

A Qualitative Study of the Found Down Syndrome Among the Elderly
Who Live Alone

by

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Abstract

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Health care providers use the term "found down" to describe persons who were found alone and unable to obtain help after an event in their homes which rendered help necessary. Within a three-month period in 1993, 367 patients who fit the case definition of found down were identified by the 911 paramedic system in a large urban area. Sixty-three percent of these patients were aged 65 or over. Of the elderly patients, 58 were selected for this qualitative study involving medical chart review and in-person interviews. Three main areas of the found down syndrome were explored in this study: 1) the demographics, medical history, and social networks of the study population prior to being found down, 2) the found down experiences, 3) the process used to decide the discharge destination after hospitalization, and 4) the impact of the found down episode.

Fifty-nine percent of the study population were female and 72% were Caucasian. Thirty-six percent of patients had multiple medical problems prior to the incident. Twelve percent were managing well at home without community support. Forty percent were visited by home service employees only.

The most common reason for found down incidents was mechanical fall. The median down time was in the 6-12 hour interval. The three most prevalent adverse conditions under which the patients were discovered were in pain, altered mental status, and incontinent.

Thirty-six percent of the patients were admitted to the intensive care unit after transport. Fifty-five percent of the patients were discharged to a skilled nursing facility and 45% were discharged home. The process used to decide on a discharge destination varied from being nonexistent to having extensive involvement of family and health care providers.

One year after the found down event, 26% of the patients were living at home alone, 11% were institutionalized, and 21% had died. Forty-four percent of the patients experienced a decline in ADL capacity and 44% underwent changes in living arrangements. The fears of falling and of living alone were some of the negative psychological consequences.

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CHAPTER I: INTRODUCTION

The Needs of the Growing Elderly Population

Margaret Coit Elwell, a well-known biographer, wrote:

For as you age, the world is still out there, beckoning you with all its pleasures and treasures, but continually, there are less and less for you. The world goes on; it does not stop, but it wants you to get off. And if older people tend to live among their memories, it is because the past is there for them. The future may not be.¹

The fastest growing population in the United States consists of individuals aged 65 and over. In 1990, the elderly accounted for 12.6% of the U.S. population. In 2025, a projected 19.6% of the U.S. population will be elderly.² Worldwide, the population aged 65 and over numbers 332 million and is expected to reach 426 million by the year 2000.³ As the elderly population increases in age and size, so must our understanding of the needs of this population. The limited resources available in terms of caregivers and capital need to be used efficiently and effectively to provide a satisfying present for today's seniors and a future for the seniors to come.

The exploding elderly population will tremendously increase the demand for medical and social services. Although the elderly account for about 13% of the U.S. population, they use about 33% of the health care resources.⁴ In Canada, individuals aged 70 and over are projected to fill all existing hospitals by the year 2022.⁵ The elderly are at increased risk for accidents and injuries in their homes which require not only emergency medical care, but also posthospitalization care.⁶ Approximately 10% of health-related expenditures for the elderly are used for nursing home care.⁷

Social support is another area of need in the elderly population, especially among seniors who are failing at home. An increasing number of elderly persons are living alone.⁸ Living alone in addition to a decline in functional capacity increases the risk for social isolation. For many older persons, a high quality of life is correlated with the ability to remain independent and to live at home in the community.⁹ The ability to remain independent is in turn correlated with strong social networks.¹⁰

Some elderly persons living at home lose the ability to maintain their homes and their health. A senior's decline in functional capacity may remain unknown to community members until the senior is involved in an emergency. A wide spectrum of events, including falls, side effects of medications, syncopal episodes, and hypoglycemia, could lead to a medical emergency at home. During such emergencies, these seniors require immediate medical care, but are not able to call for help. These seniors may not be discovered until days later. Paramedics often find elderly people after such an incident in their homes and describe these patients as being "found down." It is thought that the people who are "found down" are predominantly the elderly and the very ill. Found down patients epitomize the need for social and medical attention. Despite the grave consequences of this phenomenon, not much is known about it.

The Beginnings of a Research Project

In thinking about the rapidly growing elderly population and its increasing needs, I became alarmed at the potential for a parallel escalation in "found down" cases. Questions came to mind which I could not answer. What

causes these elderly persons to be found down? How frequently are people found down? Who are at risk? How will the explosive growth in the elderly population affect the rate of found down events? How can these events be prevented?

Dr. Jan Gurley and I became interested in finding the answers to some of these questions concerning what we called the "found down syndrome."¹¹ We asked the paramedics in the San Francisco Department of Public Health Paramedic Division to help us identify persons who were "found down." We formulated three questions which we felt would help us identify found down victims. We then asked the paramedics to fill out a form containing these questions for each patient they encountered. The form read:

1. Are you seeing the patient at their place of residence? yes no
2. Does the patient live alone? yes no
3. Has the patient been down, missing or unable to get help? yes no

Affirmative responses to all three questions became the criteria for inclusion in a study on the found down syndrome. Within a three-month period in 1993, we identified 367 persons in a large urban area who fit the case definition of found down.¹¹ Here are two descriptions of found down experiences provided by paramedics to illustrate the syndrome:

Case 1:

79-year-old male who complains of sudden onset of shortness of breath for the past two hours...He is able to speak 3 words at a time with accessory muscle use. Skin is warm to hot, dry, cyanotic...History of fibrosis, angina, myocardial infarction within the last year and history of "water in the lungs." Patient had to bang on the wall to summon help. Found by apartment manager.

Case 2:

73-year-old patient found alert and oriented in bed with complaint of lightheadedness for the past 2 weeks resulting in falls when standing. Patient non-compliant with oral hypoglycemics and with poor eating habits. Patient unable to get up from bed for fear of syncope. The patient remained in feces covered and urine-soaked bed for last 2 weeks.

Using this population of found down victims from San Francisco, we conducted a study to find out more about the found down syndrome. We were interested in the demographics of the found down population, including the age, gender, income, and ethnic distribution. In addition, data was collected to ascertain the incidence and outcomes of found down events. The outcomes investigated include survival, duration of hospitalization, and return to independent living.

Taking a Second Look

Subsequent to this quantitative study, I conducted a qualitative study on a subset of the 367 found down victims identified. This second study focuses on the elderly subgroup of the entire found down population. I was interested in a more in-depth investigation of the found down experience which included the victims' perspectives. This paper will present the results of my qualitative study.

Before I discuss the results from my study, I will provide some background for my work. The results from the quantitative study was the starting point for the qualitative work. Therefore, a summary of the methodology and results of the quantitative study will be presented first. Secondly, the demographics of the entire found down population will be compared to the demographics of the United States and San Francisco

populations. Thirdly, falls will be contrasted with the found down syndrome. Fourthly, I will describe the methodology used for my study. This will be followed by an overview of the elderly population in the United States to be used for comparison with the my study population. Lastly, the results of my study will be presented along with suggestions for the prevention of found down events.

A Summary of the Found Down Study

Study Design

Enrollment of Study Patients

The Found Down Study was a prospective, population-based study which included all eligible residents in the City and County of San Francisco. During a twelve-week period from March through May 1993, paramedics of the San Francisco Department of Public Health Paramedic Division enrolled patients who met the case definition for inclusion in the study. This paramedic division responds to approximately 95% of all calls for emergency medical service within the city. During the study period, the paramedics were asked to answer the following three questions for every patient they encountered:

1. Are you seeing the patient at their place of residence?
2. Does the patient live alone?
3. Has the patient been down, missing or unable to get help?

The patients for whom "yes" was answered for all three questions were enrolled in the study. The paramedics were also asked to estimate the length of time the patient had been down by choosing from a list of times ranging from

less than one hour to greater than 72 hours. The medical charts of the patients identified by the paramedics were reviewed to verify the patients' inclusion status. The medical charts of 367 patients confirmed the affirmative responses to the three questions listed above and were enrolled in the study.

Data Collection

All patients had information abstracted from the paramedic pre-hospital assessment. In addition, the hospital charts of patients who were transported were reviewed and abstracted at 13 hospitals in San Francisco. Finally, death certificates were obtained on the 90 patients who were found dead.

Data Analysis

Data from the review of paramedic forms and medical charts were entered in Filemaker Pro and Statview software packages. Incidence rates were determined based on 1990 Census data. The rates were calculated as the average annual age-, race-, and sex-specific number of cases divided by the population at risk. The population at risk was the number of persons living alone whenever sufficient census data was available. The annual number of cases was determined assuming a constant rate. While P values are not strictly meaningful in a population based study, they have been included in some subgroup analyses as an aid to the reader. Census data on average income in each housing tract was used to assign average income levels to patients, referred to as the average community income.

The outcomes included survival, duration of hospitalization, and a return to independent living. Patients who were discharged to a nursing home, skilled nursing facility, board and care facility, rehabilitation facility,

or to a family member's home were considered discharged to alternative care. Information on who contacted the paramedics was obtained from the paramedic pre-hospital assessments and hospital charts. In cases where no family member was mentioned, the contact person was categorized as not family. All patients aged 65 and over were assumed to be Medicare eligible. Costs were estimated using charges discounted to 70% for paramedic evaluation and hospital and intensive care days.

The Results of the Found Down Study

Demographics

Within a twelve-week period in 1993, 367 found down patients were identified with the help of the San Francisco Department of Public Health Paramedic Division. The found down population was 51% female and 63% Caucasian. (Table 1.1). The majority of the patients were aged 65 and over. The median age was 65 years for the males and 78 years for the females.

The median average community income for the sample was \$31,782. The majority of the Caucasian study patients were in the middle to high community income levels. Among African-Americans, the majority of study patients were from low community income levels. The majority of Asian study patients fell in either the very lowest or middle community income level.

Medical insurance information was available for 78% of patients. Patients under 65 most commonly had Medicaid, while patients 65 and over had private insurance most frequently. Only 20% of those 65 and older had Medicare as their only insurance.

Table 1.1: Demographics of the Found Down Population

Age	
Median years (range)	73 (25-101)
Gender	
Female	199(51%)
Male	188(49%)
Ethnicity	
Caucasian	245 (63%)
African-American	57 (15%)
Asian	36 (9%)
Unknown	26 (7%)
Hispanic	19 (5%)
Other	3 (1%)
Native American	1 (0.4%)
Chief complaint	
Unable to get up/weakness	95
Found Dead	86
Falls	67
Shortness of breath or chest pain	21
Altered mental status	18
Found unresponsive	16
Cerebrovascular accident	13
Miscellaneous*	78
Estimate of time down	
<1 hour	100
1 to <3 hours	52
3 to 6 hours	31
6 to <12 hours	37
12 to <24 hours	44
24 to <48 hours	20
48 to <72 hours	17
>72 hours	39
Unknown	46
Median time down	4.5 hours
Insurance by category	
Private	159
Medicaid	76
Medicare	38
None	13
Income	
Median dollars (range)	\$31,782 (\$7,747-\$76,170)
Disposition	
Found dead	90
Not transported	36
Transported	261
Admitted	245

* Each category included in miscellaneous had 8 or fewer patients per category. These were (in order): overdose, suicide or attempt, seizures, no identified complaint, syncope, severe pain, diabetic patients with hypoglycemia, and status cast assault.

Clinical Presentation

The found down patients presented with a wide variety of precipitating problems. The most frequently cited causes for being found down were the inability to get up (not related to falls), being found dead, and all falls. For those aged 65 and over, the most commonly cited cause was the inability to get up or weakness. For those under 65 years of age, being found dead was the most frequent clinical presentation. None of the patients under 65 suffered from multiple falls, or fell and became lodged. However, suicide and overdose occurred only among patients under 65 years of age. Sixteen percent of patients under 65 had HIV infection or AIDS. Other presentations included shortness of breath or chest pain, altered mental status, and cerebrovascular accidents.

Down Time

The duration of time from the onset of the found down incident to the arrival of help is known as the "down time." The estimated down time for the found down population ranged from less than one hour to over 72 hours. Twenty-seven percent of the patients were found within one hour, while almost 13% were found over 72 hours later. The median down time was 4.5 hours. Longer down times were associated with worse outcomes. For instance, the median estimated down time among those who were transported, but not admitted was less than one hour, compared to 18 hours for individuals found dead at home. The majority (67%) of persons with down times of over 72 hours were either found dead or died in the hospital.

Discovery

Persons who found the victims and called for help included relatives, friends, neighbors, caretakers, and home health aids. Persons providing home care services such as visiting nurses, caretakers, housekeepers, and home health aids were the most common sources of contact that led to discovery of the patient. Only 8% of the population were found by relatives. Persons who were eventually able to summon help themselves had the shortest down times. Patients who were discovered by friends had the second shortest down times. Those found by relatives, neighbors, landlords, and home care service providers were associated with much longer down times.

Rates of Occurrence

The rate of occurrence remained under 5 per 1,000 persons per year for persons below aged 65 and rose exponentially to a peak incidence of 27 per 1000 persons per year among those aged 85 and over. When the rates were adjusted for living alone (using persons living alone as the population at risk), the rate was over twice as high for those aged 65 and older than for those younger. The rate of occurrence was higher among men than women in all age groups and almost twice as high among African-Americans as among Caucasians, Asians, or individuals of Hispanic origin.

Outcomes: Survival, Duration of Hospital Stay, Independent Living

The in-home mortality was 23% and the in-hospital mortality was 5%. The median age for those who died at home was 65, two-thirds of which were male. Eighty-eight percent of the found down population were transported to a hospital, 70% of whom were admitted. The average duration of stay in the hospital was 8 days. Over 50% of those who survived to discharge did not return

to independent living. Persons who were admitted after transport and those who were discharged to supportive care, tended to be older and predominantly female.

Summary

To summarize, Gurley et al. found two main subgroups in the found down population. One group consisted of very elderly, predominately Caucasian women with private insurance who were from communities with middle income ranges. The other subgroup consisted of patients who tended to be younger, poorer, and disproportionately African-American. The inability to get up, being found dead, and all falls were the three most common presentations of the victims. Longer down times were associated with worse outcomes. Persons providing home help services were the most common sources of contact that led to discovery of the patient. Given these features of the found down syndrome, how does the found down population compare to the general populations of San Francisco and the United States? The following section will make these comparisons to provide a better understanding of the groups of people at risk for being found down.

A Comparison of the Found Down Population with the United States and San Francisco Populations

The found down population consists of residents of San Francisco, a city with an older and more ethnically diverse population than the rest of the United States (Table 1.2). The found down population has a higher percentage Caucasians and African-Americans and a lower percentage of Asians and Hispanic persons than the overall San Francisco population. The median

income of the found down population is about equal to that of the San Francisco population, but higher than of the U.S. population. A lower percentage of found down victims have private medical insurance or no insurance than the U.S. population. The large elderly component in the found down population may in part account for the higher percentage of Medicaid recipients. The most striking difference between the found down population and the U.S. and San Francisco populations is the much larger portion of individuals aged 65 and over in the found down population.

