

Self-Neglect in the Elderly: Ethical Considerations

OVERVIEW:

An estimated 2 million American elderly experience abuse and neglect each year, most of them repeatedly and in multiple forms.¹ Estimates on incidence and prevalence of abuse and neglect of those aged 60 and older have ranged from 3 to 40 per 1000, to as high as 100-120 per 1000, depending on the definition used and population studied.^{2 3 4 5} Self Neglect in the elderly annually accounts approximately 1.2 million cases within the United State, and more than 50% of all cases investigated by the elder protective services.⁶ Other forms of elder abuse and neglect annually accounts for approximately 1.1 million cases. Various studies showed that self neglect accounts for 40-77% of all cases brought to elder protective services in the United States, and it is estimated the trends are on the raise.^{7 8 9} Self neglect has an estimated incidence rate of 23/1000, which is similar to the incidences of new onset diabetes, and cataracts in the elderly. It is estimated to affect 3-8% of elderly population.

Self neglect was first described in 1966 as "senile breakdown syndrome"¹⁰ and "social breakdown syndrome"¹¹ interests waned till 1980's in the medical literature. Macmillan and Shaw (1966)-(ref 10) described the deteriorated self presentation and slovenly environment attributed to the person's disregard and setting:

"Patient's home are conspicuously filthy and neglected...a strong stale and often suffocating smell...half-empty bottles, dirty glasses and dishes with rotting food are scattered around and mixed with dirty clothes, books, faded pictures, and old newspapers...The patient...when confined to bed lies under a pile of ragged grimy blankets, newspapers, or cardboard. Patients appear as if they never undress, wash, or comb their sometimes infested or matted hair (p21). "

The phenomenon of self neglect has been documented for centuries: isolated, frequently unkempt, and often eccentric individuals such as hermits, witches, tramps, and recluses have long been depicted in the social history, literature, folklore, and opera of western society. These were the early sources of cultural stereotypes depicting extreme examples of self neglecters. Often arousing fear, discomfort, and disgust, some of these man and women were seen as mentally ill; some were expected to be able to call on fearful supernatural powers; some were thought to hoard treasures. All were considered strange and lived on the social, if not the physical, periphery of their communities.

Diogenes syndrome has often been described as the one end of the self neglect.¹² It is referring to fourth century Greek philosopher Diogenes, who reportedly admired lack of shame, outspokenness, and contempt for social organization and paid little attention to his appearance or condition of his surroundings. The Diogenes syndrome often characterizes elderly patients who appeared filthy and unkempt, whose homes were dirty and untidy and usually full of hoarding rubbish, but who showed no shame for these circumstances. Although not necessarily poor or in substandard housing, these self neglect individuals were usually known to social services agencies, who efforts were frequently resisted.

There is not a national standardized definition of self neglect, though the general concepts are very similar. This has hampered research in the field. Some of the more colorful or historical notable terms used include "biopsychosocial failure", "the dwindles", "passive suicide", "elder in crisis", and "indirect self destructive behavior". Medical terminology such as "Failure to Thrive" has been used to describe this phenomenon sometimes as well. National Center on Elder Abuse (NCEA) defines: Self-neglect is characterized as the behavior of an elderly person that threatens his/her own health or safety. Self-neglect generally manifests itself in an older person as a refusal or failure to provide himself/herself with adequate food, water, clothing, shelter, personal hygiene, medication (when indicated), and safety precautions.¹³

There have been very little epidemiological studies examining risk factors for self neglect. Dementia and depression has been associated as potential cognitive risk factors for self neglect.¹⁴ Hip fractures and prior history of stroke also have been associated as medical risk factors for self neglect. Many other factors has been postulated; including personality disorder, other psychiatric illness, alcoholism, executive function deficits, functional disability, and lack of social support.^{15 16 17 18}None has been rigorously demonstrated to have a definitive causation through epidemiological studies. Furthermore, small case series have noted higher unadjusted rate of mortality for elderly with self neglect, but only one prospective longitudinally followed cohort study has been demonstrated that self neglect carry a higher mortality in a longitudinal study of 12 years follow up, even after adjusting for many other confounding factors.¹⁹

Clinical concept of self neglect lacks clarity. Although psychiatric conditions may play a role in the development of self neglecting behaviors, effort to describe a syndrome imply that a larger array of behaviors is present, often without clear symptoms of mental illness. Cultural background and lifestyle may play a role, but they are not in themselves causes. Helplessness and increased frailty with aging may have significance but offer little to establish causation.

Many older people are not necessarily self neglectful, rather many people with disabilities seek out assistance or willingly accept it to help them maintain adequate living standard. Dementia are sometimes characterized by these behaviors in the middle stages of the disease, but many individuals without the diagnosis of dementia or related cognitive impairments engages in self neglecting behaviors that warrants legitimate clinical concerns.

ETHICAL PRINCIPLES:

The root of the word ethics come from the Greek “ethos” or “ethikos” meaning moral or character. It refers to the development of a script for good conduct that take place in ongoing organized groups to signal right from wrong. This lays the foundation for what the group “ought to do” in our conduct as compared to with what we may actually “choose to do”. Ethics, as a subject of study, belongs to the field of philosophy. However, the practice of ethics is a part of every aspect of our lives whether personal or professional. Foremost, philosophers are not expected to be practitioners, and most health care professionals certainly do not have the leisure of study philosophical theories to any great length. Therefore, we need a bridge between the two worlds if we are to benefit from the contribution of both. While we identify principles of ethics and self neglect, and conduct daily practical issues, we need to purpose a unifying framework that incorporates both.

Ethics in cases of self neglect may function in two dimensions. It may center on issues or dilemmas (or both). Joan Callahan defined issues as questions arising from singular values, and dilemmas as questions that emerge because two or more values are in conflict.²⁰ For example, adequate care, guardianship for mentally disabled adults, and protecting vulnerable adults are values. The issues tied to these three might be: Can the son provide adequate care for his elderly dependent parents? Should community volunteers serve as legal guardians for an older adult? Is a moderately demented adult, living alone, able to protect herself? These are singular points of concern in which decisions are based on the unit values. On the other hand, ethical dilemmas refer to those situations in which there are conflicts among two or more values. These values may be found within an individual or between or among individuals. An example of a dilemma within the individual’s need for beneficent services and medical advices to protect oneself from potentially dangerous living environment while at the same time, yet wishing to be left alone and respecting the right to individual self determination.

If an individual’s well being, are being threatened, our professional and humanitarian instincts logically lead us to wish to intercede in order to restore persons to optimum levels of their existence. Dubler in 1987 writes, “Caregivers are trained to decide and to intervene, not to negotiate, mediate or withhold”.²¹ Quinn wrote “bedevils practitioners who work with the frail elderly. They are trained to intervene and help solve their client’s problems, and by temperament they wish to be of service. It also concerns those who give priority to the rights of all adults to be free of governmental interference.”²² Often in the cases of self neglect, wishes to remove obstacles to the wellbeing of an elderly may be directly in opposition to the individual’s wishes. This underlies the conflicting values between freedom and safety, and further reflects the dilemma between principles of autonomy, nonmalficence, beneficence and paternalism. Those basic principles of ethics and ethical dilemma it creates appear to be present at almost every turn when health care professionals are attempting to work with issues of self neglect. We hope that through our discussion in this paper, we will outline the fundamental principles of medical ethics relating to self neglect and explore the ethical dilemmas that often arise from dealing with cases of self neglect and hope to be able to offer some strategies to deal with those dilemmas.

Autonomy:

Autonomy is a term derived from the Greek *autos* (self) and *nomos* (rule, governance or law).²³ It was first used to refer to self rule or self governance in Greek city states, where citizens made there own laws rather than having them imposed. Autonomy has since been used to refer to a set of diverse notions including self governance, liberty rights, privacy, individual choices, liberty to follow one’s will, causing one’s own behavior, and being one’s own persons so long as the rights of others are not denied. Autonomy stresses respecting and promoting self determination, the right to choose freely from among the available options, and the right to carry out that choice. The autonomous person acts in accordance with a freely self chosen and informed plan that is voluntary and intentional, and not the result of coercion, duress or under influence, just as a truly independent government acts to control its territories and policies.

