) at the time of the alleged malpractice a legal duty existed between the social worker and the client; (2) the social worker was derelict in that duty or breached the duty, either by commission (misfeasance or malfeasance) or omission (nonfeasance); (3) the client suffered some harm or injury; and (4) the harm or injury was directly and proximately caused by the social worker's dereliction or breach of duty.

***Morality*** - a collection of ideologies and rules that helps one distinguish right from wrong, behave in accordance with them and be rewarded for proper actions and rebuked or penalized for noncompliance.

***Negligence*** – when such claims are made, they typically allege that social workers engaged in malpractice in that the practitioners failed to adhere to specific standards of care. The standard of care is based on what ordinary, reasonable, and prudent practitioners with the same or similar training would have done under the same or similar circumstances (*Madden, 1998; Reamer, 2003; Woody, 1996*). Departures from the profession's standards of care may result from a social worker's acts of commission or acts of omission.

***Old Age Dependency Ratio*** - measures the number of elderly as a share of the working age population.

***Physician Assisted Suicide (PAS)*** - originated in Oregon in 1998, PAS is currently legal in the states of Oregon, Washington, Vermont, Montana, and New Mexico. The laws allow physicians to provide patients, who meet the state requirements, with a prescription for a lethal dose of medications that will end their lives when they wish.