CONSUMER COMMISSION ON THE ACCREDITATION OF HEALTH SERVICES

CCAHS QUARTERLY

SPRING NURSING HOME TRANSFER TRAUMA - THE PUBLIC INTEREST 1975

STARVATION AND ISOLATION!

Increasingly the public is being made aware of the horrors which exist within many of our nursing homes. We have come to realize the existent fire hazards; the harsh and inhuman treatment; the lack of rehabilitation programs; the deficiencies of available medical care and the near starvation of some patients. We now know there is a lack of meaningful interaction between the human being in the nursing home and its staff. We have seen how the artificial isolation of nursing home patients has deprived them of basic human rights. The New York State Health Department has moved to decertify the worst nursing homes and as a result of this, many homes are being closed. Their residents are being relocated or transferred, hopefully, into better facilities.

A CURE THAT MAY BE WORSE THAN THE ILLNESS?

For some of these patients however, the worst is about to begin. During the transfer, or soon after, many nursing home residents will succumb to untimely death! It will be brought on by a phenomena, little understood and often ignored, known as transfer or discharge trauma. The purpose of this CCAHS QUARTERLY will present an overview of the entire transfer process.

- What is transfer trauma?
- What prevailing conditions subject a person to this life threatening process?
- What has the public sector done to protect the individual to this harm?
- Why is the public sector ineffectual?

The outcome of a small scale investigation will be presented to indicate the snarls and roadblocks that effectively preclude a meaningful solution.

Finally, we will present alternatives and recommendations directed towards ameliorating the present administrative disaster.

Transfer trauma starts when a nursing home resident (patient) is moved from his or her facility. Transfer trauma also occurs when patients are moved from floor to floor within the same home. Patients undergo a tense and stressful alteration in their established environment during the period preceding transfer. The move is a precipitous change in the individual's living space and daily routine. The new staff is unfamiliar, "buddies" and acquaintances disappear and the shape of the rooms and the hallways change. Much of what had come to be regarded as ongoing and predictable has been drastically altered. Many studies have shown that this change exacerbates the existing medical condition of residents and results

in sometimes startling increases in mortality rates among nursing home transferees. In a controlled study at Stockton State Hospital in 1968, it was found that within the first four months after transfer, ambulatory transferees exhibited a mortality rate which was 500% greater than that of the non-transferred control group. This rate appears low when it is contrasted to deaths among their non-ambulatory counterparts, who died at a rate which was 900% higher than the control group. Additionally, there are believed to be other less deadly effects of transfer trauma, such as regressive behavior and depression, but these are less easily measured and present less dramatic consequences.

FACTORS AFFECTING TRAUMA DEATH RATES

All patients are not as likely to suffer from movement and disruption. A distinct group of patients has been identified as especially prone to suffer from relocation. In a case paper prepared by Mr. Stephen Hitov, a New York University law student, for a nursing home resident threatened by involuntary transfer, several factors are outlined which predispose an individual to suffer shock.

> "Several factors have evolved that may offer some guide as to who is most susceptible to the stress of changing environment. Margaret Blenker, in an article in Gerontologist, June 1967, entitled 'Environmental Change and the Aging Individual', found that there was a positive correlation between the severity of a patient's brain dysfunction and the probability of mortality following transfer. Having evaluated data from several studies, she was able to say:
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> > '...When there is evidence that the older person's intellective capacity, his memory and his orientation to time, place and person are seriously impaired, his chances of survival following relocation are considerably lower than that of a person who shows no or only minimal signs of such impairment regardless of how emotionally or socially disturbed or maladjusted such a person may be.' "

A second factor that seems to correlate with a person's vulnerability is a length of residence in the original institution. However, this factor seems to be one of extremes. People who have resided in a place for one to five years tend to have a greater adverse reaction to transfer than do residents of six months to a year. It is believed that patients with long residence histories suffer greater stress upon transfer because they have become more accustomed and attached to their surroundings. There are also patients who have lived in the nursing home for less than six months who exhibit a high death rate. This phenomenon is most likely caused by the rapid succession of two transfers. If the first transfer is not lethal, the second one almost certainly will be.

A third factor involved is that of age. While no definite correlation has emerged, evidence is strong that both men and women between the ages of 70 79 are highly susceptible to the stress of moving.

It is apparent from these findings that the group of people not likely to be affected by transfer is small.

WHY CHANGE THE NURSING HOME PATIENT'S ADDRESS?

Residents are moved for various reasons. One reason, already mentioned, is the decertification of a home due to its failure to comply with state regulations and standards. The failure to meet standards leads to the cut-off of federal, state and local funds which forces state agencies to move residents.