Therefore, autonomy holds the uppermost precedence in self governance. Autonomy involves both the “freedom to” act and acting with “freedom from” external sanctions. Any notion of moral decision making assumes that rational agents are involved in making informed and voluntary decisions. In health care decisions, our respect for the autonomy of the patient

would mean that if the patient has the capacity to act intentionally to make medical or legal decisions, if they understand the risks and consequences of those decisions, if they are free of controlling influences that would mitigate against a free and voluntary act, and if the wellbeing of others is not being violated, respect for those as autonomous person should lead us to accept a nonjudgmental stance. We should not interfere with the action they have chosen, even if that course of action, in our own judgment, may be harmful to their physical, legal, social, emotional or financial wellbeing. This principle is the basis for the practice of informed consent in the physician and patient transaction regarding health care. As a result, autonomy, literally defined as self direction, has emphasized non-interference. This position assumes that individuals have the capacity and resources to make such choices and that, in most situations, society has only minimal stake in what individual choose.

Literature of general medical ethics has focused on autonomy as applied to patient decision making per se, so called decision making autonomy. Patient decision making capacity is certainly important to healthcare professionals; healthcare professionals are often involved in preserving the opportunity and rights of patient to make autonomous choices. However, many elderly patients are often compromised in their general or day to day, functional autonomy as well as their capacity for making independent, rational decisions. As a consequence, health care professionals have a broader or more fundamental concern with what may be called long-term autonomy or autonomous living.^{24 25} When conflict arise, health care professionals often urges the promotion of the individual's long term ability to act as independently, rationally, and fully in all aspects of life as possible. The central value is on long term and comprehensive concept of autonomy, rather than the circumstances surrounding the freedom of choice exercised around a treatment decision, i.e., decisional making autonomy. As a consequence, health care professionals tend to focus on the underlying problems that interfere with long term autonomy. When there is a conflict between decision making autonomy and long term autonomy, health care professionals may be willing to compromise decision making autonomy to the minimal extend necessary to support long term autonomy. Individuals suffering from serious mental illnesses often do not have the self control, judgment, or understanding necessary to make decisions that fulfill their goals. Focusing on such disabilities and their long term consequences may lead health care professionals to propose to patients, families, legal systems to accept short term or limited intrusion upon decision making autonomy to invest in treatment resources that in the long term will restore long term autonomy and their ability to minimize disability.

Nonmaleficence:

Societal values, professional ethics, and criminal and civil legal system place strong instruction against doing harm to others, referred to as non-maleficence. *Primum non nocere* (above all do no harm). This principle, expressed in the Hippocratic Oath for physician as "first, do no harm", reverberates in the professional ethical codes of physicians, nurses and social workers.(19) The principle of nonmaleficence holds us accountable for our decisions or actions that do not impose harm. The principle of nonmaleficence applies to professionals involved in self neglect cases. The application of this concept to self neglect is, not only health care professionals are obligated not to harm patients by the suggested interventions, but also, although somewhat less obvious, the obligation of health professionals to consider indirect or secondary harms that may evolve from steps and intervention taken in helping a patient. We must think through the risk and benefits of suggested treatment and cautious of violation of right and needless harm or injury created either through acts of omission or commission without intend.

In common language, we consider it negligence if one imposes a careless or unreasonable risk of harm upon another. Providing a proper standard of care that avoids or minimizes the risk of harm is supported not only by our moral values, but also by the laws of society. In a professional model of care, one may be morally and legally culpable if the standards of due care are not met. The legal criteria for determining *negligence* are such that: the professional must have a duty to the affected party; the professional must breach that duty; the affected party must experience harm; and the harm must be caused by the breach of duty. This principle affirms the need for medical competence. It is clear that medical mistakes occur; however, this principle articulates a fundamental commitment on the part of health care professionals to protect their patients from harm. In the cases of self neglect, intervention as beneficent as it might be to some health care professions, we must consider the possibilities of inducing indirect harm produced either emotionally or physically through the acts of commission or omission. Systems designed to respond to self neglectful elderly must be sensitive to these issues and provide reasonable protections for our seniors.

Beneficence:

The value of beneficence, articulates our obligation to perform acts that will benefit others, including those positive acts taken to prevent harm being done. Concept of beneficence is derived from the utilitarian theories of Bentham and Mill, who stresses a different set of obligation. According to Childress, beneficence “requires the provision of benefits (including the prevention and removal of harm as well as promotion of welfare)... and a balancing of benefits and harms.”²⁶ The ordinary meaning of this principle is the duty of health care professionals to be of a benefit to the patient, as well as to take positive steps to prevent and to remove harm from the patient. These duties are viewed as self-evident and are widely accepted as the proper goals of medicine. These goals are applied both to individual patients, and to the good of society as a whole. For example, the good health of a particular patient is an appropriate goal of medicine, and the prevention of disease through research and the employment of vaccines is the same goal expanded to the population at large. It is sometimes held that nonmaleficence is a constant duty, that is, one ought never to harm another individual. Beneficence is often regarded as a limited duty. For example; a physician has a duty to seek the benefit of any or all of her patients, however, the physician may also choose whom to admit into his or her practice, and does not have a strict duty to benefit patients not acknowledged in the panel. Physicians and other health care professional, lawyers, social workers, and others in the personal services section traditionally have a duty to individual patients/clients. As their advocates, these professional make decision that they hope to benefit particular elders. When cost-benefit assessments suggest individual gain or benefit become unaffordable or impractical, most professionals choose the personal good. Public servants, such as Medicaid administrator, city health workers, and housing authority workers may, predictably, assign very different weights to individual cost-benefit values when thinking about overall level of beneficent to individuals.

Beneficence is often in contrast with autonomy. Beneficence emphasizes an individual’s welfare and safety, autonomy is fundamentally concerned with the freedom of the individual and liberty to make their own decisions. Autonomy argues that right to self determination, should not be compromised, even if harmful consequences for the self neglecting person are certain. Beneficence advocate those interests must be balanced, that harms and benefits must be weighed, and that the proper course of action, which is in the best interests of the individual, may not be what that person would have wished for. With autonomy, the principal focus of decision making is with the affected individual. With beneficence, outsiders such as professionals and family may voice the decision making rights.

Beneficence would require health care professionals to promote patients welfare and prevent injury or harm. Most public, social, economic, and health care programs reside within those moral and ethical values. Implicit in the concept of beneficence is the concept involving a balancing of good and harm. Will a particular intervention produce, on balance, more good than harm? Many societal interventions or actions taken on behalf of self neglecting older persons are obviously correct and morally justified: the target of real estate swindlers should be prevented from squandering their life savings; a demented widow must not be allowed to live in an unheated hovel; and the near blind retiree should not drive on crowded interstate highways. Yet, many other well meaning actions are less purely beneficent and raise a fundamental question: Whose welfare and benefits? Whose injury and at what cost? Henceforth, it sets the ground to bring the issues of paternalism.

Paternalism:

Decision made or actions taken on behalf of a recipient against his or her wishes constitute paternalism (*Parens patriae*), reflecting a sort of “father knows best” presumption of wisdom. Elderly are often subjected for paternalistic treatment of various degrees. Whether grandpa should be wearing shoes and false teeth when company comes to visit, whether grandma should be allowed to eat chocolate cake for breakfast, whether it’s time for another visit to the eye doctor, whether they should spend the evening playing bingo: these mundane decisions will often be made for the elderly by their care-givers, without much regard being paid to the old person’s own sense of what he or she wants. Paternalism becomes even more likely when the stakes become high - such as when a choice must be made between competing surgical operations, or a decision is required about the disposition of major financial holdings. For many older people, the decision whether to continue the struggle to live in one’s own home or, or to seek accommodation in an assistive living facility or nursing home placement, is the most important decision facing them at this stage in their life. The choice they ultimately make is one which reflects their most basic values and priorities. Its importance is of a different order of magnitude compared to decisions of what to wear or what to eat. That is to say, it reflects who they are as human beings.