As shown, the found down syndrome occurs predominately among the elderly, similar to the incidence of falls. How is the found down syndrome different from the phenomenon of falls? The following section provides an overview of the literature on falls and a comparison of the found down syndrome and falls.

Falls Among the Elderly - A Literature Review

The definition of a fall varies from study to study. According to Isaacs, a fall is an event in which "a person inadvertently finds himself on the ground starting from either a sitting or standing position."¹⁵ Robbins et. al. defined a fall as "a sudden, involuntary, and unexpected landing on the ground or assumption of the horizontal position with or without loss of consciousness or injury, reported either by the faller or a witness."¹⁶ Tinetti, Williams, and Mayewski defined falls as an "unintentional change in position occurring under circumstances in which a 'fit person' could have resisted the external hazard, if one were present."¹⁷

Despite the variations in the definition of a fall, most researchers studying the phenomenon of falls agree that falls account for many injuries and hospitalizations of elderly individuals. Falls account for two-thirds of all accidental deaths in the United States.¹⁸ One study showed that 54% of all injuries recorded in the study and 75% of the hospitalizations for injuries were due to falls.¹⁹ Three-fourths of the deaths from falls occur among persons aged 65 and over.¹⁸ Twenty percent of community-dwelling elderly fall each year. The percentage is doubled in institutionalized ambulatory populations.¹⁶ The rate of falls increases with age.²⁰ In a study conducted in Israel, falls proved to be the most common accident to occur among people 65 and over.²¹ The incidence of falls increases rapidly after age 65 as well as the rate of hospitalization after a fall.²² There has been an increase in the rate of falls among the elderly from 1971-1986, amounting to even greater hospital costs.²³

The literature suggests that many factors are associated with falls among the elderly. Physiologic factors include changes in vision, balance, and gait.²⁴ Elderly people often require more time to adapt to changes in lighting. Proprioceptive and vestibular feedback are not as efficient with increased age and can affect balance. Age-related musculoskeletal changes frequently affect gait. One study showed that the risk of falling increased with the number of chronic disabilities. Subjects with seven to nine chronic disabilities all had a history of falls.¹⁷ Use of sleeping pills, vision problems, and previous falls were other physiologic factors associated with falls.²⁵

Sociologic factors also have a role in falls among the elderly. Living alone is linked to high rates of falls. In a study conducted in East Anglia, 43% of the elderly (75 years of age and over) studied lived alone. Many of the seniors did not have frequent visitors, while some had informal support networks.²⁶ The amount of social contact with family and friends was

negatively correlated with the number of falls, while living alone, depression, fear of falls, and poor self-perception of health were positively related.²¹

According to Ryyanen et al.'s study, those who have lost their spouses have a higher incidence of falls than those married.²⁰ Living alone, being female, and the home environment were associated with falls in a study done in Britain.²⁷ Thus, the phenomenon of falls is a global concern associated with many factors common among the elderly.

A Comparison of the Found Down Syndrome and Falls

Although the found down syndrome among the elderly shares many of the characteristics of falls, the syndrome has distinct features that merit separate consideration. A separate consideration is especially significant when examining methods of management and prevention. The following section will explore the similarities and differences between found down incidents and falls in terms of five areas: 1) the demographics of the two populations, 2) persons included in the studies, 3) the focus of the studies, 4) the impact of the two phenomena, and 5) prevention. Because the many of the studies on falls have study populations consisting of persons aged 65 and over, the found down victims 65 years of age and over (63% of the entire population) will be used for the comparison. (See Chapter III: Study Design).

Demographics

The incidence rates of being found down and of falling both increase with age.^{11,18,20} Like falls, found down incidents occur more frequently among elderly men than women. Furthermore, death rates are higher among the men than the women for both falls and found down incidents.^{11,18} While

the proportion of falls occurring among institutionalized seniors is higher than among those living in the community,²⁰ the found down syndrome occurs only among community-dwelling individuals by definition.

Inclusion in Studies

A large portion of the seniors in the found down population would have been excluded from many of the studies on falls. According to Isaacs, a fall is an event in which a person "inadvertently finds himself on the ground starting from either a sitting or standing position."¹⁵ Using this definition of falls, the found down patients who were not found on the ground or who did not start from a sitting or standing position would have been excluded. For instance, some found down patients were bedridden for days unable to get up after lying down. Robbins et. al. defined a fall as "a sudden, involuntary, and unexpected landing on the ground or assumption of the horizontal position with or without loss of consciousness or injury, reported either by the faller or a witness."¹⁶ Under this definition, the fraction of found down persons who were found dead would be excluded from the study, since the fall was reported by neither the faller nor a witness. Tinetti, Williams, and Mayewski defined falls as an "unintentional change in position occurring under circumstances in which a 'fit person' could have resisted the external hazard, if one were present."¹⁷ Using this definition of falls, the found down persons who intentionally lowered themselves to the ground due to weakness or dizziness would be excluded from the study on falls. Other individuals have reasons for being found down that seem completely unrelated to falls, such as chronic, severe shortness of breath that made obtaining help difficult, or gradual failure to thrive. Thus, many individuals who were found down would not be included in a study on falls.

The hallmark of a found down incident is that of a precipitating event which leaves a person at home alone unable to obtain help. Being found down can be viewed as similar to discussions around the health consequences of violence in our society. As such, the found down precipitating events can vary, but the subsequent experience of the patient, and the complications from this experience (such as prolonged down times) make the consideration of the event as a whole valuable in defining precipitating factors and outcomes.

Focus of Studies

Furthermore, the studies on falls tend not to focus on some of the issues that are central to the discussion of the found down syndrome. For instance, many studies on falls discuss the physical deficits that increase the risk for falls.^{27,28,29} In found down events, physical deficits must be investigated both as a precipitant of the event and as a determinant of the ability to obtain help once down.

The social network is a significant predictor of persons at risk for the found down syndrome, since living alone is a criteria for being found down. Some studies have shown that a low level of social support is positively associated with falls.²¹ However, for found down patients, not only the level, but also the types of social contacts may determine how long a person is down. The down time may in turn determine the chance of survival and degree of recovery. Investigation of the persons who discovered the victims and the means of discovery may not be pertinent in the study of falls, but may be useful in looking at means to improve the outcome for found down patients. Thus, even if found down incidents due to falls were included in a study on falls, many factors unique to the found down syndrome may not be considered.

Impact

Hospitalization

The impact of the found down syndrome may differ from that of a fall. About 2% of falls among the elderly lead to hospitalization,¹⁸ compared to 77.2% of found down incidents. The average length of hospital stay for a hip fracture is 21 days, almost double the average stay for all other causes of hospitalization of the elderly.³⁰ The average length of hospital stay for found down incidents is 6.9 days for those aged 65 and over. One study found that 50% of fall injuries that required hospitalization resulted in the patient's being discharged to a nursing home,³⁰ compared to 36.7% of all found down incidents.

Mortality

One study found that the mortality rates for falls were 0.010% to 0.035% for persons aged 65 to 74 and 0.065% to 0.240% among those aged 75 and over.¹⁵ Mortality rates from found down incidents were much higher at 8.2% for those aged 65 to 74 and 15.9% for those aged 75 and over.[†] Thus, the percentage requiring hospitalization and the mortality rates were greater for the found down syndrome than for falls. However, the average length of hospital stay and the percentage of patients discharged to nursing homes were lower for found down incidents than for falls. These lower percentages may be due in part to the much higher mortality rate for found down incidents.

[†]includes those found dead on arrival, pronounced dead prior to transport, those who died in the emergency room, and those who died in the hospital.

Psychological Impact

The psychological impact of a found down episode may be greater than that of falling. The fear of falling is one psychological consequence of a fall. Murphy and Isaacs described the "post-fall syndrome" which is characterized by an unreasonably high level of fear of falls resulting in stricter limitations on ambulating and slower progress with rehabilitation.¹⁵ In the found down syndrome, the fears of living alone and of subsequent found down events may be present instead of or in addition to the fear of falls. The fears of living alone and of being found down may have a greater impact on the recovery and on living arrangements than the fear of falling.

Prevention

Although some of the strategies for the prevention of falls would be useful in preventing found down incidents, additional concerns such as social isolation and emergency contact systems need to be addressed. Methods of reducing the negative impact of found down incidents need to be considered in addition to primary means of prevention. Personal call-beepers and daily well-being checks are means of tertiary prevention in the post-fall stage.¹⁵ Such strategies, by reducing down time, are considered secondary methods of preventing found down incidents. For found down victims, the fear of living alone in addition to the fear of falling should be addressed. Chapter X will provide an in-depth discussion of the prevention of found down incidents.

Summary

Thus, the found down syndrome is unlike falls among the elderly in many ways. The dissimilar characteristics indicate a need for separate

consideration of the two phenomena, especially in developing strategies for management and prevention. Given these differences and the prevalence of the found down syndrome among the elderly, this thesis project will expand on the original quantitative study to incorporate a more detailed study of the elderly found down patients.

Introduction to a Qualitative Study of the Elderly Found Down Population

While Gurley et al. investigated the demographics, rates, and outcomes of the found down syndrome, many areas have yet to be explored. For instance, the details of the patient's functional capacity, living arrangements, and social support networks prior to the found down incident were not pursued. Gurley et al. did not provide in-depth discussion of the circumstances of the found down incidents, particularly from the victim's perspective. Although the number of patients who did not return to independent living was described, there was no mention of the process used to determine which patients were discharged home. Finally, the impact of found down incidents on the lives of the patients, including changes in physical function, living arrangements, psychological well-being, social networks, and finances have not been investigated.

This study will describe in greater depth four main parts of the found down syndrome among the elderly: 1) the demographics, medical status, and social support networks of the seniors prior to the found down episode, 2) the circumstances of the found down episode, 3) the impact of being found down, and 4) the means to prevent and reduce the negative consequences of the syndrome. Chapter II will expand on the goals and design of the project.

CHAPTER II: STUDY DESIGN

Study Aims

1. To describe the demographics, medical history, and social networks of the study population prior to being found down.
2. To present the study population's experiences with the found down syndrome, including the circumstances of discovery.
3. To describe the process used to decide the discharge destination after hospitalization and the patient's opinion of the process.
4. To discuss the impact of the found down episode on the patients' physical capacity, living arrangements, social network, psychological well-being, and financial status.
5. To suggest means to prevent found down episodes and decrease their negative consequences.

Hypothesis

Many factors are significant in determining whether a found down patient returns home or moves to some form of supportive care after discharge from the hospital. Some of these factors are inherent to the patient, including the patient's functional capacity, psychological well-being, and financial status. Others are environmental factors which include availability of housing and social support. Factors inherent to the hospital may include physician biases and staff efforts to locate the relatives or friends of the patient and to utilize community resources. For each patient, none, some, or all of these factors may influence the decision on a discharge destination.

Because this is a qualitative study with 58 subjects, it will be used to generate hypotheses concerning the found down syndrome rather than to prove or disprove any hypotheses. This study will capture as much of the

complexity of the found down syndrome and its aftermath as possible in order to uncover areas for further investigation.

Methodology

Patient Enrollment

The subjects in this study are a subset of the 367 patients in Gurley et al.'s study. To compare found down incidents to falls among the elderly, the population of all individuals aged 65 and over from Gurley et al.'s study was used. For the remainder of the study, a subset of the persons aged 65 and over was used. This subset was chosen using the following criteria:

- 1) The patient was aged 65 and over at the time of the incident.
- 2) The patient was admitted to a hospital after transport.
- 3) The patient survived to be discharged to home or a nursing home.

Under these criteria, persons who were found dead were not included in the study. The exclusion of this group leaves some of the causes of longer down times unexplored. The exclusion of persons who were not admitted after being transported excludes from the study the cases with less severe consequences. Persons who were discharged to a relative's home, to a board and care facility, or to a destination other than home or nursing home were not part of the study. Exclusion of these groups of patients limits the consideration of the impact of found down events to the two extremes of the spectrum.

One hundred patients met the three criteria listed above. However, only 58 were transported to hospitals where the medical charts were readily available. Thus, the study population includes only patients transported to eight of the thirteen hospitals included in Gurley et al.'s study. However, the

demographics of the persons included and excluded were not significantly different. (See "Data Analysis" below.)

Data Collection

Data collection for this study is divided into two phases. The first phase involves an in-depth review of the medical charts, including the paramedic pre-hospital forms. The second phase involves in-person interviews with the patients.

Phase One - Review of Medical Charts

The medical charts were obtained from the hospitals to which the patients were transported. The data gathered from the first phase encompassed six areas:

- 1) the demographics of the patient, including age, gender, ethnicity, and insurance type,
- 2) the patient's social conditions prior to hospitalization, including living arrangements and social support networks,
- 3) the patient's medical history and functional capacity prior to and during the hospitalization,
- 4) the circumstances of the found down incident and conditions under which the patient was found,
- 5) the plans for discharge from the hospital, including the process used to arrive at these plans, and
- 6) the impact of the event on social network, living arrangement, physical capacity, psychological well-being, and financial status.

(See Appendix A for the form used to collect data from the medical charts.)

Phase Two - In-Person Interviews

The second phase consists of in-person interviews with the patients. The patients were asked about the same six areas listed above in order to supplement data from the medical charts and to solicit the patients' perspectives. (See Appendix B for the interview guide used.) Due to the fragile health condition of the patients and the unstable housing circumstances inherent to the found down episodes, diligence was taken in trying to locate patients who would be willing to participate. These efforts are summarized below.

The 58 subjects were sent letters which introduced the study and asked for participation in an in-person interview (See Appendix C for a copy of the introduction letter used.) The following table shows the responses to the introductory letter.

Table 2.1: Response to Letter of Introduction (n=58)

Response	# of Persons (%)
Agree to interview	2 (3.4)
Deceased	3 (5.2)
Not interested	1 (1.7)
Not in a condition to be interviewed	4 (6.9)
Mail returned with no forwarding address	2 (3.4)*
No response	46 (79.3)
Total	58 (100)

*Second letters were sent to the two persons whose letters were returned with a forwarding address. The results were included in the table.

Attempts were made to call the 46 patients who did not respond to the letter. These patients were asked over the telephone whether they had received the letter and whether they were interested in participating in the

study. Four of the nonresponders did not have a phone number listed in their medical charts, while thirteen of them were no longer at the telephone number listed. These patients therefore did not receive follow-up phone calls. Table 2.2 summarizes the responses to the follow-up telephone calls.