Another reason for transfer are the regulations which require a review of the medical need of patients to remain in a hospital, skilled nursing facilities, etc. This process, known as utilization review, can require a patient to be transferred at some future pre-determined date. Unfortunately, the potential harm due to transfer is rarely considered during utilization review, nor are steps taken to protect patients before the move. There is growing incentive to transfer patients from Skilled Nursing Facilities, where care is both more intense and, therefore, more expensive, to Intermediate Care Facilities which provide less service and therefore lower cost. Altered reimbursement guidelines have been set forth which use a stricter Medicare classification in order to determine the level of need and reimbursable care. The State is economically and legally obliged to follow federal regulations by relabeling the needed level of care. Again, the patient's requirements may be ignored or not acted upon, which indicates that proprietary and other nursing home operators can have a great influence on how and when nursing home patients are transferred. Empty, but newly built facilities can cause many patients to be moved too soon. The testimony that follows is excerpted from the New York Times of June 24, 1975.

> "The city shipped 200 nursing home patients to new private facilities during the Christmas holiday of 1973 without asking them whether they wanted to move or giving them medical examinations, according to testimony at a state hearing yesterday.
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> The transfer began one week after a delegation from the Metropolitan New York Nursing Home Association met with Jule M. Sugarman, then Commissioner of Social Services, and reportedly shouted, pounded on the table and threatened to expose the alleged failure of officials to plan for the opening of the new facilities.
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> ...The 1973 crisis developed as a result of an earlier official decision to license the construction of a score of 'health-related facilities,' for patients who did not require the more intensive care of 'skilled nursing facilities.'
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> When the first two health-related facilities opened, operators of the skill nursing facilities held on to their patients, and many refused to be transferred.

> A telegram by Mr. Carr to Commissioner Sugarman called this a 'catastrophe' to the promoters and demanded that he fill the beds 'simultaneously.' The Commissioner testified that at the meeting he agreed to move in 200 patients 'expeditously.' "

Therefore, we observe that patients may be moved to promote either nursing home operators or the public sector's interests. It is ironic, that while the state's closure of nursing homes is based on the fire hazard and other unsafe conditions existing in these homes, the hazards of moving patients without proper preparation are just as unsafe.

Homes are decertified on the basis of potential deaths since the State will be blamed if a fire occurs in a violation-ridden home. Unfortunately, the deaths which may be brought about due to poorly prepared and rushed transfer of patients have never been considered. The public is concerned, and rightfully so, about the danger to the life and safety of nursing home residents. However, the hidden danger to the patients which the closing and abrupt transplantation forces upon residents is not visible to the public and therefore is not considered. Many public and community leaders are not aware of "transfer trauma." In testimony before the Moreland Commission on Nursing Homes and Residential Facilities, now investigating ways to reform the system, one voluntary agency director related how his plea before New York State officials was received. He tried to present the case for sixty-two dislocated patients who would be transferred without any planning to ease the move. He related their plight and desperate efforts to remain at the home even though it had been decertified. One patient even attempted suicide to avoid the move. It was the eleventh hour of the hearings, the patients were set to be moved, but his words fell on unresponsive ears. The state officials, although familiar with transfer trauma and its effects, proceeded to close the institution <u>without making plans</u> to prevent unnecessary hardship and death of residents.

<u>TRANSFER TRAUMA - WHAT CAN BE DONE?</u>

Do we move on the heels of fear or do we positively direct our action to the ultimate benefit of the nursing home resident? There are ways which have been shown to greatly reduce the dangers of transfer trauma, but they require time and increased expenditures of effort and resources.

The New York State Department of Social Services issued an Administrative Letter on December 11, 1974 (74ADM-178) which directed the Commissioners of Social Services throughout the State to conduct transfers in a manner which had been shown to present maximum potential for patient benefit and survival. This Administrative Letter was based on an intensive study carried out at the University of Michigan, Institute of Gerontology. It contains directives aimed at easing the initial shock by providing the patient with an introduction to the new facility either through a preferred pre-transfer series of visits or minimally the patient should be given a slide presentation which would allow him/her to become acquainted with the new home. The guidelines suggested that the patients tour the new facility prior to transfer. Discussion groups were to be conducted in order to familiarize the patient with the new procedures and staff

members, and three of these meetings were to take place before the transfer. Consideration should be given, the Letter dictates, to those patients who have come to rely on each other over a period of time and an attempt made to keep them together. These transfer directives, based on the Michigan study, are aimed at the transfer of entire populations. But, with slight modification these procedures are to be used for individuals as well. The continuity brought about by discussions and visits by patients to their new surroundings is crucial. It is this component which forms the basis of the study's findings for improved potential outcome of transfer. To the extent that the patient could be made to feel less uncertainty about the future there is less chance of disintegration and death.