In elderly with severe cognitive impairment whose life is being jeopardized, paternalistic interventions are justified. It would, after all, be nothing short of cruel to allow seriously

demented elderly persons to put themselves at grave risk of serious harm, especially when what they want to do now is out-of-character with their previous wishes or well-established values. To allow them to take such risks is not to respect their autonomy; it is to abandon them to their illness. On the other hand, when competent adults are denied the opportunity to participate in the decisions, small and large, that affect their lives, they tend to become dispirited and unhappy. Worse, their lives lose all significance for them, and their capacity for choice and decision withers away. The danger of over-protectiveness is that it becomes a self-fulfilling prophecy.

Frequently, well meaning and beneficent health care professional and families intercede with opinion, decisions, or actions presumed to be in the recipient's best interest even though the person in question may have other wishes. Ethicist has written extensively about the tension between autonomy and paternalism. Some, like John Stuart Mill, insist that autonomy or individual liberty must be respected in all instances except when a particular action would cause real harm to others.²⁷ If an elderly is lacking decisional making capacity, the affairs of the individual may be managed by a beneficent person or agency and this is often called weak paternalism. Weak paternalism refers to making decisions for another who is unable to decide for him/herself and is morally justified by principles of beneficence and justice. Strong paternalism refers to the making of decisions for another who is capable of decision making for him/her self. The role of health professionals frequently involves weak paternalism in some older patients with impaired in decision making capacity. However, because of widely held societal values and stereotypes, there is substantial risk of strong paternalism with older adults. Ethicist have discussed around the issues of "intrusive beneficence", where the individual may be denied autonomy in the name of her own well being as defined by others.²⁸ We must take cautions that societal aberrations may accordingly be misconstrued as mental aberrations, physical frailty may be mistaken as indicative of cognitive frailty, and periodic lapses if judgment as proof of permanent incapacity. This is directly relevant to self neglect cases, where there is a considerable debate as to the appropriate role of health professionals when a competent client refuses assistance, services, or a care plan developed in response to self neglecting behaviors. One third to one half of patients will fail to follow a physician's treatment recommendations. Labeling such patients "noncompliant" implicitly supports an attitude of paternalism, in which the physician knows best. Patients filter physician instructions through their existing belief system; they decide whether the recommended actions are possible or desirable in the context of their everyday lives.

Ethicist like John Mills advocates that "In the part that concerns only him, his independence is, of right, absolute. Over himself, over his own body and mind, the individual is sovereign" (Mills 1863). A competent individual's failure to exercise self care when the welfare of others is not at issue, however regrettable this may be to outside observers is not sufficient to justify paternalistic intervention. Persons who possess all relevant information about the possible or likely outcomes of their actions, who are able to deliberate rationally about alternatives, and who have reached a voluntary and informed decision about the course of action (or inaction) they wish to pursue based on their values and preferences should have that decision respected. This is true regardless of the severity of harm that may befall the individual.

Few philosophers favor strong paternalism that is the overriding of a competent and informed person's wishes about his or her affairs. There are many other intervention, however well intentioned and basically beneficent in nature, do threaten the independence and dignity of the older person. For example: the careless widow has her bank account taken over by her over solicitous daughter; an anxious son persuades a physician to recommend cancellation of his father's driver license; a vigorous, retired 80 yr women is told by her children that it is unsafe for her to live alone in her lake cottage. Differences in opinion regarding lifestyle and judgments made by others do not necessarily entitle family, professional, and society to develop a general policy of coercing elderly into institutional neatness. Even mentally ill patients have an increasing amount of protection from others who would act out of a blatant or subtle desire to control behavior that is considered unacceptable by some sectors of the community. Would-be benefactor, whether individual or agencies, should analyze each action and decision proposed for the welfare of a client, determine the client's wishes, values and priorities, and weigh carefully the possible impact of each effort on the recipient. Paternalistic action, if absolutely needed, must be limited in both degree of imposition and duration.

Justice:

Justice in health care is usually defined as a form of fairness, or as Aristotle stated, "Giving to each that which is his due." Justice is concerned with the fair and equitable distribution of benefits and burdens. This implies the fair distribution of goods in society and requires that we look at the role of entitlement. The question of distributive justice also seems to hinge on the fact that some goods and services are in short supply, there is not enough to go

around, thus some fair means of allocating scarce resources must be determined. It is generally held that persons who are equals should qualify for equal treatment. Society ought to help by providing resources to help overcome the disadvantaged situation, in order to reduce the inequalities. One of the most controversial issues in modern health care is the question pertaining to "who has the right to health care?" And as a society, do we want to be beneficent and fair and provide some decent minimum level of health care for all citizens, regardless of ability to pay?

In the case of self neglect, how should a society's scarce resources to be distributed when there are competing claims on those resources? And within these areas, how should limited resources to be distributed? When the fiscal pie is not large enough to provide for all worthy programs, how should the claims of programs and services for needy children be weighed against the claims of programs and services for needy elders? How much time is justified to spend on individual patient, conducting an assessment, gathering data, providing information, or doing family counseling, when compared to other patients needed to be seen, and at the same time, trying to ensure the financial stability of the practice? Even though proper distribution of resources among competing programs and services has been decided, it still remain as question which individuals or groups of individuals are eligible to the recipients of those resources. For many years, in Great Britain, government did not provide for older patients with end stage renal disease that needs hemodialysis,²⁹ yet in United States, this option is available to needed patients regardless of their age.

In self neglectful elderly, is it justice for a willful elderly to impose unfair burdens on others by requiring extensive resources to which community members have contributed? In times of fiscal constraints and limited services resources, is it proper to take into account cost-savings that may be realized from paternalistic interventions in the lives of self neglecting elders, even if those interventions may come at the expense of compromising personal autonomy? Should demented self neglecting widow be penalized by clinic physicians for his poor medical compliance? Is an older person morally obligated to protect and promote his or her own health? Should society provide the same benefits to a knowingly self neglect elder that are offered to others who work toward their own health and welfare?

These issues of distributive justice are most relevant to self neglecting elderly. Most ethicists do not consider obligation to self or to health promotion a moral principle. Self neglectful but competent older person may tax the tolerance and resources of medical, social, and other types of agencies, denial of appropriate benefits and services rarely leads to reform and may, in fact, invite disaster. Although primary role of health care professionals involve advocacy for a specific patient, both individual professionals and the organizations in which they work also have responsibilities for population of patients as well. It is not uncommon that the interests of a single patient are weighed against the interests of other patients or groups of patients. Totally just decisions of this sort may rarely be reached. The goal of the health care professionals should be to avoid inequality when assigning recipients of economic, social or medical benefits.

Confidentiality and Professional-Patient relationship:

Confidentiality is one of the core doctrines of medical practice and refers to the right of individuals to control their own information. This right is based on respect for autonomy that entails the freedom to determine how information about oneself is used. Yet physicians often face challenges to this long-standing obligation to keep all information between physician and patient private. When patients share personal information with physicians, we have a duty as a physician to respect the patient's trust and keep this information private. This requires the physician to respect the patient's privacy by restricting access of others to that information. Furthermore, creating a trusting environment by respecting patient privacy can encourage the patient to be as honest as possible during the course of the visit. The ethical codes of most health care professionals also include confidentiality provisions based both on autonomy arguments and, to some degree, self protection for the professionals themselves.

The obligation of confidentiality both prohibits the physician from disclosing information about the patient's case to other interested parties and encourages the physician to take precautions with the information to ensure that only authorized access occurs. The context of medical practice does constrain the physician's obligation to protect patient confidentiality, yet in the course of caring for patients, we will find ourselves exchanging information about our patients with other physicians. These discussions are often critical for patient care and are an integral part of the learning experience in a teaching hospital. As such, they are justifiable so long as precautions are taken to limit the ability of others to hear or see confidential information.

Confidentiality is not an absolute obligation. Situations arise where the harm in maintaining confidentiality is greater than the harm brought about by disclosing confidential information. Legal regulations exist that both protect and limit your patient's right to privacy, noting specific exceptions to that right. Federal Privacy Act of 1974 restricts access to medical

information and records. On the other, clinicians have a duty to protect identifiable individuals from any serious threat of harm if they have information that could prevent the harm. The determining factor in justifying breaking confidentiality is whether there is good reason to believe specific individuals are placed in serious danger depending on the medical information at hand. The most famous case of this sort of exception is that of homicidal ideation, when the patient shares a specific plan with a physician or psychotherapist to harm a particular individual. The court has required that traditional patient confidentiality be breached in these sorts of cases.