Table 2.2: Response to Follow-Up Telephone Call (n=46)

Response	# of Persons (%)
Agree to interview	5 (10.9)
Deceased	6 (13.0)
Not interested	8 (17.4)
Not in a condition to be interviewed	7 (15.2)
No longer at address & phone # listed	13 (28.3)
Not available at present	2 (4.3)
New address provided	1 (2.2)
No phone available	4 (8.7)
Total	46 (100)

Due to the low response rate and high number of potential subjects who had moved, letters were sent to the relatives or friends listed as emergency contact persons in the patients' medical charts. Eighteen of the patients who are alive and had not participated in an interview had an emergency contact person with an address listed in the medical chart. These eighteen emergency contact persons were sent letters introducing the study and asking whether they would be willing to provide the new location of the patient (See Appendix C for a copy of the letter used.) Patients whose new addresses were found were introduced to the study in the same manner as before. The letters to contact persons also asked whether the contact person or any other relative or friend would be willing to participate in a telephone interview should the patient be unavailable. Consent forms were mailed with the introduction letter to be

signed and returned before telephone interviews were conducted. The instrument used for the telephone interviews is the same as the one used for in-person interviews, except for minor changes (See Appendix B for the interview guide used.) The responses to this third attempt to contact patients were as follows:

Table 2.3: Response to Mailing to Contact Persons (n=18)

Response	# of Persons (%)
Agree to interview	1 (5.6)
Deceased	2 (11.1)
Not interested	3 (16.7)
Not in a condition to be interviewed	0
No longer at address listed	3 (16.7)
Lost to follow-up	9 (50.0)
Total	18 (100)

After extensive efforts to contact patients, the whereabouts of 72.4% of the patients were obtained and 13.8% of the study population agreed to be interviewed. The following table summarizes the results of all attempts to contact patients:

Table 2.4: Summary of Responses to Attempts to Contact Patients (n=58)

Response	# of Persons (%)
<u>Agree to interview:</u>	
Patients	7 (12.1)
Contact Persons	1 (1.7)
Deceased	12 (20.7)
Not interested	12 (20.7)
Not in a condition to be interviewed	10 (17.2)
Lost to follow-up	16 (27.6)
Total	58 (100)

Data Analysis

Data from the review of paramedic forms and medical charts were entered on the data entry forms in Appendix A. Portions of the data were also entered in Filemaker Pro and Statview database systems. Data from the in-person interviews were audiotaped and transcribed. Data from the telephone interviews were recorded on paper.

Statistical analysis was used to determine whether the study population is significantly different from those who were excluded due to the unavailability of medical charts (42 of the 100 who met the study criteria). Chi-square analysis ($\alpha=0.05$) showed that the 58 patients were not different from the 42 who were excluded in gender, age, ethnicity, and insurance type distributions. The chosen population had a mean median time down that was three hours greater than the excluded group. The 1990 Census data on the average income in each housing tract was used to assign average income levels to patients. Prior to discussing data obtained from the study, a description of the elderly population in the United States will be presented as a basis for comparison with the found down elderly population.

CHAPTER III: OVERVIEW OF THE ELDERLY POPULATION IN THE UNITED STATES

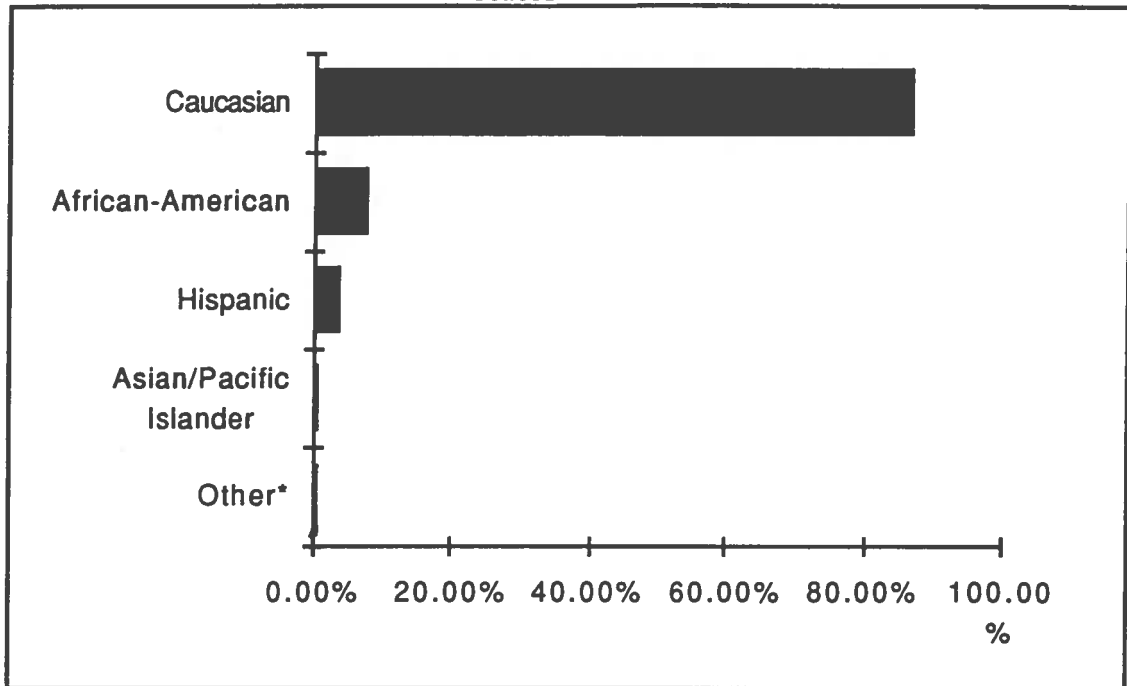
This section provides a summary of six areas of the elderly population in the United States: 1) demographics, 2) living arrangements, 3) social support, 4) health status, 5) psychological well-being, and 6) economic conditions. This information will serve as a basis for comparison with the elderly portion of the found down population.

Demographics

In 1993, individuals over the age of 65 accounted for 12% of the population. The elderly will represent a projected 20% of population by 2020.³¹ The projected rate of increase is 7.8% from the year 1990 to 2000 for those aged 60 and over. This rate is estimated to almost triple to 21.8% from the year 2000 to 2010.⁸ Worldwide, the population aged 65 and over is 332 million and is expected to reach 426 million by the year 2000. The fastest growing group is those aged 80 and over.

In 1990, the majority of those aged 65 and over in the United States were Caucasian³ (Fig. 3.1). The ratio of females to males in the elderly population is three to two. Among those aged 85 and over, the ratio is greater with 100 females to every 39 males. One reason for the larger number of elderly females is the longer life expectancy of females (78.6 years) compared to males (72 years). Meeting the needs of this exploding elderly population is a major challenge for society today. The limited resources available, both human and material, must be used efficiently and effectively in order to accommodate this tremendous growth.

Ethnic Distribution of Persons Aged 65 and Over in the United States in 1990



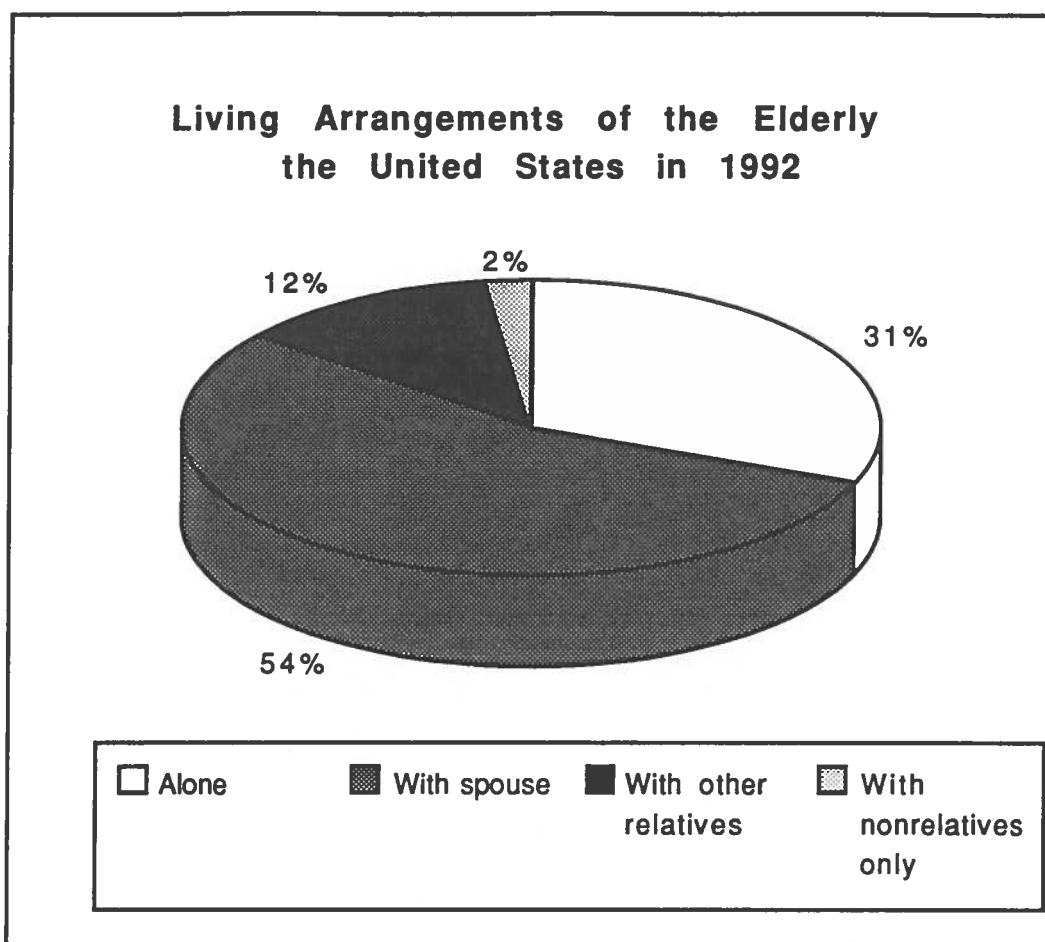
*less than 1%.

Data for graph abstracted from *Statistical Handbook on Aging Americans*³

Figure 3.1

Living Arrangements of Elderly in the Community

Seventy-four percent of the total aged population is living in metropolitan areas,³ but there is a net migration to nonmetropolitan areas.^{3 2} Thirty-one percent of the population aged 65 and over live alone, 54% live with a spouse, 12% live with other relatives, and the remaining 2% live with nonrelatives. Twenty-five percent of those aged 65-74 years live alone, compared to 40% of those aged 75 and over³ (Fig. 3.2).



Data for graph abstracted from *Statistical Handbook on Aging Americans*³

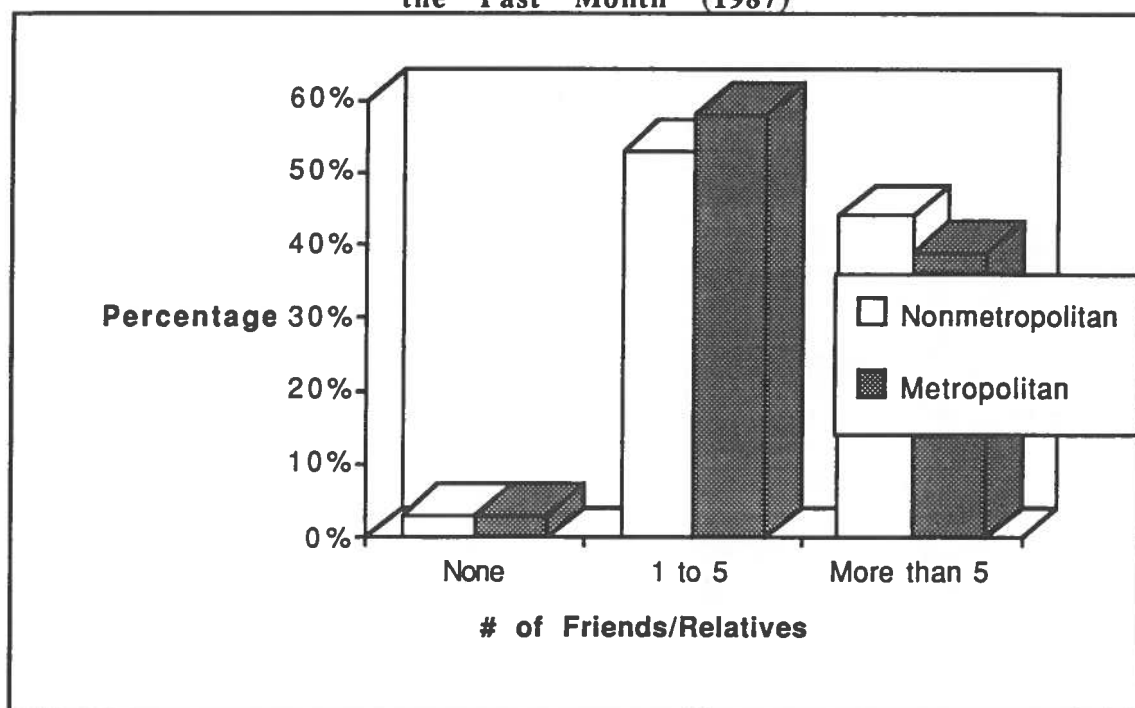
Figure 3.2

Since World War II, more and more seniors without a spouse have chosen to live independently.³³ The proportion of noninstitutionalized elderly persons living alone increased by close to 9% among males and 13% among females between 1960 and 1980.⁸ There has been only a small change in the number of children available to their parents in the past 12 years. However, the frequency of interaction among parents and their children has decreased from 50% to 33%.³⁴ Thus, in general more and more elderly persons are living alone.

Social Support

Many studies document the potential for social isolation among the elderly. Three percent of the elderly population have not talked to any friends or relatives in the past month (Fig. 3.3). Ten percent of those living in nonmetropolitan and 13% in metropolitan areas have no relatives whom they can call for help³ (Fig. 3.4). In O'Connor's study of 200 elderly persons living alone, 39.4% did not have the means to obtain emergency help.³⁵ Twenty-five percent of those living in nonmetropolitan areas and a higher percentage of those living in metropolitan areas have no friends whom they can call for help (Fig 2.5).