HOW ARE AGENCIES RESPONDING TO PATIENTS' NEEDS?

Over six months have passed since this official letter was forwarded to the local Commissioners of Social Services. In New York City, during this period of time, one witnessed the closing of dozens of homes. Contacts with representatives of the Department of Social Services, the Medicaid office, the local office of the State Department of Health, revealed that those responsible for the transfer of these patients felt that the Administrative Letter was "unrealistic" given the massive closings in the City. The available staff was considered to be totally inadequate for the task at hand. In addition, there was a lack of time and a lack of sufficient transport vehicles to bring patients to new facilities. The problems of communication and coordination within governmental bureaucratic units were formidable.

GOVERNMENT BUNGLING - WHO'S ON FIRST?

The various federal, state and city agencies soon found themselves in conflict and at odds over how, when, and where to transfer patients. The Department of Health Education and Welfare stops payment to a nursing home after it is decertified for thirty days. This put pressure on the State Department of Social Services to remove the patients expeditiously. This economic pressure mediated against proper transfer. It was virtually impossible to carry out the directive of 74ADM-178 to conduct pre-transfer visits for over one thousand patients in a period of only a few months. At the same time, the State Department of Social Services was insisting that the State Health Department fulfill its obligation to issue the requisite form indicating that medical examinations had been conducted on the transferees. Based on these medical examinations, patients can be directed to the proper institution. The extreme urgency and unusually large number of patients to be transferred made provision of humane transfer procedures unattainable if we accept the position of health officials. The State Department of Health has a long standing regulation that only ten patients per day could be moved. At the same time this Department insisted that all patients be removed within weeks. The only transfer aid which the Department of Social Services could make available to the family and patient was an attempt to keep them informed of where the patient was going on what day. The slides and group work outlined in the Letter were out of the question. It was felt that the dictates of the Letter could be followed only by smaller nursing homes and under less trying circumstances.

THE EXODUS - A VIEW FROM ALBANY

As events unfolded in New York City, the State Department of Social Services had an opportunity to test the values and goals of its Administrative Letter 74 ADM - 178 on the procedures to be followed during the transfer of nursing home patients.

Telephone calls to the resource and technical assistance specialists listed in this Letter revealed that:

1. The New York City Social Service Department paid lip service to Administrative Letter 178.

2. No enforcement mechanism monitored the transfer process,

3. There was little concern for the affects of transfer trauma on residents,

4. There was a great concern to move patients fast,

5. There is inadequate statistical and research activity being pursued to determine the impact of the massive transfers,

and 6. Administrative letter 178 was ignored.

It is apparent that the agencies responsible for the safety and well-being of nursing home residents were not prepared to handle an emergency, nor capable of handling the near emergency when it occured. These agencies also failed to develop a realistic timetable and schedule to move patients in a safe manner. These agencies also reacted to extreme pressure brought on by proprietary nursing home interests.

NURSING HOMES - ACT III

Finally, we should understand how the nursing homes reacted during the recent transfers. What could and did they do to help the patients?

The Administrative Letter dictates that personnel from the receiving facility and personnel from facilities whose provider agreements have been revoked should, whenever feasible, ease the transfer. Those receiving homes which had the staff to send out teams did so to ease the transfer. On the other end of this helping spectrum we find that one of the homes scheduled to close was so callous that it said to the State Departments of Health and Social Services, "You take over! You get them out of here!"

One example of proper transfer procedures which take into account the needs of an entire residential population in the Cleveland area was described by Howard Baum in a speech presented to the American Association of Homes for the Aging, November, 1969:

"Preparing the residents for the move, of course, was our prime concern. Basically our intention was to confront members of the resident population with the fact that we were moving and to make it possible for them to accept this as a definite likelihood. We knew that this would arouse a multitude

of anxieties in them and we hoped that we would be able to assist them in organizing their thoughts. Announcements to the resident population were made at every opportunity, keeping them abreast of the planning, and to seek their advice in some of the design concepts of the building. For example, we constructed and furnished a sample room so that the residents could react to the furniture and express their likes and dislikes. As many residents as we could possibly bring, were present at the groundbreaking ceremony. We brought our residents by bus to the site every two or three months to observe the progress of the work. This was arranged for wheel chair patients as well, utilizing a special wheel chair bus borrowed from another institution. Only the grossly mentally impaired were excluded in the process. Our feeling was, that whatever the intellectual capacity of the resident, he would probably be able to benefit in some way by observing the new site. This mobilized much feeling in all of the residents, making the move, for them, an inescapable fact. A majority of our residents also participated in a Jewish ceremony known as "Chanukus Ha Beit", blessing of the new house, and the transfer of torahs from the synagogue in the old facility to the new facility."