In many states, there are mandatory reporting laws that mandate health care professionals to report suspected cases of elder mistreatment and particularly self neglect. When a case of self neglect is suspected, there is the legal responsibility to report the case, at the same time, there are obligations to patients as well in continuing that relationship, explaining the benefits of the reporting and protect the confidentiality to the greatest extent possible. On one hand, self neglect reporting laws in many states pre-empt this duty of confidentiality in patient-health professional relationships, and professionals express justified concern that a self neglect report and the subsequent investigation will have deleterious effects on their relationships with patients. Progress has been made in improving the response system and investigative approach to self neglect and in planning appropriate interventions. Nonetheless, even the most skilled response to such a report may damage the relationship between professionals and patients.

There is considerable healing power in the physician-patient alliance. A patient who entrusts himself to a physician's care creates ethical obligations that are definite and weighty. Working together, the potential exists to pursue interventions that can significantly improve the patient's quality of life and health status. *Fiduciary* derives from the Latin word for "confidence" or "trust". The bond of trust between the patient and the physician is vital to the diagnostic and therapeutic process. It forms the basis for the physician-patient relationship. In order for the physician to make accurate diagnoses and provide optimal treatment recommendations, the patient must be able to communicate all relevant information about an illness or injury. Physicians are obliged to refrain from divulging confidential information, unless mandated by law. This duty is based on accepted codes of professional ethics which recognize the special nature of these medical relationships. If confidentiality must be breached by law, we need to find ways to reduce the negative impacts, including informing the patient that such a report is to be made, describing the process, identifying potential positive outcomes of the process and suggested interventions, working with family as a unit if possible, and recognizing the needs and concerns of all involved.

ETHICAL DILEMMA:

Autonomy vs. Beneficence:

The ethical dilemma raised often in the cases of self neglect includes the values of self determination, society's responsibility to protect its citizens, a family's responsibility to protect its members, and the principle of nonmaleficence or doing no harm. The dilemma created by conflicting or competing values poses an additional problem for professionals in resolving the dilemmas. Perhaps the most difficult and frequent ethical dilemma for health care professionals working with self neglect cases, is the effort to respect the expressed wishes of patient (autonomy) while society role to protect the patient from harm (beneficence). It is not uncommon for individuals to act in ways that place themselves at risk or are personally injurious, or to choose to remain in risky circumstances. Seniors may take a choice to remain at home before experiencing a decline in their physical or mental health. Even when such a decision had been reached, professionals often find the need to question what is best for the senior after that person suffers a severe decline in health. Respecting the autonomous wishes of such an individual may be in direct conflict with the professional's judgment of what is in the patients' best interest. This also raises the question of whether society's role changes when elderly adults experience such as a high degree of functional loss that their lives are endangered.

The broader role of society to protect all of its citizens also plays a part in the cases of self neglect. In the cases of self neglecting senior hoarding garbage and infesting rodents at home, the neighbors have a right to be protected from any health hazards created by the garbage being thrown into the yard. A conflict may exist between elder's rights and those of the neighbors that would require drawing professionals into a decision-making role. At what point does the garbage become a health hazard? When should health authorities be notified, and who should be responsible for this?

The principles of respect for autonomy of an individual would prevent the health professional from intervening with a service or action that is in opposition to the expressed wishes of a competent patient. Yet, health care professionals are required, by law in many states, to report cases of suspected elder self neglect. Moreover, there is also an obligation to determine

that the patient's refusal of assistance is an autonomous decision, free of coercion or undue duress. Disagreement with a health professional's judgment or advice is not sufficient evidence to make a determination of decisional capacity. We have moral obligations to protect incompetent elders from incapacitated decision making, but we are also obligated to determine if they are truly incapacitated before intervening against their wishes. Such a determination requires a formal evaluation of decisional capacity. If the patient is determined to be competent, even if suspected self neglect is confirmed, the competent patient has the right to refuse interventions.

Decision Making Capacity: The Core of Self Neglect

When we approach the topics of competence, we must distinguish between legal competence and clinical competence. Competence generally refers to the individual's ability to perform a task. An adult is presumed to be legally competent, and remain so, unless and until declared incompetent by a court of law. Legal competence is dichotomous concept. One either is or is not legally incompetent. An individual can be adjudicated incompetent to function in all or only one or more specific areas. Clinical competence, usually referred to as "decision making capacity", is task specific in that the issue is whether the individual is able to perform a particular act in question, whether it is making a decision about one's health care or completing a particular task of daily need. Decision making capacity is also time specific in that a person's capacity can vary over a period of time, even a few hours. A patient's changing clinical status means that the person's capacities may be correspondingly altered. Decision making capacities are not dichotomously present or absent but vary in degree.

Criteria or standard for competence, whether clinical or legal, vary among jurisdictions and with the particular issue, e.g., competence to execute an advance directive or to refuse treatment. Typically, to be competent the person must be able to understand, if not appreciate, the current situation or problem, the nature of the proposed action, including its risks and benefits, and must be able to communicate this understanding to others. The individual may also be required to make and communicate a decision that is rational based upon the available information. The President's Commission for study of ethical problems in medicine and biomedical and behavioral research 1982 determined, in concept, that competency involved possession of a set of values and goals, the ability to communicate and understand information, and the ability to reason and deliberate about one's choices.³⁰ At more practical level, it refers the test whether the person in question possessed sufficient mind or reason to enable him to understand the nature, the terms and effects of the transaction.

Decision about an individual's clinical capacity is value-laden, which is part may explain differing opinions between disciplines about an individual's decision making capacity. Furthermore, it is difficult if not impossible to opine about an individual's capacity without knowledge of that person's previously expressed attitudes, opinions, values, and decisions, and whether a currently expressed preference or decision is concordant with earlier ones, i.e., "authenticity".³¹ The point which should be emphasized here is that the spectrums of clinical competence is wide, and even someone who is confused some of the time may have moments of lucidity in which they can participate in decisions about their life. If they are no longer capable of making the big decisions on their own, they may nevertheless be quite capable of having some say in these decisions, as well as capable of making a host of smaller decisions on their own or with help. Many authors speak of a "sliding scale" of decisional making capacity based on the balance between the functional capacity of the individual and the risk/benefit ratio of the particular task or procedure that must be decided.³² Specifically, the greater the potential harm or the smaller the potential benefit of a proposed intervention, the higher the level of clinical competence required of the consenting individual. For example, a client who can make health care decisions may not be able to handle his or her financial affairs and planning; or a client who cannot make health care decisions may be able to make decisions about which visitors he or she wants to see. Individual may be considered competent to refuse a low risk intervention, such as home delivered meals, but may not be considered to have decision making capacity to understand a risk and benefits of interventions, such as cardiac bypass surgery. Capacity for decision making is often situational, and shouldn't be viewed as an "on or off" switch or "all or nothing" concept.

Beyond the extreme cases of uncontested competence or uncontested incompetence lie numerous situations where the decision making capacity of individual is variable or questionable. A person may be clinically competent in some domains but not in others. Decisional making capacity may be intermittent and fluctuate over time. Depending upon applicable state law, individuals may be adjudicated incompetent based upon a variety of conditions, all of which are relevant to the setting of self neglect. These conditions include mental disorders, mental retardation, physical handicap and medical disorder. The presence of such conditions, of course, is not sufficient to be adjudicated incompetent. Most psychiatric patients,

whether symptomatic or not, are capable of making and communicating appropriate decisions regarding their welfare. Thus, the most difficult cases of self neglect involve older person with inconstant evidence of impaired or diminished competence or “borderline” individuals who suffer from emotional illness, who have sustained brain damage such as Alzheimer’s disease or stroke, or who manifest bizarre or eccentric behavior. As health care professional, we have to ask: is this particular person capable at this particular time of making this particular decision? In these cases, health care professionals should try to look for potentially reversible causes of reduced decision making capacity: failing or changing mental status should be assessed; medical conditions that affect thinking and behavior should be investigated; quality of intellectual capability and health literacy need to be examined; and obvious social or economic stresses that could affect perception and behavior should be noted and, if possible, corrected before outside standards are imposed on the self neglecting person. Treatment of crippling depression often transforms the elderly patient; provision of transportation may liberate an elderly recluse; and visits by senior companion have energized many old shut-ins.