Number of Friends/Relatives the Elderly Talked with in the Past Month (1987)



Data for graph abstracted from *Statistical Handbook on Aging Americans*³

Figure 3.3

Number of Relatives the Elderly Can Call for Help (1987)

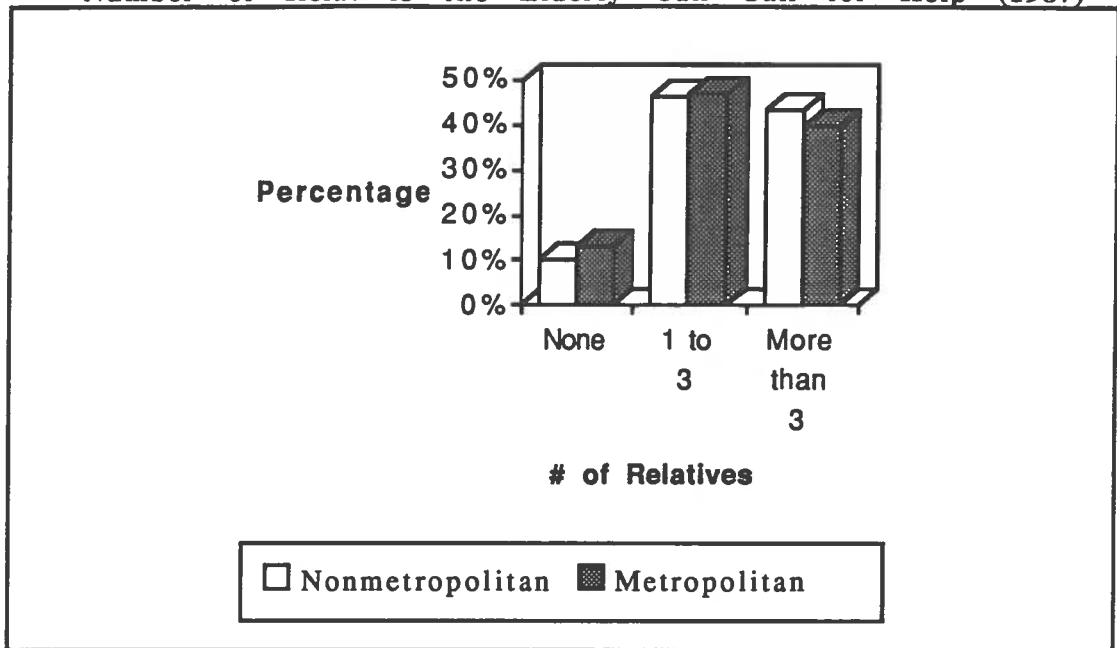


Figure 3.4

Number of Friends the Elderly Can Call for Help (1987)

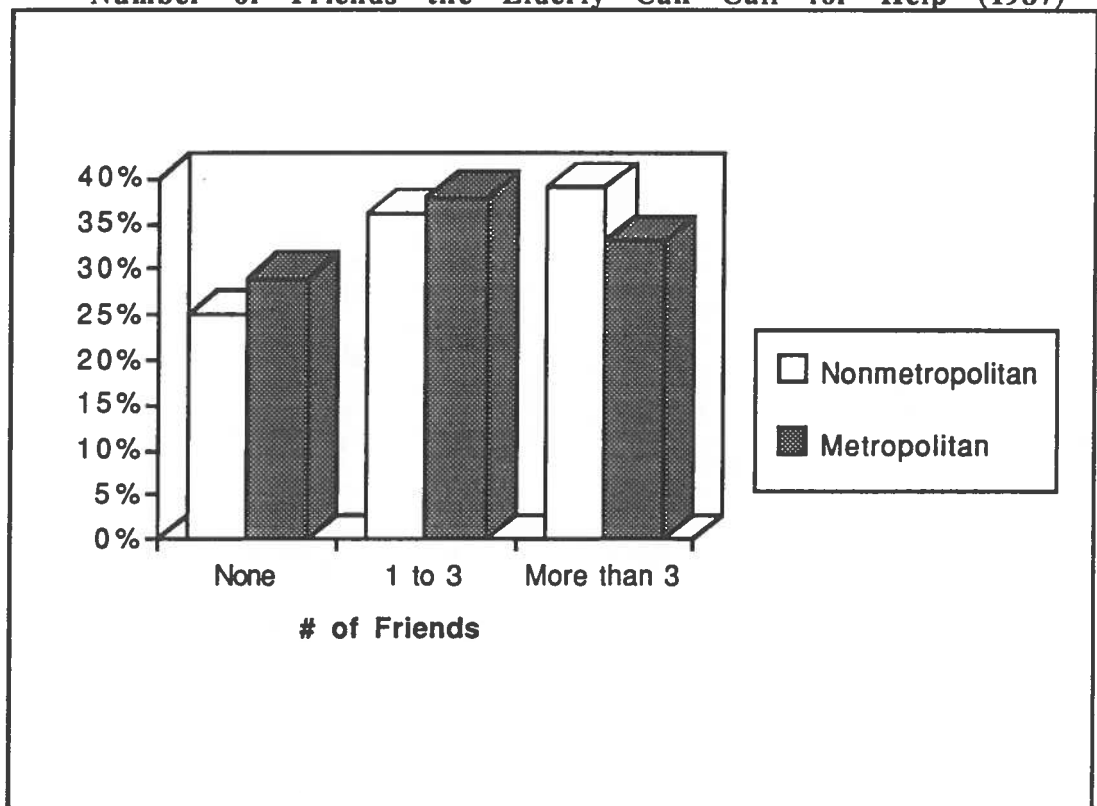


Figure 3.5

Data for graphs abstracted from *Statistical Handbook on Aging Americans*³

Many studies have documented the role of social support in decreasing the risk of institutionalization.^{36,37,38} Pearlman and Crown showed that seniors who have a spouse or an adult child as the caregiver for at least 3 years reduced the risk of institutionalization by 32% and 29% respectively.³⁹ Soldo et al. showed that at "all levels of disability, a child is the most likely primary caregiver and an unpaid helper other than a child is the second most likely" (in the example of a woman with one daughter and one son).⁴⁰ Thus, many seniors live in social isolation which increases the risk of institutionalization.

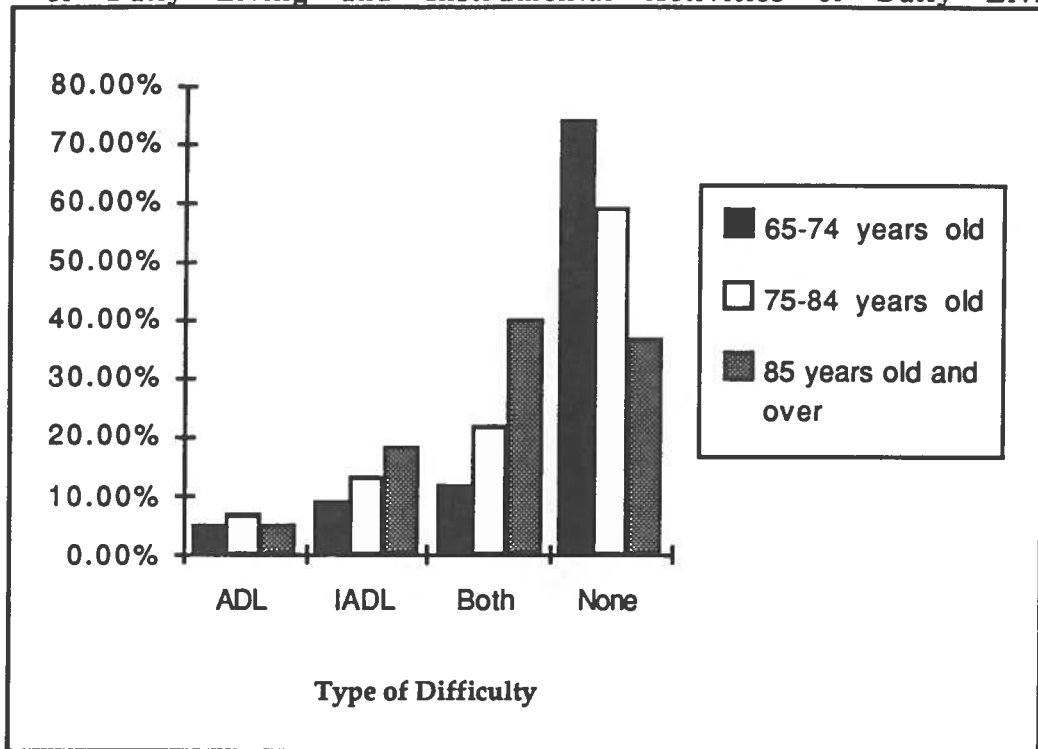
Health Status

In the United States, chronic diseases, including those of the frail elderly, have become more prevalent than the acute diseases and infections that once predominated. Although a quarter of the seniors in America find their health to be good or excellent, 20% have at least one minor disability and 80% have at least one chronic condition.³

Functional Capacity

The majority of individuals between the ages of 65 and 85 have no difficulties with the activities of daily living (ADLs) or instrumental activities of daily living (IADLs).³ Most individuals over 85 years of age, however, have some difficulty with ADLs or IADLs (Fig. 3.6).

**Distribution of Persons with Difficulty with the Activities
of Daily Living and Instrumental Activities of Daily Living**



Data for graph abstracted from *Statistical Handbook on Aging Americans*³

Figure 3.6

Chronic Illnesses

The chronic physical illnesses most prevalent among the elderly are arthritis, hypertension, heart conditions, hearing and visual impairments, cancer, and diabetes.³ Seventy-five percent of all deaths are caused by three conditions - heart disease, cancer, and cerebral vascular accidents.⁸

Cognitive impairments, including disorientation and senility, are also found among the elderly (See "Psychological Well-Being" below).

Access to Medical Care

Despite increased prevalence of chronic conditions, access to medical care among the elderly has not necessarily increased. Clarfield and Bergman found that 25% of the 105 elderly patients in their study population lived alone. One-third of the patients had no primary care doctor, and one-third had physicians who refused to make home visits.⁴¹ Salamon states that older patients are more likely to see their family doctor retire or relocate. As a result, these seniors would lose the physician they have had for many years. Another reason some seniors no longer see their regular physician is that relatives may have convinced them to switch to younger doctors who specialize in geriatrics.⁴²

Emergency Care

Persons aged 65 and over often have accidents that require emergency medical services and hospital care. Twenty-two percent of 14,000 emergency medical service dispatches in a mid-sized city were to persons over 65 years old.⁶ In a study of 1,154 injuries requiring emergency medical service, falls accounted for 60.7% and motor vehicle accidents for 21.5% of the injuries.⁴³ Seniors are hospitalized more frequently than younger persons. They also tend to have longer hospital stays, although the duration of hospital stay has decreased as a result of technological advancements, attempts to control costs, and the increase in home health services.³

Responsibility for the Care of the Elderly

Both "low fertility and low mortality" have led to an increased number of people in the oldest age ranges and a decreased number of caretakers. Prior to the establishment of the Social Security Act of 1936, many people expected

the children to take care of the majority of the aging parents. Now many people expect the state to take responsibility for the elderly.³³ The U.S. government spends 10.2% of its total expenditures on health services and supplies for nursing home care.³ Medicare and Medicaid covers almost all seniors. Close to 1% of the elderly have no insurance.¹³

Psychological Well-Being

Contrary to common belief, psychopathology is uncommon in old age. Results from the NIMH Epidemiological Catchment Area studies show that the prevalence rates of all psychological disorders, excluding cognitive impairment, were lowest among individuals over 65 years of age.³¹ The following sections will discuss some of the more common psychiatric disorders present among the elderly.

Psychological Disorders

Depression is the most common psychological disorder among the elderly. Nonetheless, it is less prevalent among the elderly than among persons of middle age. Although the overall rate of depression among the elderly is less common, the prevalence rate of depression among seniors in nursing homes is much higher than among community-dwelling elderly persons.³¹

Although depression is the most common psychological disorder among the elderly, other disorders have also been recognized. The incidence of schizophrenia in the over-60 age group is only slightly lower than in the

general adult population. The prevalence rates of anxiety disorders are lowest among persons over 65 years of age. Eating disorders and malnutrition are common problems among the elderly, especially among institutionalized individuals in some areas of the country. The Health and Nutrition Examination Survey showed that 16% of Caucasians and 18% of African-Americans over 60 years of age consumed less than 1000 calories per day. A survey of nursing homes in Florida showed that as high as 58% of residents were malnourished to some degree.³¹

The prevalence of alcohol abuse was 22 per 1000 for those aged 65 to 74 and 12 per 1000 for those aged 75 and over. The highest rate, 105 per 1000, were found among elderly widowers. Alcohol abuse with an onset in the later years is often associated with stressful life events such as retirement, relocation, bereavement, and financial concerns.³¹

Five to ten percent of the seniors in the U.S. have dementia. Decline in intellectual capacity with aging varies on an individual basis. Many seniors demonstrate no significant reduction in intellectual capacity in their eighth decade of life, while some elderly persons even showed continued increases in intellectual abilities.³¹

Suicide

The elderly account for 12% of the total U.S. population, but 17% of the suicides.³¹ The highest suicide rate of any age group in the United States occurs among persons over 65 years of age. Caucasian males are at the greatest risk, accounting for over 73% of the suicides among men.⁴⁴ Suicide, however, is not one of the major causes of death among the elderly. For instance, the rate of suicide among elderly white males is one per cent of the mortality rate for cardiovascular disease.⁴⁵

Psychiatric disorders are estimated to be present in over 90% of all suicide victims. However, a smaller number of elderly suicide victims have a psychiatric history than younger victims. Fifty percent of suicide victims have a diagnosis of major depression and ten percent of thought disorder. Seventy-five percent of the elderly who commit suicide do so within one month of a visit to their personal physician. The events that may trigger a suicide attempt include the death of a relative or close friend, the necessity of an undesired move or change, and the diagnosis of a major illness. Losses are the most prevalent reasons for suicide, particularly the loss of functional or cognitive ability or the loss of self-esteem.⁴⁴

Life Satisfaction

Studies have shown that the majority of the elderly persons are satisfied with their lives.³¹ Costa et al. found that subjective well-being does not decline with age.⁴⁶ A senior's perceptions of death and institutionalization and ability to adapt to changes in living arrangements may influence his or her degree of life satisfaction.

Views on Death

In terms of the elderly population's views on death, there appears to be two categories of elderly persons. Most of the elders in one study have accepted death, while a small portion found ways to evade the subject.⁴⁵ Weisman and Kastenbaum found that there were two almost equally prevalent approaches to death. One group of elders gradually worked on "closing down operations," such as discussing funeral arrangements, saying farewell to friends and family, and making wills, to bring their lives to what they believe to be a

proper conclusion. Another group continued with their daily lives as if death were no where in sight.⁴⁵

Views on Institutionalization

Many elders perceive placement in a nursing home as the "loss of place and purpose." Pending or recent placement in a nursing home is the most frequently cited reason for suicide. In one study, about 20% of the long-term care facilities that responded reported at least one suicide within a two-year period. Those over age 75 tend to use "indirect intentional life-threatening behaviors" such as refusing to eat or drink or to take medications to reach death.⁴⁴

Adaptation to Changes in Living Arrangements

Part of what determines whether an elderly person survives relocation to a nursing home includes what Rosowsky calls "goodness of fit" which refers to how the person's personality interacts with the system of the institution. "Fit" will influence how the individual adapts to the system as well as the care he or she receives. Rosowsky mentions that iatrogenesis can refer not only to harm caused by medical diagnosis or treatment, but also to "the restriction of autonomy, denial of self-control, and interruption of multiple psychosocial threads used to weave the tapestry of our lives."⁴⁴

Economic Conditions

Over 20% of males and 13% of females aged 60 and over contributed to the labor force in 1990.⁸ Nine out of ten seniors in America are on Social Security which accounts for 35% of their income. Groups with high rates of

poverty include the oldest old, people living alone, African-Americans, Native Americans, some Asian groups, and Hispanics. Half of the elderly population are women, yet they represent over 75% of the poor. In 1990, 3.7 million persons aged 65 and over were below the poverty level, while another 2.1 million were within 125% of the poverty level.³

Conclusion

The above section provided an overview of the general aging population in the United States. A subgroup of this population have been victims of the found down syndrome. Gurley et al.'s study found that the rate of occurrence of this syndrome increased exponentially with age. For persons aged 60 to 64, the rate of occurrence was 3 per 1000, while for those over aged 85 and older, the rate was 27 per 1000.¹¹ The following chapters will present the results of a qualitative study of the found down syndrome among the elderly.