The following report of the New York State Department of Health to the Public Health Council, May 30, 1975, on the Garden Nursing Home, speaks for itself. It is an example of how the transfer of patients was accomplished at a given nursing home.

New York State Health Department Report - Excerpts

Termination of the Operation of Garden Nursing Home - - - On March 24, 1975, the Department received a telephone call from Mr. Maged that he would terminate the operation of Garden Nursing Home as soon as possible after April 7, 1975. A letter was hand-delivered to Mr. Maged, explaining the Departmental procedures for ceasing operation. Mr. Maged refused to initial a copy of the letter to indicate that he received it; his position was that he was being forced to close.

These procedures were reiterated in another letter to Mr. Maged, and staff were scheduled to monitor the transfer of patients and to make sure that Mr. Maged was properly executing his responsibilities.

On-site visits at the Garden Nursing Home by State Department of Health staff during the actual transfer of patients revealed the following:

1. Patients were partially dressed, all were untidy and had poor body hygiene;

2. Patients were not aware of where they were going, only that they were being taken from the home;

3. Not all patients had their personal possessions. A few had a plastic bag on their lap with a collection of soiled objects, shoes,magazines and other objects;

4. Patients' clothing was jammed into a couple of plastic bags collectively and not identified.

5. Medications were not being sent with each patient, now was personal allowance money;

6. Medical records and transfer forms were incomplete, did not reflect patients' status, and lacked a discharge summary. Continuity of care was impossible;

7. Families arrived to question the transfers and stated that they had not been notified of any changes being made;

8. On the day of the transfer of 22 patients, 9 charts were scattered all over the first floor, and 5 medical charts could not be located;

9. On the day of the transfer of 33 patients, there was so much confusion that clerks could not keep track of patients, which had been transferred and to where;

10. Some rooms still had the unmarked personal effects of patients that had already been discharged. Although it was stated by Garden Nursing Home personnel that all these items would be sent as soon as they could be sorted, the objects were unmarked and thrown all over the rooms;

11. Two discharge orders indicated patients could be transferred to a health related facility; they were sent to a nursing home;

12. There was a strong foul odor throughout the first floor and a number of patients needed a bath. The entire patient floor was in disarray; some beds were stripped, some clothing was bagged, other clothing was lying around rooms. Four patients had no name tag, some of these were aphasic or too confused to give their name.

The patient's welfare is precariously balanced between the strained resources of the State, the benevolence and capabilities of the receiving homes and the angered disinterest of the decertified facilities.

SOLUTIONS AND RECOMMENDATIONS

Is there a solution to this debaucle? We have learned that present administrative directives designed to carry out public responsibility to protect the lives of nursing home residents had been dangerously ignored. The failure of the State to ensure the safe and orderly transfer of patients jeopardized nearly 1000 people. The failure to enforce regulations allowed embittered nursing home owners to further endanger patients' lives. The failure to carefully follow-up the consequenses of the rushed and inhumane transfers through proper statistical research will not permit us to judge the effects of our actions.

Therefore, the following is recommended:

(1) The procedures outlined by the New York State Department of Social Services on the method to transfer nursing home patients should be followed:

a. Additional funds should be appropriated to hire temporary staff to affect safe and humane nursing home transfers.

b. The creation of an Office of Relocation within the Department of Social Services which has a direct ongoing link to the Department of Health and concerned community groups. This office would coordinate all gov-

ermmental units involved in discharge procedures and would conduct epidemiological studies on the population at risk. It is imperative that moved patients be followed over time in a consistent and ongoing manner.

(2) The patient's right to a fair hearing and choice of transfer facility must be upheld. The patient has a right to be involved in decisions affecting relocation.

(3) The timetable to transfer nursing home patients must be more flexible to avoid the risks associated with transfer.

(4) Utilization review personnel should consider the adverse affects of transferring this high risk group. Recognition should be given to the psychological and social aspects of the patients' needs. Patients should not be transferred as a result of this procedure without implementing adequate provision for the move.

(5) Hospitals and nursing homes should train family members and community residents who can participate in transfer procedures.

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