The question of self neglecting elderly decision making capacity determination may in itself create such as dilemma. The circumstances of this case may require a definitive answer to the questions of one’s decision making capacity and may subject her to the stress of a court hearing. If a hearing were held, the dilemma would still not be resolved. If one were found to be clinically competent, the question might be raised of how much monitoring by agencies, friends, and family would be needed and appropriate. If one were to be found incompetent, a dilemma might still exist in deciding how much decision making power one should retain especially if one does have some ability to make choices and state preferences. The search continues for some universal criteria for competency, but the wide diversity of medical conditions, competing factors and related decisions makes success quite unlikely. Legal and clinical definition may differ; assessment can be imprecise; and competency varies across functional domains and fluctuates over time. One must be careful not to view clinical competency (or decision making capacity) as a categorical, either-or construct.

When Harm Present to Others:

The situation is more complicated when actions of the self neglectful elder have consequences for others. Of course, one can conceive of circumstances in which all of those directly involved are competent, do not wish to infringe on the elder’s right to self determination, and are willing to endure any harms that may befall them. So long as others are uninvolved, or so long as they are competent and willing to put themselves at risk as a consequence of the self neglecting behavior, we have little basis for infringements on the rights to self determination. It is just as clear and morally permissible, to intervene when the elder’s self neglect is the product of incompetence or decisional incapacity. When older person are grossly or obviously incompetent, relative few ethical or legal problems interfere with preventing and correcting self neglecting behavior with beneficent and paternalistic interventions. However, when the others who are implicated are unaware of the consequences, unwilling to suffer them, or when the other person’s competence is somehow compromised, there may be reason to intervene. If an individual with a stroke and functionally very limited, is being cared for by someone who is self neglectful, and consequences of the caregiver behaviors have direct effect on the wellbeing and safety of the patient with stroke. Harm may be present in those cases, and we are left to deal with the dilemma of respecting self neglecting senior’s preferences balancing with the need of the care recipient or other affected. Here, the dilemma may be the frail stroke victims right to adequate care versus self neglector’s right to be a caregiver. When self neglector’s care for frail elderly becomes inadequate, even though this decline in care is unintentional, should frail elderly be provided with a different caregiver? The issue of nonmaleficence to the stroke patient and respecting autonomy of the caregiver are raised here. More harm may be done by professionals interfering with this relationship and taking away from self neglecter a role that she believes is hers. On the other hand, serious harm may result if there is no intervention.

Whenever the caregiver and care recipient are present and potential self neglecting behaviors are suspected. The clinical competence of the individual in question would be evaluated based on his/her capacities and on recipient’s needs. If a recipient simply needs antihypertensive medications and if a visiting nurse can elicit caregiver’s cooperation in setting up a medication box that would insure this outcome, then such senior can continue to function as the caregiver, although, in fact, he/she is now sharing these responsibilities with the visiting nurse. On the other hand, if caregiver cannot meet recipient’s elementary hygiene, environmental, medical or safety needs, he/she will not be able to continue in this role at all. Thus, evaluating caregiver’s clinical competence entails determining recipient’s needs, the risks if these are not being met, and the probabilities that such caregiver can meet some or all of these needs. This information is then evaluated in light of caregiver and recipient’s values and the

availability of the necessary resources within the household, the family, or the community. This approach provides a useful way of answering the question, "Should the particular senior in question be permitted to remain recipient's caregiver?" Rather than answer the question in purely ethical terms or in all-or-none fashion, we would analyze the many aspects of the problem in practical and specific terms, guiding ourselves by the knowledge of the recipient's values.

In the cases where self neglecting elderly environment directly impact the neighbor's welfare and safety, different set of ethical and legal dilemma arise. If a demented elderly lives in a dangerous environment and that is directly impacting the neighbor and community, paternalistic actions certainly may be justified to protect everyone involved. In the cases of a competent and sound minded individual who wishes to live in squalor, and home infected with animals or rodents, and the harms are presents either to the neighbor or to the community directly, when do we begin to question the limits of autonomy? How do we balance the right of the self neglecting senior's self determination and self rule, vs. the safety of the neighbor and community justice? Not only does this bring ethical dilemmas, but also legal and civil issues as well.

Culture Issues in Self Neglect:

Self neglect in elderly is multifaceted and culture norms and values are also important aspect of understanding. In US, it is projected that by the year 2030, 11% of our population will be Hispanic origin, 9% will be black, 5% will be Asian and Pacific Islander, and 74% will be white.³³ Self care hygiene and living with plants and animals often are essential part of certain culture, and unless we understand their values and culture, it is easy to be misjudging other's way of living. In India, co-existing with certain rodents is of culture norm and many temples and houses are crowed with them. In certain Arabic culture, bathing and personal hygiene standard and what is considered accepted, may not be considered as sanitary in America. It is crucial we do not ask other to conform to our societal norms and initiate intervention based on incomplete or lack of understanding. The misunderstanding often leads to the dilemma of understanding and respecting values and our perception of beneficence and paternalistic actions that might follow. We should respectfully try to gain deeper understanding through discussion and continued learning and should understand and respect the individual wishes, as long as other's rights are not violated.

In many cultures, particularly Asian society, issues of decision making autonomy are complex. Individual decisional making are often replace with familial decision making. Frequently, it is the family that decides what is best for the elderly individual. The role of first son in Asian families plays much more of a different role compared to that of western families. That individual habitually assumes the parental role when elderly parents become progressively frail regardless of their decisional making capacity. When health care professionals encounter those cases in clinical setting, and discussion relating to treatment options and medical advices, are often complex and other members of the family assumes a role that we are not often used to. What are perceived as exploitative and inappropriate may indeed be the culture norms of their society, and we must not readily pass judgment without understanding issues at hand.

Research Issues: (not sure should be part of this paper)

Conducting research on self neglect poses a multitude of challenges. Besides presenting methodological and practical difficulties, studying self neglect of older people raises formidable ethical and policy problems. Two general features of the research account for these problems. First, the study population includes older persons with various mental, physical, and social vulnerabilities. Second, research involves collecting information that could have negative legal, financial, and social consequences for older persons being studies. The ethical analysis is further complicated by an absence of regulatory and ethical consensus regarding the appropriate procedures to govern research involving persons who lack the ability to decide about research participation.

The Belmont Report, a document that identifies ethical principles and guidelines for research involving human participations, articulates three ethical principles that apply to such research. These principles are: respect for persons, beneficence, and justice. The principle of respect for person underlies the requirement for informed consent to study population. The principle of beneficence underlies the requirement to evaluate and balance risks and expected benefits in human studies. The principles of justice address fairness in selection research participants. Provisions in the Common Rule, also known as the Federal Policy for the Protection of Human Subjects, incorporate these Belmont Report principles and requirements.

Institutional review boards rely heavily on the Belmont Report and Common Rule when they evaluate research proposals. Choices to participation in research on elder self neglect should be capable, informed and voluntary. When someone is unable to make valid decisions to participate, researchers should obtain the capable, informed, and voluntary permission of a

relative or other individual concerned with protecting the incapable person's wellbeing. If such person is not available, we should utilize the task specific measure to determine the decision making capacity of the individual for this specific task at hand and whether the individual is indeed capable to understanding the details of research participation, and risk and benefits involved. Departures from these rules require compelling justification, including a showing that research intervention will not expose participants to significant risks.

Members of the relevant communities may be of help to investigators to determine the facts that should be disclosed to prospective research participants and create effective methods for conveying the information. They could help researcher discern the appropriate balance between protecting participants' privacy and preventing harm to vulnerable older persons. They could join researchers and social services workers in developing appropriate responses to suspected self neglected senior in the course of the study. Awareness of the basic ethical considerations combined with insights from the community of research participants, will supply the most solid moral foundation for research on self neglect. A research program built on this foundation is most likely to receive continued public support, as well. The need for increased knowledge about this senior problem is great, but so is the need to respect and protect the individuals, families, and communities affected by research.