CHAPTER IV: PRIOR TO THE FOUND DOWN INCIDENT

Examination of the demographic, social, and medical background of the study population is significant in the identification of risk factors for the found down syndrome. This section provides an overview of the 58 elderly found down victims prior to the found down incident. A description of the general demographics and living arrangements of the study population will be presented first. This will be followed by a discussion of the patients' social and medical backgrounds prior to being found down.

Demographics and Living Arrangements of the Elderly Found Down Population

This section compares the study population with the general elderly population in the United States. Table 4.1 summarizes the demographics of the two populations. The study population is 51% female, a lower percentage than in the U.S. population. The study population has a lower percentage of Caucasians, but a higher percentage of African-Americans, Hispanics, and Asians than the U.S. elderly population (Fig. 4.1). Almost half of the study patients are aged 75 to 84, (Fig. 4.2) while over half of the U.S. elderly are aged 65 to 74. All 58 of the elderly persons in the study lived alone when the found down incident occurred. Sixty-two percent of the elderly persons in the U.S. live alone.³ Of the study population, 48% were widowed, compared to 14.2% of the U.S. population.³ Forty-six percent of the study population had both Medicare and private insurance. One of the patients had no insurance (Table 4.2). In the U.S. elderly population, 68.3% had private insurance and 0.9% had no insurance.³ The median incomes for both males and females were

significantly higher than the corresponding incomes in the U.S. elderly population.

In summary, the elderly found down population has a larger percentage of males and persons aged 75 and over than the elderly population in the U.S. The study population is also more ethnically diverse. The percentage of widows and persons who live alone is higher in the study population than in the elderly U.S. population. The median income of the study population was higher than that of the elderly in the U.S.

Table 4.1: Demographics of the Study Population and United States Elderly Population

	Study Population	U.S. Elderly Population †
<u>Gender</u>		
Males per 100 females	96	67.2
<u>Ethnicity</u>		
Caucasian	72%	87%
African-American	12%	8%
Asian	10%	1%
Hispanic	2%	4%
Other	2%	<1%
Unknown	2%	---
<u>Age</u>		
65-74	26%	58%
75-84	46%	32%
>= 85	28%	10%
<u>Widowed</u>	48%	14%
<u>Live Alone</u>	100%	62%
<u>Health Insurance</u>		
Medicare	84%	96%
Medicaid/Medi-Cal	25%	9.5%
Private	60%	67.7%
Not Covered	2%	0.9%
Unknown	2%	---
<u>Median Income</u>		
Male	\$31,966	\$10,893
Female	\$36,199	\$8,746

† Data from Frank L. Schick & Renee Schick, *Statistical Handbook on Aging Americans*.³

Ethnic Distribution of the Study Population

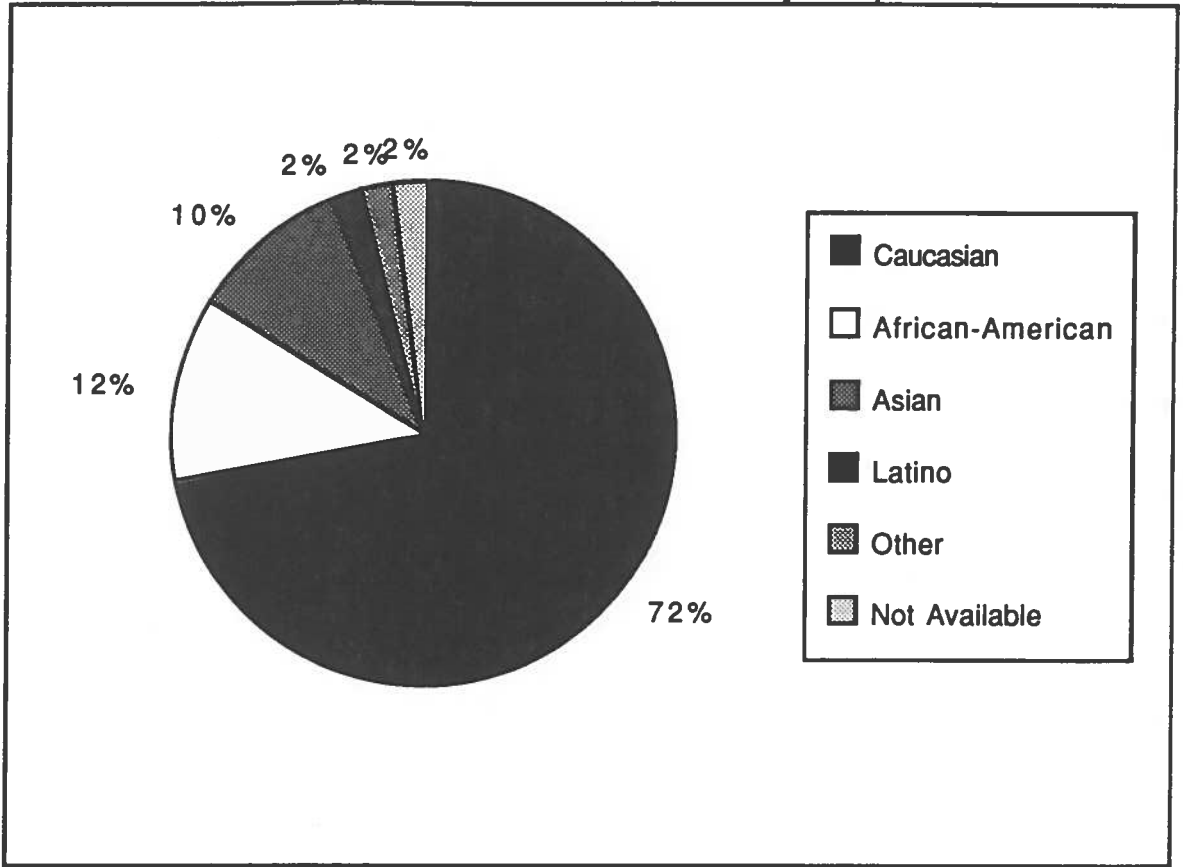


Figure 4.1

Age Distribution of the Study Population

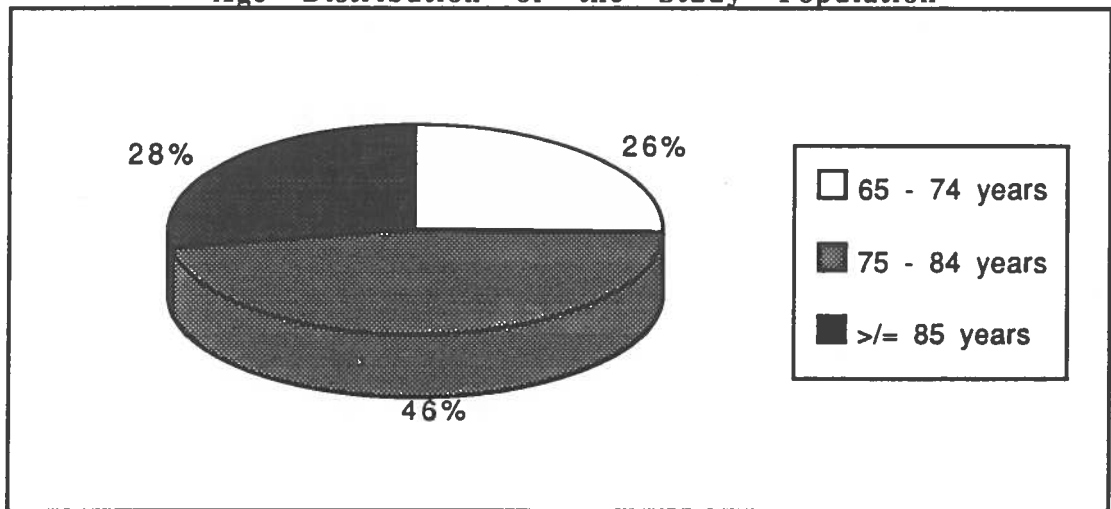


Figure 4.2

Table 4.2: Type of Health Insurance

Type(s) of Insurance	Number of Patients	Percent of Patients
Medicare	9	16
Medi-Cal	2	3
Medicare & Medi-Cal	10	17
Medicare & Private	27	46
Medicare, Medi-Cal, & Private	3	5
Private	5	9
None	1	2
Not Available	1	2
Total	58	100

Social Background Prior to the Found Down Incident

To better characterize the found down population, a few of the social aspects of the victims' lives will be discussed. Some of the found down victims have friends and relatives who visit regularly. Others live in social isolation.

Widowhood

Almost half of the population is known to be widowed. Of those who have lost their spouses, the women were, in general, widowed for a much longer period of time than the men. Some of the women have lost their husbands over 25 years ago; most were widowed at least eight years ago. Of the widows interviewed, only one person mentioned her husband without being asked about him. None of the widows showed any signs of maladjustment to the loss of their husbands. In contrast, the majority of the widowers with known years of widowhood had lost their spouses recently. The longest known period of widowhood among the males was two years. Mr. W., who lost his wife two years ago, misses her deeply:

Without my wife, I'm real lonesome, because she's about the nicest woman I'd ever met... We were married forty-seven years. That's a long time...I know at the end she was very very sick and I did all I could for her. I wouldn't have minded doing it even more, but she just died...My life began when I met her and it ended when she died.

A widow or widower is more likely to live alone than a married individual and therefore may be at increased risk for being found down. A longer duration of widowhood may mean more years of living alone which may further increase the risk of being found down.

Relatives

Studies have shown that among the elderly who live alone, individuals with greater social ties have higher survival rates.⁴⁷ A majority of the seniors have relatives living within two hours' drive (Tables 4.3 & 4.4). For instance, Mrs. Z.'s relatives visit her daily, and Mrs. D.'s relatives help her with her activities of daily living. However, 24% of the population did not have any relatives who lived nearby. Some of the seniors interviewed mentioned that most of their relatives have died. Ms. O. explained that her family had "all gone since the 80s, leaving her alone." Similarly, Ms. R. states, "I have an aunt who's ninety-three and some cousins in New York, but otherwise I do the rest of it [taking care of herself] myself."

Table 4.3: Social Network

	Number of Patients	Percent of Patients
Relatives within two hour's drive	33	57
Relatives farther than two hour's drive away	14	24
No relatives within two hour's drive but have friends to contact in case of emergency	14	24
No relatives/friends within two hour's drive	6	10
No relatives or friends anywhere	3	5

Table 4.4: Relatives In the Bay Area

Type of Relative	Number of Patients	Percent of Patients
Daughter	9	16
Son	7	12
Sister	5	9
Brother	4	7
Niece	4	7
Nephew	3	5
Cousin	3	5
Grandson	3	5
Unspecified Relative	3	5

Data from the medical charts and interviews showed that although 57% of the patients are known to have relatives in the Bay Area, only 12% of the total population were known to be visited regularly (at least once a month) by relatives (Table 4.5). For instance, Mrs. H. has sons who live less than one hour's drive away, but told her nurse that her sons would not be able to help her after discharge. She explained that she has not maintained close relationships with them. The percentage of seniors who have relatives who contact them regularly is likely to be much smaller than the percentage with relatives nearby.

Home Service Providers

Forty-one of the seniors have regular visitors. The majority of the visitors are not relatives or friends, but people who provide home health or home maintenance services. Mr. G.'s only regular visitors are a visiting nurse and a Meals on Wheels employee. Mrs. S.'s regular visitors are a cleaning person who comes to her home once a week and a friend who helps her with the groceries.

Table 4.5: Patients Who Have Regular Visitors

Type of Visitor	Number of Patients†	Percent of Patients
Home Maintenance/ Health Service Provider	23	40
Neighbor/Friend	10	17
Relatives	7	12
No Visitors	1	2
Unknown	17	29

†Patients with more than one visitor are counted more than once.

Friends/Neighbors

A large portion of the friends who visit the seniors on a regular basis are apartment managers or neighbors who have become their caretakers. Mr. P.'s regular visitor is his apartment manager who helps him with grocery shopping and cleans his commode daily. One patient's medical chart read: "This patient has no friends or family members. Hotel manager is [person's name]." Mr. M.'s neighbor visits him regularly to see if there is anything he needs. Five of the seniors have authorized someone to have their power of attorney. Two such persons are neighbors of the patients.

No Visitors

Some of the found down patients not only live alone, but also live in social isolation. The medical charts of 59% of the seniors made no mention of regular visitors. Five percent of the population have neither relatives nor friends. Mrs. H. lived "in a residential hotel with no transportation, no phone available, and no help available after discharge." Another patient's medical chart read: "He has never been married and has no children and he currently lives alone...No help available after discharge."

As shown, many of the found down victims do not have close friends or relatives as sources of social support. These seniors would live in social

isolation if they did not have neighbors or home health service providers who check on their well-being periodically. Such isolation may have significant implications for the found down syndrome and its outcome.

Health Status Prior to the Found Down Incident

A senior's health status prior to being found down may be the reason for a found down event. The health status may also influence the senior's ability to get help and thus affect the outcome of the incident. The following section will discuss three areas of the health status of the study population prior to the found down incident: 1) the number of medical conditions, 2) the doctor-patient relationship, and 3) functional capacity.

Multiple Medical Conditions

Forty-five percent of the population had multiple medical problems. Only 8% were known to have less than three medical problems (Table 4.6). For instance, Mrs. G. has a history of a cardiac condition, diabetes mellitus, Broca's aphasia, renal insufficiency, anemia, hypercholesterolemia, hypertension, and syncope. Another patient's medical history included cardiac condition, diabetes mellitus, cerebral vascular accidents, hypertension, toe amputations, cataracts, auditory deficits, hemiparesis, and aphasia. Some of the conditions such as syncope, anemia, and cerebral vascular accidents may precipitate found down incidents. Other conditions including aphasia and auditory deficits may make obtaining help when down more difficult. Hypertension, diabetes mellitus, and renal insufficiency are three of the many conditions that may be

exacerbated by being found down. In the literature, multiple medical problems has been cited as a predictive factor of medical emergencies (See Chapter II).

