

SURVEY PROCESS

Available data suggests little interaction between the long-term care industry and the criminal justice system. Surveys of long-term care workforce suggest substantial rates of witnessed abuse as well as staff acknowledgement of abusive behaviors. Nursing home complaint data indicates that one-third of nursing homes in the U.S. had at least one reported complaint of abuse and neglect registered against the facility. Available data cannot define the number of such reports that resulted in criminal prosecution or investigation.

The role of the criminal justice system in assessing potential abuse and neglect is undefined and the interactions between these two systems are unknown. Several T-groups are involved at the interface between long-term care systems and the criminal justice system. Nursing home surveyors and survey agencies handle complaints and incident reports generated by the local facility. Local state-level surveyors must investigate incidents and assess the need for involvement by the criminal justice system. Nursing professionals play an important role in reporting these incidents.

Dying patients present a unique challenge to the regulatory and criminal justice system. Weight loss, dehydration, and aggressive prescription of psychotropic medications are part of any standard hospice practice; however, these same conditions can also represent abuse or neglect. Little data is available on professional attitudes toward potential abuse and neglect and the end of life or in the hospice setting. New precedence setting prosecution of professionals for under-treatment of dying patients or assisted suicide complicates the medical legal aspects of end of life care.

This survey samples specific groups of individuals in the long-term care industry over the last two years in Alabama and at the national level. The survey samples national leadership of long-term care regulatory agencies, long-term care survey professionals in a state agency, nursing home professionals and hospice workers. These anonymous surveys were conducted during educational programs where anonymity was assured to maximize compliance. A questionnaire about a potential abuse or neglect produces understandable anxiety in any long-term care professional.

Two separate survey instruments were used to sample opinions about long-term care and about end of life care. Some professionals completed both

surveys where they had experience in long-term care and end of life management.

The survey attempted to assess several key domains of information. The one-page document was designed to assess the extent of the problem and interventions that the professional groups would support to enhance the quality of investigation by law enforcement. The measurement for scope of problems was divided into three broad categories: first, opinions about the frequency of abuse or neglect occurring in specific locations; second, the frequency of notification by providers of appropriate law enforcement agencies; and third, the likelihood that law enforcement agencies would investigate potential criminal abuse or neglect. The second blocks of information covered educational or technical assistance that might assist law enforcement for investigation of these incidents as well as mechanisms to enhance communication between providers and investigators.

Surveys were distributed during educational programs conducted by the investigators. Specific identifying data was not included on the survey document. Participants were advised about the goals of the survey and potential use for the information.

Data was collected at a national meeting for the heads of state survey agencies, three nursing home educational programs for long-term care workers in Alabama, an educational program focusing on Alabama state surveyors, and two educational programs focused on end of life care for dementia patients. All questionnaires were hand-tabulated by the investigator to prevent misidentification of data.

A second, simplified questionnaire was constructed for healthcare professionals who provide end of life care for hospice services. The hospice survey queried providers about the frequency of suspected abuse or neglect, the inappropriate use of medications to hasten death, and concerns among healthcare professionals about allegations of euthanasia. Hospice care carries a double risk and the dying patient presents a specific challenge for the identification of abuse and neglect. Frail, dying patients are at risk for bruising, fractures, and other injury. Proper hospice care allows for dehydration and malnutrition during the dying process when hydration and nourishment would enhance or prolong suffering. Dying patients with severe pain are encouraged to use large amounts of narcotics to suppress suffering.

Physicians can assume civil or criminal liability when managing dying patients. Patients who receive excessive, i.e., lethal amounts of narcotics or suppressants, may be accused of euthanasia. Physicians who order inappropriate starvation or dehydration may assume criminal liability. These clinical and legal boundaries are poorly defined and highly subjective.