PROPOSED STRATEGIES:

Further Understanding of Values:

Issues surrounding self neglect in elderly often present in complex settings. When the cases of self neglect are in its extremes, proper courses of action are often clearest. Yet, most cases of self neglect are often multifaceted and there are difficult questions raised to all involving parties. Such complex circumstances for ethical analysis demands the widest possible vision and the systematic exploration of possibilities that surpass the simple dichotomy between autonomy and beneficence. Whiles both ethical principles are often used as anchors for open discussion regarding morally troublesome situations, they often cannot take us far enough. An individual may make an autonomous choice to reject certain actions or treatments that is deemed beneficial by involved parties. Decisions made by the individual may seriously trouble social workers, physicians, family members, or others. Yet, the moral responsibilities of the practitioner rarely end at the point when the client says "no". Honoring autonomy does not preclude further understanding of the values underlying individual's choice or helping to clarify patient's anxiety and awareness of what is at stake. Respect for autonomy does not denote that involved parties detach themselves from an elder's autonomous decision making process. Understanding values, persuasion and continued conversation are also ethically valid choices.

In the cases of competent self neglecting elderly, we are not to suggest that health care professionals, family and caregivers should discard all concern for the self neglecting elder's wellbeing, when autonomous decision has been made. There are certainly many cases in health care setting where a patient's initial preference to have treatment withheld or discontinued was ultimately reversed by the patients themselves. It should not be considered unethical nor presents as unnecessary intrusion to continuing to monitor the individual's wellbeing, providing relevant information and being alert to any signs of a change in decisions made. Furthermore, informed consent, autonomy and capacity determination become part of an ongoing, open ended dialogue that involves all relevant participants and agencies. Fundamental point of this endeavor is to keep the dialogue going in order to create continued follow up and to mediate conversations that continues. This approach is essentially dialogic, where different individuals from different agencies have vested interests in the outcome. What an individual might want is indispensable but it may not always be the only influential aspect in attempting to resolve the ethical dilemmas.

Multidisciplinary Team:

An essential component for working through ethical dilemma is the involvement of a multidisciplinary team that involves patients, family, and other key professionals and agencies involved. They may be medical physicians, mental health experts, nurses, legal agencies, social services, adult protective services, ethicist, ombudsman, community members, clergy and law enforcement agencies. While each team member might begin with the values or ethical norms of their discipline, that is only the beginning. When several professionals are helping one's client or clients, their ethical standards may not be uniform. Each of these public agents arrives with the backdrop of his/her respective ethics protocols. These protocols range from rules established by the federal, state, and local government to the governing bodies of the various professions, to agency or workplace politics, to specific profession's codes of ethics for their practitioners. This does not mean that the professionals involved must compromise their own social distance or objectivity. To move beyond specific disciplinary approaches, it is critical that each discipline educate each other about their own perspectives. In this way, the risk of misunderstandings is

reduced. To develop a unified plan, it is often useful for the team to have a mediator who does not necessarily assume a value-neutral position but rather ensure that different points of view are represented in the dialogue, that critical questions are considered, and that different approaches are explored.

However, while professionals are engaged in ethical discussions, we must try to have clearer understanding of the client's ethical values. For example, it may be important to know that the client is an Asian, never-married, Buddhist, disable female or one's clients are homosexual male couple, one of whom is a Christian Scientist and other is a Catholic, and both of whom are on welfare. Each of these pieces of information carries with it its own ethical history. As professionals, there are principles of decision making we can utilize to support client choices. These include informed consent, best interest, and substituted judgment, the use of which depends upon a client's decision making capacity. This information might include advanced directives; social or values history documents or other records; past conversations with family, friends, and professionals; and accounts of previous lifestyle.

For a team to function well, the members must meet regularly and come to know and trust one another. Until that is done, it may be impossible to overcome problems caused by differing professional identities, hierarchy, status, and unequal power relationships. The dominance of one professional group or another can hinder open communication and frequently silence the voice of the patient or client. Communication surrounding ethical discussions requires free and open communication unhindered by power relationships. Moreover, the narrative approach to ethics requires time to hear stories unfold, to examine options informed by those stories, to test possibilities, and to revisit the problem, more than once if necessary. Outcomes based on multidisciplinary professional decision-making using information, deliberation, and negotiations are the best protection against exploitation. It is critical that everyone on the multidisciplinary team have equal voice and authority in the decision making process.

Self Examination of Ethical Values:

In actuality, multidisciplinary team and ethical discussion are not always available due to limited resources. Often ethical dilemma presents to the individual professional, and decisions has to be made without luxury of time. Before deciding which interventions to take and in what form, we must examine our own ethical values, understand our own views of family responsibility and attitude toward aging and frailty, examine our own culture differences with the patients, and how all of these factors can influence care, desired intervention and management. More specifically, we should ask ourselves: what kind of person and professional do I want to be?; what are my major and guiding moral principles?; Am I able to distinguish between my personal values and those of the patient?; What is good for the older person?; and Is the help given what older person really wants and will it truly benefits him/her and improve the quality of life? Along with the clarifications of our personal values, honest answers to those questions will help professionals make the most ethical decisions for the good of the elderly persons while respecting their freedom and dignity.

It is important that when professionals are deciding on issues of decision making capacity, we should not confuse the questions of that capacity with nature of decision made by patient, however grave the consequences. The view of patient may reflect differences in value rather than an absence of decision making capacity and the assessment of decision making capacity should be appreciated with this firmly in mind. Professionals must not allow their emotional reaction to (or strong disagreement with) the decision of the patient to cloud our judgment in answering the primary questions whether the patient has the decision making capacity to make that particular decisions in question. Acknowledging what is happening to the patient, promoting autonomy, being sensitive to culture believes, understanding our own ethical values, and utilizing least restrictive alternative is the most effective ethical practice to care for a self neglectful elderly.

Comprehensive geriatric assessment:

Another critical aspect of assessing self neglecting elder is the role of comprehensive geriatric assessment. This assessment requires examination of the biological, psychological, social, and environmental structures of the person's life and functioning. The comprehensive assessment integrates all of these domains of information into a diagnostic evaluation of the patient's symptoms. A treatment plan is then developed based on the clinical diagnosis and the psychosocial context of the patient's current life. Personal and culture values, family and community resources, legal precedents and restrictions, and a host of other variables are considered as part of this process. A self neglectful, mentally ill elderly living in a trailer might be placed involuntarily in a long term care facility on the grounds of incompetence and endangerment. However, from health care professional's view, this would be premature and potentially inappropriate. If this person's mental illness is due to hypothyroidism or

schizophrenia, diagnosing and treating these conditions would offer a reasonable possibility that the patient could continue to live in their existing environment. Such treatment might even be accomplished without hospitalization. Obtaining appropriate clinical assessments of patients; understanding senior's resistance, using clinical and interpersonal strategies and organizing community and legal resources are potential ways to safeguard them. The comprehensive geriatric assessment is based on the knowledge that the cognitive status of patients may be caused or aggravated by medical, neurological, or psychiatric disorders that are often treatable. Progressive dementia in this setting is most often due to irreversible neurological disease, especially Alzheimer's disease and vascular dementia. But there are many causes of dementia that are themselves reversible. Examples include, but not limited to, hypothyroidism, vitamin B12 deficiency, normal pressure hydrocephalus, and subdural hematoma. Furthermore, even if an irreversible dementia is a correct diagnosis, it may be complicated by delirium, depression, psychosis, irritability, apathy, or other behavior abnormalities that constitute important reversible factors. Evaluating these possibilities requires competent, comprehensive medical evaluations. Arranging for such an evaluation is required to meet the standard of care of health care professionals.