Table 4.6: Number of Medical Problems Prior to Hospitalization Last Year

Number of Medical Problems	Number of Patients	Percent of Patients
>3	26	45
2	3	5
1	2	3
Unknown	27	46

Cardiac condition is the most prevalent medical condition among the elderly found down patients, followed by a history of falls and hypertension (Table 4.7). Cardiac disease and hypertension are two of the most common chronic conditions found among the elderly population in the U.S. The prevalence of cardiac disease among found down victims is greater than that in the general U.S. elderly population. The incidence of hypertension is about equal in the two populations. An estimated one-sixth of the seniors in the U.S. have had multiple falls, compared to 40% of the study population. Because falls is the leading cause of found down incidents, a history of falls will be discussed further.

A history of falls was noted in the medical charts of 40% of the patients. The actual percentage may be higher due to the possibility of under reporting. For instance, Mrs. K. had fallen two weeks prior to her most recent admission, sustaining a head injury that required paramedic transport. Another senior's most recent admission is her fourth in the past two and a half months for injuries due to falls. The large number of found down victims with a history of falls suggests that this condition would be a useful indicator of those at risk for being found down.

Table 4.7: Medical History

Type of Medical Problem	# of Patients	% of Patients
Cardiac Condition	26	45
History of Falls	23	40
Hypertension	21	36
Alcoholism*	15	26
Cigarette Smoking*	15	26
Degenerative Joint Disease	15	26
History of Fractures	15	26
Tumor	14	24
Pulmonary	13	22
Renal	13	22
Visual Deficit	13	22
Herpes Zoster	12	21
Cerebral Vascular Accident	11	19
Gastrointestinal	10	17
Psychological	9	16
Diabetes Mellitus	7	12
Anemia	6	10
Dementia	6	10
Peripheral Vascular Disease	6	10
Auditory Deficit	4	7
Syncopal Episodes	4	7
Amputation	3	5
Electrolyte Imbalance	3	5
Failure to Thrive	3	5
Hemiparesis	3	5
Obesity	3	5
Seizures	3	5
Thyroid Abnormality	3	5
Weight Loss	3	5
General Pain	2	3
Skin Condition	2	3
Speech Deficit	2	3
General Weakness	1	2

* present or history of

Doctor-Patient Relationship

Although elderly persons may have more chronic medical conditions than the younger members of a community, they do not necessarily have more long-term relationships with their physicians. The medical charts and

interviews with found down victims indicate that approximately half of the seniors in the found down population have regular medical providers. For instance, Mrs. C.'s regular doctor recently passed away. He "was like family" to her. Another patient's regular doctor "stopped coming" to see her for reasons unknown to her. One reason some of the elderly persons did not have regular providers is that they have been healthy and did not seek any medical care until they were found down.

Functional Capacity

This section will focus on the functional capacity of the individuals in the study prior to the found down incident. Seniors who were reportedly capable of performing the activities of daily living independently prior to the found down incident were categorized as "managing well." Persons whom the paramedics considered unable to care for themselves or who had multiple emergency room visits within the year were categorized as patients who were "managing poorly." Fifty-nine percent of the study population were managing well prior to their hospitalization last year.

Managing Well Without Community Support

Twelve percent of the seniors in the study were managing well without support from the community while living alone (Table 4.8). Mr. W. explains how he was able to maintain his home prior to being found down: "I didn't call plumbers. I did my own painting, carpentry. I redid my own kitchen. I did the plumbing." Similarly, Mrs. C. said, "I did my own home. I did my own garden and everything it takes to maintain a garden and a home. I was able to take care of it." Although previously hospitalized with a diagnosis of dementia, Mr. R.S. was completely ambulatory as recently as one day prior to being found

down and said he went out to buy groceries for himself. This subgroup of seniors required no community services to maintain their homes and life affairs prior to being found down.

Table 4.8: Management Prior to Being Found Down

Community Help	Managing Well # (%)	Managing Poorly # (%)	Management Status Unknown # (%)
Yes	7 (12)	3 (5)	0
No	15 (26)	4 (7)	4 (7)
Unknown	12 (21)	6 (10)	8 (14)

Managing Well with Community Support

Twenty-six percent of the population were managing well at home with at least one source of community help. The help required varied from a few hours of house cleaning per month to 24-hour nursing care. Housekeepers were the primary source of help for the persons utilizing community support. Mrs. F. had a person come twice a month to help her clean the house. Some of the seniors were unable to prepare their own meals and had help from Meals on Wheels or a homemaker. Nine percent of the population required a visiting nurse. Some of these seniors required a home nurse to give the correct dosage of medication. For instance, one 85-year-old man in the study received intravenous heart medication twice a day from a visiting nurse. Some seniors required periodic checks on blood pressure or glucose levels. Of the found down victims who were managing well, the number utilizing community support exceeded the number without support.

Managing Poorly While Receiving Community Help

Nine percent of the population were managing poorly despite receiving help from the community. For example, Mr. F. was found by the paramedics dehydrated and starving with "obvious failure to thrive" in a "chaotic and dirty" home. Another senior spent all of his days except for one in a hospital during the three months prior to the found down episode.

Managing Poorly While Receiving No Community Support

Three percent of the population were managing poorly and did not receive community help. One senior was hospitalized for the fourth time in the past 2.5 months. His physician wrote:

The patient does poorly at home where she lives alone. She falls sustaining these injuries. It has been recommended that she find some assisted living, but she has not done this.

Thus, close to a tenth of the seniors were managing poorly prior to the found down incident. Some of these seniors had help from community support services, while others did not.

Conclusion

Although the study population is diverse in terms of demographics, living arrangements, social background, and medical histories, some factors are highly prevalent in this group of seniors. The majority of the seniors were Caucasian females, although the found down phenomenon occurs in persons of both gender and all ethnic backgrounds. All of the victims lived alone due to the criteria for inclusion in the study. However, many of the patients lived in social isolation or had community health care providers as their only source of social contacts. A large percentage of the population had multiple medical

problems, with cardiac condition, a history of falls, and hypertension being the three most prevalent conditions. Despite having multiple medical conditions, the majority of the seniors were managing well in their homes either with or without community support. Thus, social isolation and multiple medical problems may place a senior at greater risk of being found down, despite the capacity to live alone.

CHAPTER V: THE FOUND DOWN INCIDENTS

The physical and mental trauma of found down experiences range widely in magnitude and duration. This section will begin with a few examples of found down incidents to provide a sense of the spectrum of experiences in the study population. Following the examples will be a discussion of the causes of found down incidents and the circumstances of the victims' discovery. The patients' conditions upon discovery will be discussed last.

Some of the victims did not recall being found down, while others remember the event vividly. Mr. W. became unconscious immediately after falling off a ladder and was discovered and transported to the hospital within minutes of the accident. Mr. R.S. experienced a much longer down time, approximately 12 hours, but does not know what happened. The paramedics who found him wrote:

Patient's friend discovered patient supine on the floor, unable to ambulate and called 911. Upon our arrival, the patient was supine near the bathroom, alert and oriented. He states that he lowered himself to the floor, no fall, sometime this morning. Denies pain. Physical exam reveals numerous bruises on the right arm, back, thorax. Yet patient denies ever falling... Neighbor states patient has alcohol abuse problem. Patient denies having any drinking, or any problem-falling-whatsoever. House appears unkempt. Last drink unknown. Last food unknown.

Another patient with a similar presentation was Ms. B.C. The paramedic who transported her wrote:

65-year-old female found seated on commode without any obvious respiratory distress - Home care person found patient...Patient extensively dehydrated...upper torso to waist emaciated - last p.o. [food intake] 7 days ago, some water only with bread. Note: Patient is home by self without any relatives - unable to cook food for self, nor clean home.

Another patient, Mrs. F., recalls her experience in detail:

I came downstairs here about midnight to make a cup of hot chocolate for myself and little did I know that a washer underneath my sink had given way and the kitchen floor had water in it. The first step over, I just went flying. I hit my leg, my femur bone, and I could hear it crack. I was just in my bathrobe and nightgown...So I knew that I had to get to the telephone. So two hours later, (people told me it was 3:00 a.m., so I figured it was two hours), I inched my way to the front door. My phone is right there by the front door...I was just praying and hoping to God that I could do it - get to the phone. I was alone in the house and I knew I had to get help, and of course the bathrobe had picked up a lot of the water. When I hit the carpet, it was very difficult to move. I had to get on to my other side and it was very difficult. I had to inch my way. My bathrobe impeded my progress on the carpet...It was painful, but I knew I had to do it, so I just kept at it for a while and kept going.

These examples of found down incidents are available, because these individuals survived the incident. Twenty-three percent of the 367 patients in the found down study did not live to tell their experiences.¹¹

Causes of Found Down Incidents

The above examples already alluded to some of the causes of found down incidents. The following section will discuss in greater depth the causes and circumstances of the found down incidents. Table 5.1 provides a summary of the events cited as the causes of found down incidents. Some of the chief complaints of the patients as recorded by the paramedics are listed in Table 5.2. The four most common causes of found down incidents will be explored further in this section.

Table 5.1: Causes of Found Down Events

Reason	Number of Patients	Percent of Patients
Mechanical Fall	25	43
Cerebral Vascular Accident	5	9
Unable to Get Up After Sitting or Lying Down	5	9
Syncope or Near Syncope	5	9
Change in Mental Status	4	7
Shortness of Breath	3	5
Transient Ischemic Attack/Myocardial Infarction	3	5
Dislocated Joint While Standing/Walking	2	3
Other	5	9
Unknown	1	2

Table 5.2 Examples of the Chief Complaints of Found Down Victims
(Quotes from the paramedic pre-hospital forms)

<p>Mechanical Fall</p> <ul style="list-style-type: none"> •"Patient found lying in left lateral recumbent position on floor with altered mental status...there is evidence that patient fell on the carpeted floor. •"Patient sitting on floor. Patient states: 'I dragged myself from the bathroom. I slipped and fell at 21:30 and got stuck between the toilet and bathtub." •"85-year-old male lives alone. States he tripped and fell at 03:00 a.m.... and was unable to get up or help...Patient was supine on floor where he made a sort of bed for himself with rug, pillow, sheets, and robe." •"68-year-old female found seated carpeted stairwell of apartment building, post mechanical buckle of left ankle while walking up the stair - patient lost her footing, then fell down approximately 8-10 steps backwards, causing injury and pain to her right leg."
<p>Cerebral Vascular Accident</p> <ul style="list-style-type: none"> •"Patient last seen one week ago and friends called 911 to have her look in on. Patient found on floor right lateral recumbent...Apartment very unkempt. Friends stated patient is normally ambulatory and alert and oriented with well kept house. Patient covered with dirt and urine and feces...has garbled speech." •"Supine on floor conscious, nonverbal, shaking on right side with some movement squeezing hand... Down 12-24 hours. Some blood or food from mouth."

Table 5.2 cont.

<p>Unable to get up after sitting or lying down</p> <ul style="list-style-type: none"> •"Elderly female with recently dislocated hip replacement complains of pain to hip area and general weakness. Left bathroom on foot (does not use walker, etc.) to go to bed, but was unable to make it, so sat on floor and dialed 911." •"78-year-old found on bed alert and oriented. States unable to get up since Saturday (2 days ago)...Patient appears dehydrated. Has dried blood on lips due to dryness."
<p>Syncope or near syncope</p> <ul style="list-style-type: none"> •"Woman found supine in bed, history of feeling dizzy with nausea for two days and epigastric cramping pain." •"Patient found alert and oriented in bed. Complains of lightheadedness for two weeks resulting in falls when standing... Patient unable to get up from bed for fear of syncope. Therefore, patient remained in feces-covered and urine-soaked bed for the last two weeks."
<p>Altered Mental Status</p> <ul style="list-style-type: none"> •"Patient found unresponsive in bed by family...Patient normally speaks English and is self ambulatory." •"80-year-old female reported absent for two days by neighbors. San Francisco Fire Department report patient was tied to chair with clothesline entangled about her body and neck...Patient confused...Does not respond to questions."
<p>Shortness of Breath</p> <ul style="list-style-type: none"> •"79-year-old male who complains of sudden onset of shortness of breath for past two hours...He is able to speak 3 words at a time with accessory muscle use." •"79-year-old female found sitting up in chair, awake, extremely drowsy. Unresponsive to verbal, with extreme respiratory distress - expelling white frothy sputum from mouth."
<p>Myocardial Infarction</p> <ul style="list-style-type: none"> •"I was on the floor in the kitchen and I couldn't tell them when and what just happened...they put me through an MRI tube and found the clot."*
<p>Dislocated Joint</p> <ul style="list-style-type: none"> •"Hip surgery two years ago. While getting out of bed, felt hip 'pop' out - did not fall, slid back into bed." •"Patient found supine on floor of kitchen after falling to the linoleum floor secondary to hearing a loud snap and experiencing extreme pain in the medial aspect of left leg."
<p>Other</p> <ul style="list-style-type: none"> •"72-year-old male, alert and oriented, sitting at home. Complains of unable to urinate or defecate for 5 days with burning ache, pain to lower abdomen for one week." •"On arrival, patient lying in right lateral position, conscious, oriented... Patient has no complaints...Patient was last seen on Tuesday ambulating. Friends became concerned and had police department check on patient. Possible assault to face, unknown when or what. Patient had blood from nose and mouth, old dried. Eyes swollen shut with eye mucus. Patient's right jaw deformed with discoloration."

*quote from in-person interview with patient

Mechanical Fall

Forty-three percent of the found down incidents were due to mechanical falls. The paramedics who found Ms. C.M. wrote:

Mechanical fall in house approximately one hour ago. Patient struggled on floor to get to phone and then to gate to let daughter in. Unable to bear weight on left leg and complains of pain in the left hip only. No c-spine pain or other trauma noted. Shortening and rotation present.

In another case, an 83-year-old woman fell from her bed and was found about twelve hours later on the floor, entangled by a telephone cord. An 80-year-old man sustained multiple bruises from a fall that may have been caused by construction workers who placed the patient's furniture in unfamiliar locations. As illustrated, falls can occur under a number of circumstances. During a found down event when help is not immediately available, the experience and consequences can be much worse than a fall that does not lead to a found down incident.

Cerebral Vascular Accidents

Cerebral vascular accidents accounted for 9%, the second highest percentage, of the found down events. Caretakers, friends, or relatives may find the senior with altered mental status and speech deficit due to a cerebral vascular accident. For instance, Ms. Q. was last seen in her usual healthy state in a well-kept home prior to being found down. She was found over 72 hours after a stroke, lying in urine, feces, and dirt. She was dehydrated and confused. Her speech was garbled. Confusion and speech deficits may prolong a victim's down time and increase the negative physical and psychological impacts of found down incidents.

Inability to Get Up

The inability to get up after sitting or lying down also accounted for 9% of the found down events. As with mechanical falls, a variety of factors may have led to a senior's inability to get up. Such factors include pain, weakness, starvation, and vomiting. One elderly individual was unable to get out of bed for two days due to weakness resulting from severe back pain and nausea and vomiting. She had no food or water for those two days. Another senior, an 87-year-old female, was found dehydrated on the floor next to the bed "unable to get up with complaint of left knee pain, possibly for one day." Although patients who were unable to get up may not sustain the types of injuries seen in patients who had fallen, complications such as decubitus ulcers, dehydration, and rhabdomyolysis (discussed below) are common.