Continuation on the long-term care survey process

Multiple questions were incorporated onto a single questionnaire sheet with individuals rated according to a 4 or 5 level rating system. The first data segment assessed the perceived frequency of abuse or neglect in different settings included nursing homes, assisted living, homecare and group homes. Those four areas were rated in all initial questions. This question block assessed the level of concern among staff. The second question block assessed the frequency that abuse or neglect was prosecuted by the criminal justice system based on the location for the occurrence of the abuse or neglect. The third data block elicited opinions on reporting practices to law enforcement by different long-term care organizations. The fourth question assessed the opinion of the long-term care providers on how well law enforcement was equipped to investigate and prosecute these complaints. The fifth question tested the opinion of long-term care of long-term care providers on the role of autopsy postmortem examination to long-term care recipients, and the sixth data block queried the respondents as to how often and effective were communications between law enforcement and regulatory agencies. This question assessed whether law enforcement was assessing available data to determine whether a future investigation was indicated.

These questions were framed based on non-systematized solicitation of opinions and information through discussion groups with long-term care providers. The second phase of the survey assessed the need for education by all components of the law enforcement community, followed by solicitation of opinions on the type of educational programming and content most appropriate to meet proceeds knowledge deficits.

Identifying data was obtained based on level of licensure, e.g., registered nurse, LPN, social worker, as well as duration of experience in long-term care. Other demographic data such as age, gender, etc., was not solicited because respondents were concerned about identification while describing potential problems with reporting abuse and neglect. Surveys were

conducted in different geographical locations on different occasions to minimize the likelihood that respondents would complete more than one survey and participants were advised to respond only once.

Long-Term Care (1/10/05)

The state level nursing home surveyors operated throughout the state of Alabama and their opinions reflected the statewide situation rather than a specific county or jurisdiction.

The hospice workers came from central Alabama representing suburban and rural healthcare providers. The nursing home professionals represented a cross-section of communities throughout the state of Alabama, including both urban and rural locations.

Few responded that abuse and neglect never occurred in the long-term care setting with the majority of individuals indicating that abuse occurred rarely and sometimes but not often.

The hospice survey focused on identifying three potential problems in hospice care: 1) abuse, 2) neglect, and 3) intentional over-medication of the patient.

The questions attempted to determine whether the practice of medicine by hospice physicians is affected by their concern over the medical-legal aspects of hospice care. The questionnaire attempted to determine whether physicians altered prescribing patterns to limit the perception that patients were intentionally over-medicated. Hospice patients consume substantial amounts of controlled substances and the questionnaire attempted to determine whether hospice recipients were the victims of medication thefts. Families are provided substantial latitude in assisting hospice recipients with pain medications. Families may over-medicate terminal patients for well-intentioned reasons or to reduce the burden of care produced by excessive requests for assistance. The questionnaire surveyed whether hospice workers identified inappropriate over-medication as a problem.

The survey attempted to measure the impact of physician concern on patient's quality of life by assessing whether staff believes patient suffered as a result of conservative prescription of narcotic medication by fearful physicians.

The criminal justice system impacts the care of dying patients at several levels. The criminal justice system is one level of protection against abuse, neglect or exploitation by family, professionals or others for the dying patient. Treating physicians may under-medicate dying patients to avoid the accusation of euthanasia. Inadequate medication of dying patients can also produce civil or criminal sanctions levied against treating physician. Specific, legal boundaries to determine whether criminal activity has occurred are non-existent. Physicians are less likely to manage patients when the threat of criminal or civil sanctions is present without clear guidelines to define civil or criminal liability. The justice system must provide physicians adequate guidance to assure protection against accusations of mistreatment or criminal activity. Criminalization of hospice care will reduce the number of physicians willing to provide services to dying patients.

Conclusion:

This study was undertaken to define civil and criminal justice issues that pertain to the delivery of long-term care by soliciting opinions from professionals who provide the service or regulate the care. The managers, surveyors, and healthcare providers were surveyed using techniques that minimize concern over self-reporting and maximize responsiveness. The survey was conducted to define issues rather than provide specific definitive data. The survey was the basis for further investigations that will aid in the construction of educational programs, investigators techniques, and public policy.

Surveys were distributed during educational programs and collected at the end of the program. Some respondents with backgrounds at multiple levels responded to several categories of the questionnaire; however, other respondents had limited professional experiences and simply responded in their areas of expertise. Our respondents were advised to only answer in those domains in where they had direct clinical experience.