Health care professionals would focus on the possibility that patient may be suffering from an unrecognized serious mental illness, including depression. Disease affecting frontal lobe function or other so called executive function can be detected by simple clinical assessment.³⁴ However, they may go undetected by what are now conventional screening devices, such as mini mental state examination. The symptoms of executive dysfunction or frontal lobe disease include many features that are important in the cases of self neglect: passivity, withdrawal, lack of initiative, lack of reactivity, perseveration, inability to make use of new information, environmental dependency, lack of drive, impairment of insight, impulsivity, and poor judgment. The issue of poor judgment is of particular relevance to the cases of self neglect. Elders may rationalize their existing living conditions by citing their parental obligations or religious beliefs, but this does not explain their poor judgment. Therefore, patient's judgment requires careful evaluation. From a clinical standpoint, the presence of depression and other mental illness are examples of useful clinical assessment in understanding the underlying symptoms.

Offering an older adult treatment options is of obvious value in resolving dilemmas between the principle of autonomy and beneficence or between long term autonomy and decision making autonomy. A reversible factor in one's dementia or in other health condition might lead to improvement in self care behavior or judgment. This would decrease the risk of continued in home living, provide an opportunity for strengthening relationships between the elderly and the service providers, and offer the possibility of a change in judgment that would eventually lead to self neglecting elderly to accept alternative living arrangements when clinically warranted. Educating patients about such options provides a useful means of approaching their reluctance to collaborate with health care professionals. The educational and psychological approach, coupled with effective communication and alliance building, may suffice to persuade an older adult at risk for self neglect to accept a treatment or safeguard that would otherwise be rejected because it was perceived as an infringement on autonomy. In the cases of self neglect, there may be diagnosable conditions whose treatment may lead to very much of a different determinations of the right thing to do.

Familial Obligations:

Determination the rights and obligation of existing family members also cause ambiguities and limitations. Although some would argue that adult children have an obligation to provide care for the frail and disabled parents, this is may be controversial. In the United States, many families agree that children have a responsibility for the care of their elderly and disabled parents. This is because of the fact that many homebound elderly are indeed cared for by their children. However, the individuals who agree in principle that children bear such a responsibility also may claim that such responsibility should not require them to use or sacrifice their own resources for this purpose. In the America, when parent's own resources have been exhausted, the government becomes the preferred sources of financial and residential support. However, his is a culture specific value system. In the People's Republic of China, children are expected to offer their financial support, resources and their homes to their aging parents in need. Family supposes to unite as a whole, and become the individual unit of the society. It is considered shameful if an elderly ill parent is not careful properly, regardless of the financial resources of the family members.

Adult children in our contemporary society are not required to provide care or services for their aging relatives, unless there is a specific legal relationship such as trustee, guardian, or other fiduciary arrangement. If families do not live with the self neglecting elderly in question,

and care of the elderly is not met, there is no legal role to force the family to visit frequently and to provide financial support. Sometimes, family's insight to a senior's needs is poor and may not be willing and able to be more involved in providing for a senior's needs. In the case of self neglecting elderly with peripheral family, we can not obligate the family member, the church, or the community to step in. We can, however, appeal to deeply held American values of responsibility and morality for members of one's own community. Reciprocity is a critical value that is often ignored when faced with an elder who is severely frail, and is in need of increased contributory responsibilities from everyone involved.

Health care professional's task is to understand and appraise the values of the children, determine whether they are consistent with the client's values and, if so, facilitate the children's finding ways to take action that express their own beneficent obligations toward their parents. Given the range of individual values and circumstances involved in such situation, a health care professional attempting to insist that a child accept a beneficent role to parent would be ethically problematic and likely counterproductive. To the extent that value conflicts exist among the children's, the clients, and the professional's ethics, these differences need to be made explicit and negotiated. It can easily lead to caregiver stress and place the client in a non optimized and potential harmful situation. When mutually agreeable values and goals are present, we should develop a plan to identify and overcome hindrances toward these goals. This may mean that the health care professional will work with the children to help obtain or identify the information, resources, support, advice, or treatment that will make it possible for them to meet their responsibilities more fully toward the frail elderly.

Legal Issues:

In the cases of self neglect to its extreme degree and elderly in question has care giving responsibility to others, faces the possibility of two different types of criminal conduct: creation of public nuisance and caregiver neglect. If self neglecting senior has assumed the role of caregiver and is unwilling to relinquish that responsibility when the recipient's health is being jeopardized, this may constitute caregiver neglect. While there is a key issue of self neglecter's intent, that is, whether he/she actually intends to neglect care recipient, until that issue is fully resolved, intervention by the criminal justice is unlikely. If self neglecter is unable to provide care because of his/her own physical or mental infirmity, she cannot be guilty of criminal neglect as she lacks the requisite intent. Often there are cases of self neglecting seniors with some levels of cognitive dysfunction; independent of their daily living activities to some degree, but the responsibilities to care recipient exceeds what can be handled. If keeping that relationship ongoing is patient's wishes, we need to identify the specific needs of the care recipient, and to examine whether that can be met by the self neglecting elderly. If not, we should then ask the questions: Can those needs be met by informal services such as meals on wheels, visiting nurses, home health aids or other caregivers? And could those supportive services be enough to ensure the safety of the elderly in order to keep them at home?

The other potential criminal conduct is creation of a public nuisance, that is, a situation which is injurious to the public health and welfare. If a self neglecting senior is hoarding garbage and house infested with animals and is failing to maintain his/her property. Garbage will likely attract animals, rodents, and vermin and will release unpleasant odors if sufficient amounts collected, it will certainly constitute a public nuisance. Nuisances are matters that are sometimes brought to the attention of the criminal system. This example brings the dilemma of autonomy of the individual and the justice to the neighbor and community at large. When the self determination of the elderly intrudes upon the welfare of others, we are often depended on legal system to resolve those issues. The degree of intrusion and the perception of levels of injustice is also worthy of discussion. If the neighbor or the community is unhappy with the self neglecting senior, because of elderly in question is isolated, eccentric, poor, and have mental disorder, does that give the community or the neighbor the right to question the individual autonomy. The allegation of public nuisance could be used as a means to generate community control. As professional, we must independently assess the degree of harm that is generated to others, and whether that constitute the potential criminal conduct, and is there enough evidence to consciously violate the right to self determination of the self neglecting elderly, in order to ensure the safety of the neighbor and the community.

Continuum of Available Interventions:

Resources constraints and the allocation of existing resources often limit the options that may be available to meet self neglectful senior's needs. The continuum of available intervention may range from the most intrusive and restrictive, representing the violation of civil rights and liberties to the least intrusive and restrictive, representing minimal or limited threats to self determination. Family and community involvement also can be very viable options for patients whenever available. In many communities, the choices are narrowed to two: remain at home or

enter a nursing home, either of which might harm the patient. Frequently little practical assistance may be available to informal caregiver and family members who assumes primary responsibility for care giving. Even some steady relief for the care may be helpful to mitigate the dangers of self neglect. Adult day health, geriatric day hospitals, or Alzheimer's programs are still unavailable in many communities. Intervention like representative payees or limited guardianships may not be available.

Utilizing informal services such as home health aid and visiting nurses to provide care to isolated elderly not only supplements one's care, but also provides an opportunity to observe improvements or deterioration in health and function. There is particular useful for elders whose cognitive function has begun to decline and for whom decisional capacity is fluctuating or deteriorating. At each junction, it is important for the health care team to meet and discuss with the patient and family members at regular intervals to determine whether or not the goals of the care plan are being met, are in concordance with client goals, and are ensuring the safety of the elder. The home health nurse can make a positive difference in stabilizing one's health and give constant feedback to physicians. However, in the absence of regular professional visits, it is likely that circumstances will revert to the previous dangerous situation. An important role for health care professionals is facilitating communication among family members, clarifying preferences and wishes, testing the feasibility of family plans of action, and suggesting viable and desirable alternatives.