Syncope

Syncope or near syncope is another cause that accounted for 9% of the found down incidents among the elderly. Syncope is defined as a sudden loss of consciousness due to decreased cerebral blood flow with spontaneous recovery.¹⁸ Syncope may be secondary to cardiac arrhythmia, hypotension, hypoglycemia, or a number of other factors. Mrs. P. fell when she attempted to stand up after experiencing lightheadedness for two weeks. The fear of syncope made her unable to get up. Palpitations and dizziness forced another woman to sit down and prevented her from getting up.

Although the reasons for found down events vary widely, the four most common causes are related to health factors. Focusing primary prevention on health maintenance may decrease the number of found down incidents. Awareness of the conditions common amongst found down victims will help designate those at risk for being found down.

Location of Found Down Incidents

As diverse as the causes of found down incidents is the location. Found down incidents can occur anywhere in a home, including stairwells, balconies, and backyards (Fig. 5.1). The following section will elaborate on the two most common sites for found down incidents, the bedroom and the bathroom.

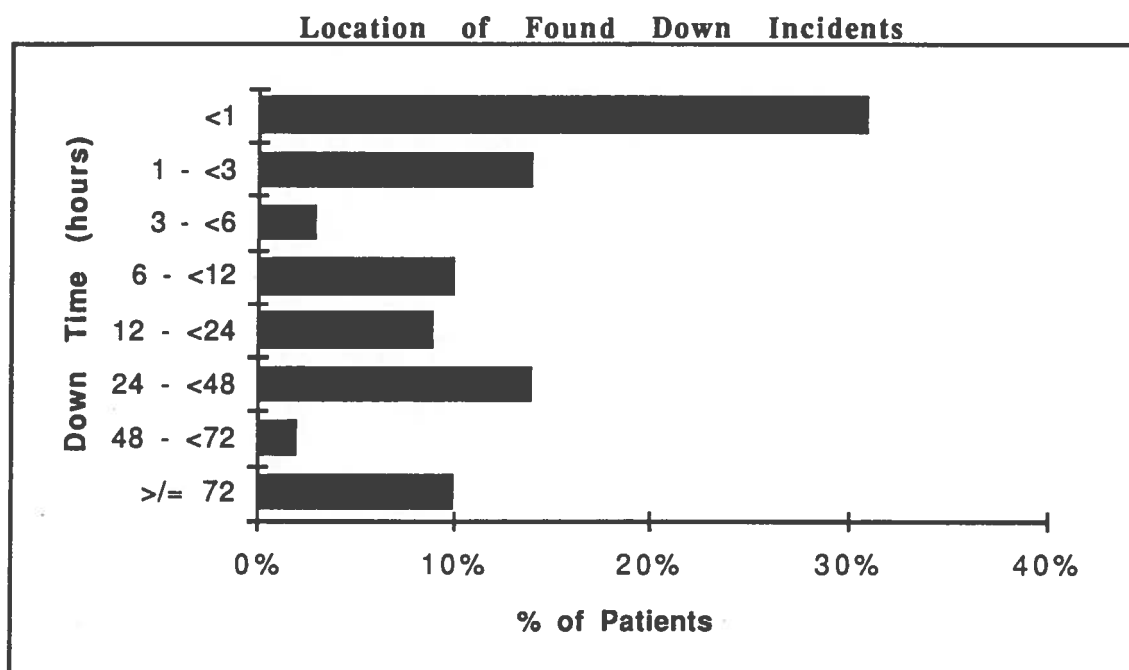


Figure 5.1

Over a third of the patients in the study were found in their bedrooms. Some patients were on their way to bed after turning off the lights. Some patients were unable to get out of bed. A few were attempting to reach the bathroom. The bathroom was the second most common location for a found

down event. Maneuvers such as climbing in and out of the shower or tub or squatting to use the toilet were all associated with found down incidents.

In one study, falls in the bathroom were associated with a lower proportion of severe injuries than falls in other locations. The bathrooms were equipped with grab rails that may prevent or break a fall and thus reduce the amount of injury. None of the found down patients interviewed, except one, had homes equipped with grab bars. Found down incidents occurring in the bathroom often led to more severe consequences than those in other locations. One reason may be the greater distance from the telephone. Another may be the lower probability of either the fall or a cry for help being heard by neighbors. For instance, Mr. P. was bleeding in the bathtub for three days before being found. He described himself as being "like a cadaver, more dead than alive" for those three days. Another victim was found "straddling half in and half out of the bathtub" after crawling to the bathroom with intentions to soak his feet. A third patient, an 88-year-old woman, slipped and became stuck between the toilet and the bathtub.

As shown, found down incidents can occur in a number of places and under all different circumstances. This wide spectrum makes predicting and preventing found down incidents a challenge. Strategies to increase the chances of rescue and to decrease down time would be effective in reducing the negative impact of the incident. Prevention methods will be discussed in Chapter X.

Discovery After a Found Down Incident

The length of time that the patient is down varied from less than one hour to greater than 72 hours (Fig. 5.2). The results from the study indicate

that the down time is positively correlated with the degree of recovery. The median time down for the patients who remained independent in their ADLs one year after being found down was 6.7 hours, compared to 28.6 hours for those who had a decline in ADL performance.†

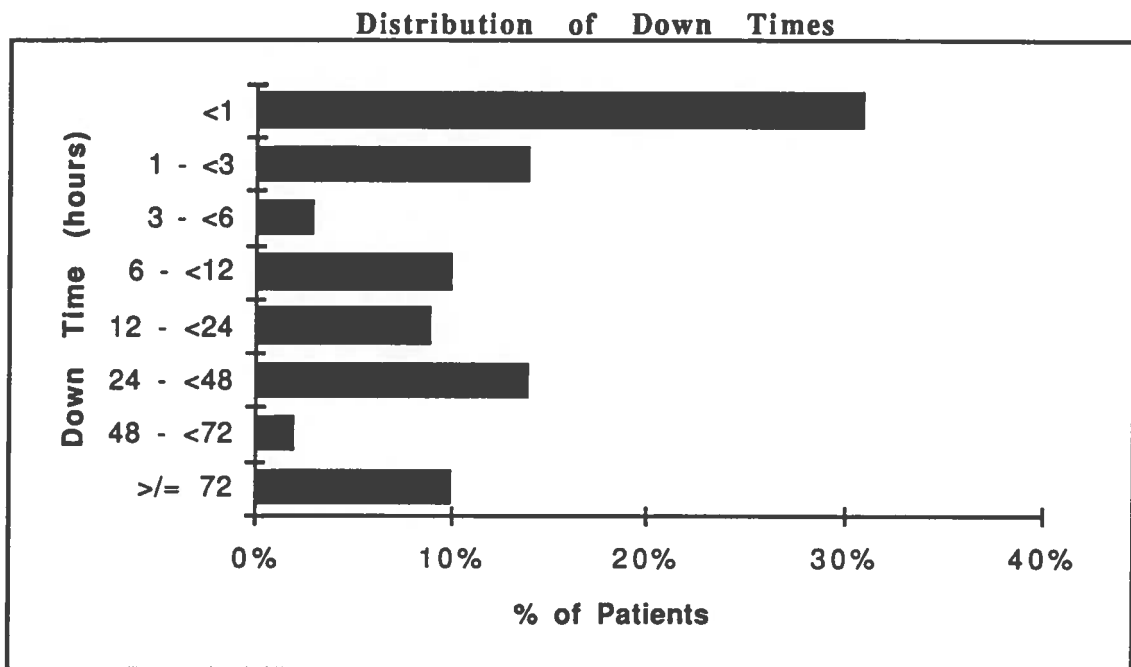


Figure 5.2

As shown, the degree of recovery is correlated with the length of time down. The length of time down is in turn correlated with the patient's relationship to the person who discovers the patient. For instance, patients who were

†calculated using the median for each range recorded, one hour for <1 hour range and 72 hours for >72 hour range.

discovered by friends had a much longer median duration of time down than those found by neighbors or relatives (Table 5.3). The following section will discuss the persons who discovered the victims and the circumstances of the discovery.

Table 5.3: First Person To Call For Help

Person Who Called for Help	# of Patients (%)	Mean Down Time†(hours)
Caretaker	14 (24)	30.5
Neighbor	11 (19)	19.3
Friend*	7 (12)	33.1
Patient	7 (12)	1.3
Relative	6 (10)	19.8
Unknown	13 (22)	-

*who is not a neighbor

†calculated using the median for each range recorded, one hour for <1 hour range and 72 hours for >72 hour range.

Caretakers

Twenty-four percent of the study population were first discovered by caretakers, including visiting nurses, housekeepers, apartment managers, and Meals on Wheels deliverers. Such discoveries were possible due to scheduled visits by the home service providers. Scheduled visits were the reason for 14% of the discoveries (Table 5.4). For example, Ms. M.L. was found by her home care person lying supine on the floor for an estimated down time of three hours. In another case, the paramedic described how the housekeeper found the victim:

Found by housekeeper at 8 a.m. when she came to the house. [Patient was] sitting on the floor. States that she fell out of bed...Housekeeper and neighbor state she lives alone with 2-3 hours of help each day.

For many of these seniors, the caretaker may be their only link with the outside world. The seniors discovered by caretakers tend to have longer down times than the population as a whole. Four of the six seniors who were down for more than 72 hours were discovered by caretakers.

Table 5.4: Reason For Discovery of Found Down Patient

Reason For Discovery	Number of Patients (%)
Patient Called For Help	11 (19)
Patient Failed to Leave House at a Familiar Time	8 (14)
Scheduled Meeting with Patient	8 (14)
Accidental Discovery	3 (5)
Someone Heard Patient Fall	2 (3)
Patient Did Not Answer Phone	2 (3)
Patient Foresaw Potential Emergency & Called for Help Prior to Event	1 (2)
Newspaper/Mail Piled Up	1 (2)
Unknown	22 (38)

Neighbors

Neighbors were the second most common category of people to discover found down patients. In one case, a neighbor noticed that newspapers were piling up in front of the patient's apartment building and called for help. Thirty-six percent of the seniors discovered by neighbors were found within one hour of the incident, compared to seven percent of those discovered by caretakers. A neighbor who is familiar with the times when the patient leaves the house or who checks on the patient daily can greatly reduce the down time of a found down victim. Unfortunately, none of the patients who were discovered because they did not leave the house at predicted times (n=8) were found less than two days after the incident. One reason may be that friends or

neighbors did not see the patient daily and therefore did not notice the patient's absence until two or three days later. Another reason may be that neighbors did not suspect something was wrong until the patient was missing for more than a day or two.

Patients

Eleven of the patients called for help themselves. Often these victims struggle for hours to reach a phone or a means of obtaining help. One victim had to bang on the wall of his apartment until the apartment manager heard him. Another patient took over two hours to crawl to the telephone to call for help. Although many of the patients had to struggle to reach help, all of the patients who managed to call for help themselves were found within three hours of being down.

Friends or Relatives

Only 20% of the found down victims were discovered by relatives or friends, suggesting that a large portion of these seniors do not have relatives or friends who visit regularly. The mean down time for persons found by relatives was similar to that of patients found by neighbors. Victims found by friends had the longest mean down time of all the categories. A regular visitor who has a key to the house can reduce the time period during which the need for help is unknown. Furthermore, no additional time would be required to enter the home forcefully. Forced entry was known to be required for nine of the patients.

Condition of the Patient Upon Discovery

The condition of the senior upon discovery after a found down incident varies with the health of the individual, the circumstances of the event, and the down time. Table 5.5 lists the various conditions of found down patients upon discovery. Only the four most prevalent conditions: 1) in pain, 2) altered mental status, 3) incontinence, and 4) decubitus ulcers will be discussed. Rhabdomyolysis will be discussed along with decubitus ulcers, since both are sequelae of being in the same position for a long period of time.

In Pain

Over half of the seniors in the study population were found in pain. For example, Mrs. J. heard a "loud snap" in her leg and suffered "extreme pain in the medial aspect of the left leg" for close to one hour before being found. Another patient endured "pain all over (face, head, hips, shoulders)" for about 48 hours before she was discovered prone on the floor confused and hypothermic. While trying to reach her walker in dim light, a third victim lost her balance and fell. She struck her head on the floor without losing consciousness and sustained many painful injuries, including a laceration across her left cheek, a nasal bridge wound, right shoulder and hip injuries and bruises on the fronto-temporal region of her head. Pain was the most prevalent condition of the patients upon discovery.

Table 5.5: Condition Found

Condition	Number of Patients	Percent of Patients
In Pain	30	52
Alert & Oriented x 3 or 4	25	43
Altered Mental Status	23	40
Incontinent of Urine and/or Feces	17	30
Decubiti/Cellulitis	16	28
Dehydrated	15	26
Speech Deficit	12	21
General Weakness	11	19
Tachypneic/Short of Breath	8	14
Lacerations/Ecchymoses	7	12
Unresponsive	6	10
Unable to Walk	6	10
Starving	5	9
Tachycardic	5	9
Rhabdomyolysis	5	9
Peripheral Edema	5	9
Acid-Base/Electrolyte Imbalance	4	7
Nausea & Vomiting	4	7
Alert & Oriented x 2	3	5
Dizziness	3	5
Fever	3	5
Hyperglycemic	3	5
Unable to Urinate or Defecate	2	3
Hypertensive	2	3
Alert & Oriented x 1	2	3
Unconscious	2	3
Focal Seizures	2	3
Trauma	2	3
Emesis	2	3
Alcohol on Breath	2	3
Hypothermia	1	2
Unable to See	1	2
Hypoglycemic	1	2
Failure to Thrive	1	2
Anemic	1	2

Altered Mental Status

Although 43% of the victims were found alert and oriented, another 40% were discovered with altered mental status. Many individuals were unable to recall the found down incident or the surrounding events. A number of factors, single or multiple, could have led to a change in mental status. These factors include dehydration, head trauma, electrolyte or acid-base imbalances, and insulin overdose. For instance, Mrs. K., who was unable to recall the incident, was found hypoglycemic and hypokalemic. Many of the study patients returned to their baseline mental status once their fluids, electrolytes, and/or glucose levels have been corrected.

Lying in Feces and Urine

A third of the seniors were found lying in feces and/or urine. Some were on their way to the bathroom, but never made it. Others were down for many hours and could not get up to go to the bathroom. For example, Mrs. R. could not get out of bed for two to three days and said that she had to urinate using "rags." Diarrhea was found in another victim's bedroom, bathroom, and clothing. One paramedic reported that one senior "remained in a feces-covered and urine-soaked bed for the last two weeks." The medical consequences of lying in feces and urine include severe skin inflammation caused by substances in the feces or urine that can lead to decubitus ulcers. Open wounds may become infected by gastrointestinal or urinary tract flora. The psychological impact of the experience may be immeasurably devastating.