Adult protective services represent another intervention mechanism, one which has the potential of being less intrusive than either the guardianship or the conservatorship. Adult protective service programs can provide the coordinated delivery of services to adults at risk, and the actual or potential authority to provide substitute decision making. Although adult protective services statutes vary widely from state to state, the broad scope and flexibility, which are typical of the statutes, do have the advantage of allowing minimally intrusive intervention to be designed. Yet grave responsibilities are at hand in making decisions involved substituted decision making for the client. If substituted decisions were to be made by the adult protective services provider, What were the circumstances under which it was determined that self neglecter was not going to accept care or help from anyone? Was the question asked on her doorstep in the last 10 minutes of a hurried evaluation? Or were these questions raised after a lengthy and perhaps extended evaluation-one lasting perhaps an hour or two, or extended over a period of two or three meetings? Were attempts made to involve available family member in getting elderly to accept evaluation and treatment? It is also important to consider that elderly may misunderstand the rationale he/she has been given for the recommended intervention. If not, it may help to reframe the rationale so that the link is clearly made to the way elderly understand her problems. Patients with Alzheimer's disease frequently deny the severity of their problems and many still resist intervention to help them with their memory problems. However, given a trusting relationship, it is common for them to accept assistance for some other purpose. Anxiety, fear, loneliness, depression, financial instability or functional immobility, are just some of the issues elderly face, and can be used to develop an alliance, and seek out appropriate professional care.

Adult day health, geriatric day hospital, respite care programs are other services that may be available and used by self neglecting seniors. These options can often resolve the issues of safety and ethical dilemmas raised, and allow the elderly to continue to stay in their home environment. Unfortunately, these services are not readily available in all communities, particularly those socially and economically disadvantaged neighborhoods. Even if those services are present, often isolated and mistrusting senior may be reluctant to be surrounded by strangers and expose their vulnerability. Frequently, for involving family who is trying to do their best, yet does not have the financial resources to provide for the 24 hours care, providing services during the day will allow some burdens to be shared, their own life to go on to some degree, provide for the need of their own children and families and at the same time allowing their parents to stay at home.

Involuntary commitment to nursing homes or hospitalization can be used to institutionalize mentally and cognitively disabled elderly who represent a threat either to others or to themselves. When crisis develops in a senior's life, committing them temporarily to the hospital, may give opportunity to allow health care professionals to comprehensively assess the patient and to look for reversible causes of incapacity and to further assess person in question's decisional making capacity. Consider the problems that patients in nursing home experience, it should be noted that society's unwillingness to expend additional public dollars sharply reduces the availability to improve nursing homes. Unfortunately, nursing homes have earned a reputation that frightens many older people. They are rarely entered as the result of a positive choice even when care and conditions are exceptional. Nursing home regulations often limit

options. While designed to protect the patient, regulations can hamper a patient's ability to live according to their prior wishes.

Less restrictive in terms of institutionalization, but equally consequential for civil liberties, is the use of guardianship and conservatorship. Both require a judicial determination of incompetence and both involve the appointment of someone to make decisions on behalf of the incapacitated senior. Conservatorship usually means the appointment of someone with power over the property of individual, and guardianship means the appointment of someone with power over the property and person of another. Another form of intervention is the use of power of attorney. The power of attorney represents a chosen designation of decision making authority to another person, and it may be used as broad or limited as the person delegating authority wishes. The power of attorney can specify that either that it is effective even if the individual still has capacity or that it goes into effect when the person becomes incapacitated.

These available services represent a continuum of interventions, ranging from the least restrictive to the most intrusive. It can infringe upon autonomous decision making in various degrees. Many of the intervention require legal court deliberation and determination. Yet whenever available, there exist other types of formal and informal intervention. Friends, families, and neighbors can provide informal assistance to the self neglecting seniors, and coexisting is wide range of formal community services. Both of which can be utilized when determination has been made that beneficent intervention is needed. If intervention is undoubted warranted, we must take into consideration of the self neglecting senior's condition, circumstances and believes. Professionals should request intervention that is minimally intrusive to a person's autonomy, at the same time maximizing the desired protective outcome. Beneficence, when morally justified or required, may take many forms. To the extent possible, paternalistic interventions should be chosen so as to minimize intrusions and retain maximum autonomy, given the circumstances of a particular self neglecting senior. It is our professional duty and moral obligation to strive toward that balance.

Preventive Ethics:

While many communities have well functioning teams, frequently it is no the case. Social and medical services are often compartmentalized, and limited involvement of in the form of home visits prevents the possibilities for dealing with ethical issues in a preventive manner. Home visits by a team of medical, social work, and nursing professionals can uncover problems long before they become unmanageable. Yet few geriatric or primary care teams conduct regular home visits. It is often not financial viable, and require extensive use of personnel, and sometimes do not have an immediate outcome. However, for those who make home visits, insights into the family, how they live their lives, who they interact with their environment, and what is important to them can yield long-term benefits if difficulties arise. At a minimum, home visits may reveal the many ways in which how people choose to live their lives over time, perhaps progressively adapting to disabilities in ways that meet their needs but may seem foreign to the outsiders. Observations over time provide information about sudden changes and dangers, as individual become more frail and disabled.

To the extent possible, professionals involved in working with self neglect might benefit from regular exchanges with one another. Team members might also join with professionals who work in the related areas to establish a community based ethics committee. Functioning like a hospital ethics committee, this kind of structure would bring together people from different human services settings to learn from each another. In this way, team members can expand their experiences with ethical dilemma and potential solutions through education and exchange of ideas about cases either retrospectively or prospectively. The goal in establishing a consortium or a community based ethics committee is to bring in new conversation in an environment where limits of the possible can be tested and ideas floated in a non-emergency and non judgmental atmosphere. The dialogues are not necessarily a series of dichotomous choices amongst principles such as autonomy and beneficence or paternalism and justice, but it is rather an engaged conversation among equal partners seeking to establish a more common ground.

SUMMARY:

With aging population growing sharply, the epidemics of self neglect in the elderly are looming. There is a large gap in the medical literatures in the areas of self neglect, yet the practical work must continue in dealing with the issues of self neglect in the geriatric population. The purpose of this paper is to gain understanding of the major ethical principles and issues relating to self neglect – autonomy, nonmalficience, beneficence, paternalism, justice and patient physician relationship. More importantly, we hope to have illustrated the ethical dilemma the basic principles can create and how does one principle interact with another. The core of the many ethical dilemmas resides in the issues of decision making capacity of the self neglectful

elderly. But other dilemmas such as familial obligation, culture values and norms and legal implications are central to the discussion as well. While the goal is not to readily allow professionals to gain easy answer in every case, it should serve a tool to engage in conversations and considerations. Competent self neglectful elderly, whose action and behavior has no effect on others, deserves to have his or her autonomous wishes and preferences respected. Just as clearly, intervention is the proper course of action when dealing with an impaired, incompetent elder whose self neglect puts others at risk.

However, most cases of self neglectful senior's circumstances are not at its extremes, and the information has to be used under non-optimal circumstances, and risk of harm and benefit cannot be determined precisely. Professionals face a spectrum of ethical concerns of values and dilemmas in addressing cases of self neglect. Optimal patient care requires that the individual practitioner develop a systematic approach to pay careful attention to relevant values and ethical concepts, to balance expected benefits with potential harms, to maintain current knowledge of relevant reporting laws and regulations, and to access those services. While there are many forms of intervention when needed, we must understand the client's value differences, frame complex issues in such a way that will promote productive disclosure amongst team members, and facilitate the discussion process in hoping to reach consensus about suitable mode of action or inaction amongst everyone involved. We need to resist the impulse to accept stereotypic and simplistic solutions to complex and multifaceted problems if we were to make an impact on the issues of self neglect.

No one person or profession should be solely responsible for the management of elder self neglect. Therefore, a multidisciplinary team from the medical, social services, protective services, mental health, law enforcement and legal professions should be utilized whenever possible to work together to achieve a clearly specified set of goals. These goals may include coordination, diagnosis or identification, prevention, treatment, consultation, and education. Elder self neglect as a public health issue is still in its early years and continues to evolve. Beyond providing clinical expertise, health care professionals can play an important role in encouraging and participating in research relating to self neglect. The amount of rigorous scientific investigation about self neglect in the elderly has been minimal. Systematic prospective research is needed in most of areas related to self neglect. Training and education need to be grounded in rigorous research based knowledge about risk factors. There is still desperate need for outcomes research and effectively screening methods in order to instill management protocols and most effective techniques in working with cases of self neglect.

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