Skin Decubiti and Rhabdomyolysis

Skin decubiti and rhabdomyolysis are two potential dangers for found down victims. Long-standing hemorrhages occurring during many hours of

down time can lead to renal failure and rhabdomyolysis, if not death. Temporary paralysis and weakness often accompany rhabdomyolysis, making attempts to reach help even more difficult. Rhabdomyolysis and skin decubiti may result from constant pressure on areas of the body from hours of immobilization. Pain from skin decubiti that are difficult to heal may add to the suffering and hinder efforts to summon help. Furthermore, some nursing homes and board and care homes do not accept applicants with decubitus ulcers which may make locating placement for the patient upon discharge from the hospital more difficult.

Summary

In summary, this chapter provides a description of the circumstances of found down episodes and discovery of victims. Although mechanical fall is the leading cause of found down incidents, many other causes, including cerebral vascular accidents and inability to get up, are worth investigating when considering prevention. Although the bedroom and bathroom are the two most prevalent locations, found down episodes can occur anywhere in a home. Patients who manage to reach help themselves had the shortest down times, in contrast to patients discovered by friends. Many victims are discovered with multiple medical conditions that require immediate attention. Many of these conditions result from prolonged down times and can cause extensive physical and psychological trauma.

CHAPTER VI: HOSPITALIZATION

Changes in a found down victim's condition during hospitalization may determine what happens to the patient upon discharge. This section will describe two areas of the hospital course of the found down population: 1) the patient's condition upon admission and 2) the patient's progress during hospitalization. A comparison of patients discharged home and those discharged to nursing homes will be made throughout the chapter to examine possible predictors of institutionalization.

Condition Upon Admission

Factors that indicate the patient's condition upon admission include the number of days spent in the intensive care unit and the number of ICD 9 diagnoses. The risks for falls and pressure ulcers are two other indicators. Each of these factors will be discussed in the remainder of the chapter.

Number of Days in the Intensive Care Unit

One indicator of a patient's condition upon admission is the number of days spent in the intensive care unit (ICU), which ranged from zero to twenty-six days for the study population. Fifty-four percent of the patients discharged home did not spend any time in the ICU, compared to 38% of those who were discharged to nursing homes (Table 6.1). Persons discharged home spent an average of 3.3 days in the ICU, compared to 7.3 days for those who entered nursing homes. Although the study suggests that the number of ICU days is

correlated with the risk of institutionalization, this needs to be investigated further with a larger study population.

Table 6.1: Total Number of ICU Days By Discharge Destination

Days In ICU	Home (n=26)	Nursing Home (n=32)
	# of Persons (%)	# of Persons (%)
0	14 (54)	12 (38)
1-4	4 (15)	2 (6)
5-9	6 (23)	8 (25)
10-14	1 (4)	5 (16)
15-19	0	1 (3)
20-24	0	3 (9)
25-29	1 (4)	1 (3)
>/=30	0	0
Average # of ICU Days	3.3	7.3

Number of ICD 9 Diagnoses

The number of different diagnoses given to a patient may be a good indicator of the patient's condition upon admission. Over 50% of the patients discharged home had less than ten ICD 9 diagnoses with the average number being 8.9. In contrast, over 50% of those discharged to an institution had greater than ten diagnoses, the average being 10.6 (Table 6.2). An example of a list of diagnoses is as follows:

Discharge Diagnosis:

1. Altered mental status
2. Probable status post cerebrovascular accident
3. Syphilis
4. Anemia
5. Hypertension
6. Mild congestive heart failure
7. Cellulitis
8. Pulmonary edema

Prognosis: Poor.

Table 6.2: Number of ICD 9 Diagnoses

Discharge Destination	Home (n=26)	Nursing Home (n=32)
# of ICD Diagnoses	# of Persons (%)	# of Persons (%)
0	0	0
1-4	2 (8)	2 (6)
5-9	12 (46)	9 (28)
10-14	10 (39)	18 (50)
15-19	1 (4)	1 (3)
20-24	0	0
25-29	1 (4)	1 (3)
>=30	0	0
Average	8.9	10.6

Risk for Falls

The scale for measuring the risk for falls is an indicator of the patient's condition during hospitalization. The scales for assessing the risk for falls vary from hospital to hospital, but all include scores for age, limitations in mental function and mobility, history of falls, and elimination needs. Examples of the scales hospitals use are provided in Appendix D.

Half of the population in the study were considered at moderate to high risk for falls upon admission to the hospital and thus required special nursing protocols (Fig. 6.1). For example, during hospitalization, Mr. F. fell out of a chair while attempting to stand up without assistance. Mrs. R. describes how she felt after falling three weeks prior to discharge and breaking three ribs: "I was okay. I could walk...They gave me physical therapy. I was in excruciating pain." The potential for falls in a hospital must be carefully monitored.

Risk for Pressure Ulcers

In addition to the scale for assessing the risk for falls, hospitals also use a scale to assess the risk of contracting skin pressure ulcers from lying in one position for too long. The scales vary from hospital to hospital, but all include a means of evaluating the patient's physical condition, mental status, level of activity and mobility, and incontinence. Examples of these scales are provided in Appendix D.

Forty percent of the elderly persons in the study were considered at risk for pressure sores (Fig. 6.1). Nineteen percent of the found down patients had decubitus ulcers prior to admission. There appears to be an association between the length of down time and the incidence of decubitus ulcers. None of the seniors with pressure ulcers prior to admission were discovered less than 6 hours after being down. Three of the four seniors who were down for more than 72 hours had stage I or II* decubitus ulcers.

The Risks for Falls and Pressure Ulcers and Institutionalization

Thirty percent of the study population were at risk for both falls and pressure sores. There appears to be a correlation between the risks of falls and pressure ulcers and institutionalization. Sixty-two percent of patients who were considered at risk for falls were discharged to a nursing home and 38% to home (Table 6.3). Similarly, there appears to be a correlation between the risk for decubitus ulcers and institutionalization. Seventy-three percent of patients who were considered at risk for decubitus ulcers were discharged to nursing

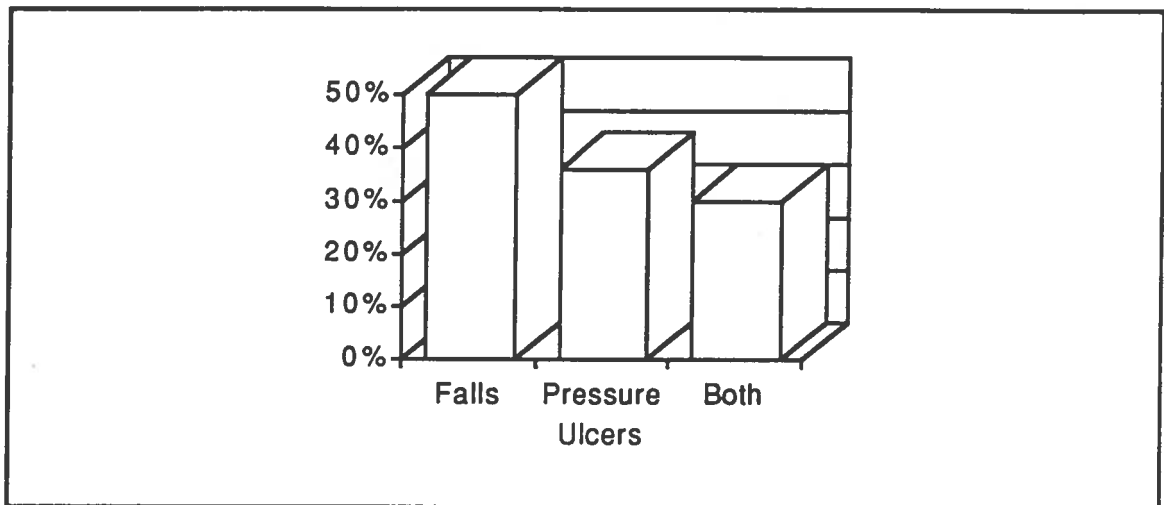
* Stage I: Redness of the skin which is not relieved by local circulatory stimulation and/or relief of pressure.

Stage II: Superficial circulatory and tissue damage which involves excoriation, vesiculation, or skin break.

[from St. Mary's Hospital and Medical Center Skin Risk Assessment Scale.]

homes, while the remaining 27% were discharged home. Data from a larger study may help substantiate these conclusions.

Patients at Moderate to High Risk* for Falls, Pressure Sores, and Both



*Moderate to High Risk scores at each hospital are those which require special nursing protocols.

Figure 6.1

The percentage of found down patients at risk for falls and/or pressure sores in hospitals may be an underestimation due to the number of charts with scores missing. Furthermore, when patients are considered at risk for falls or pressure sores, their nurses must initiate special protocols. When nurses are overworked, they may neglect to give a patient a score or to add up the points on the scale. Increased thoroughness and accuracy when using these two scales may render these scores useful predictors of institutionalization.

Progress During Hospitalization

The majority of the found down patients showed varying degrees of improvement in their health status during their hospital course. Examples of patients' progress during hospitalization will be provided in this section. Ms. O.W.'s physician wrote on the discharge summary: "much improved - the patient states she is at her baseline, with the exception of still having a component of cough." Ms. R.S. was admitted with weakness in her left face and upper and lower extremities, but showed "magnificent improvement" on the third day of hospitalization. Others, like Mrs. R.O. progressed more slowly: "Postoperatively, the patient did well. [She] gradually improved within the bounds of her severe multiple disabilities [which were] pre-existing."

Some patients did not show any improvement during hospitalization. Mrs. C.'s physician wrote: "At the time of discharge, the patient was still very weak, with minimal improvement despite aggressive physical therapy." Another patient was discharged to a skilled nursing facility with a "poor prognosis for recovery":

The patient was evaluated by the occupational therapy and physical therapy services to work on his speech therapy as well as to attempt to increase the patient's mobility. However the patient did not respond to such therapy. At the time of discharge to [a skilled nursing facility] , the patient's mental status remains unchanged (periods of agitation).

Twelve percent of those discharged to a nursing home did not show improvement in their health condition during their hospital course, compared to 3% of those discharged home.

Summary

A patient's condition upon admission and progress during hospitalization may be significant in determining his or her discharge destination. Patients discharged home tended to spend less days in the ICU and to have fewer ICD 9 diagnoses than patients discharged to nursing homes. Furthermore, of the patients who went home, a smaller percentage were at risk for falls or pressure ulcers than patients who were institutionalized (Table 6.3). The degree to which physicians consider these factors in deciding a discharge destination has not been determined. The number and extent to which these factors are considered most likely varies from physician to physician and patient to patient. While the data generally supports the conclusion that patients in poorer condition upon admission and during hospitalization are at greater risk for institutionalization, there are exceptions to this generalization. For instance, the patient with the greatest number of ICD 9 diagnoses was discharged home. Clearly, factors beyond those relating to the hospital course of the patient are considered in deciding the living arrangements after discharge. In the next chapter, a look at the process used to decide the discharge destination for elderly found down victims may uncover some of these factors.

Table 6.3: Summary of Health Factors

Health Factor	Discharge Destination	
	Home	Nursing Home
Average # ICU Days	3.3	7.3
Average # ICD 9 Diagnoses	8.9	10.6
% of Patients At Risk for Falls	38	62
% of Patients At Risk for Pressure Sores	27	73

CHAPTER VII: BACKGROUND ON CHANGES IN LIVING ARRANGEMENTS AMONG THE ELDERLY

After hospitalization, found down victims often undergo a change in living arrangements. The literature shows that elderly persons frequently change their living arrangements in relation to changes in life-style. Litwak and Longino described a "life course typology of elderly migration" which included three types of migration. The first move usually follows shortly after retirement and occurs for life-style reasons other than deterioration in health. The second move generally occurs later in life as a result of a decrease in instrumental functional ability. When care by a relative is no longer possible due to progression of chronic disability, a third move to an institution occurs.⁴⁸ This chapter will discuss factors that may determine changes in living arrangements among the elderly with a focus on institutionalization. A look at such factors will allow for a better understanding of discharge planning for found down victims after hospitalization. The following sections provide background on three components of changes in living arrangements: 1) types of changes, 2) determinants of change, and 3) discharge planning.

Types of Changes in Living Arrangement

Changes in living arrangement can occur in many forms. Altering the physical features of the present home is one form. Moving into a relative's home or relocating to a new home are two other types. Three ways of changing one's living arrangements will be discussed further: 1) altering

features of a home, 2) moving into a relative's home, and 3) institutionalization.

Altering Features of a Home

Improving lighting and installing wall-to-wall carpeting, grip bars, or emergency alert systems are examples of ways to alter the features of a home. Such changes often permit seniors to remain in their homes despite changes in functional capacity. However, Wister found that most (74%) of those over age 74 living in the community do not alter the physical features of their homes. According to Wister, seniors have not chosen homes with features that facilitate mobility, and do not think about making such improvements. The elderly are more inclined to adjust to changes in functional capacity using psychological strategies than making changes in their physical or social surroundings. Psychological adaptations include altering standards for "adequate" living conditions and denial of decreasing functional capacity. Many elderly people gradually accept the inconveniences associated with declining health, thinking that death is near. Financial instability may prevent attempts to modify the physical features of a home, but this was not found to be true in Wister's study.⁴⁹

Moving into a Relative's Home

Relocating to a new home can mean moving in with a relative. About one out of six elderly individuals lives with a child.⁵⁰ A quarter of persons aged 65 and over live with relatives. Those aged 75 and over have the highest portion of persons living with relatives of all elderly people.³

When an elderly relative can no longer live independently, younger individuals often insist that the senior move into their home. In some cases,

this is done out of guilt or a sense of obligation and may not always be beneficial for the elderly person. Often relatives are not as able to care for the patient as they had believed. A potential caretaker for an elderly relative must consider multiple factors, including access to the bathroom, increased costs, time availability, someone to relieve the primary caregiver, activities of teenagers if present, and personality conflicts within the household.⁴²

Furthermore, moving into a relative's home does not necessarily mean that the senior will be in more familiar surroundings than entering a nursing home. Home may become more depressing than a nursing home if the senior feels isolated from the daily activities of the family members. Changing a home to accommodate the senior's functional deficits may be more traumatic and depressing for some individuals than placement in a nursing home. In one study, twelve home care nurses reported that 65% of their patients were isolated and lonely.⁴²

Institutionalization

Relocating to a new home may mean entering an institution. Because funding for acute care hospitals has become more limited, a greater number of patients are being discharged from the hospital to a nursing home earlier.⁵¹ According to the *Statistical Handbook on Aging Americans*, 77.5% of those aged 65 and over were discharged home after acute hospitalization, with 7.3% requiring home care services. Persons discharged to nursing homes made up 10.2% of hospitalized seniors.

Between 1980 and 1990, the nursing home population increased by 24% from 1.4 million to 1.8 million.³ During the 25 years before 1980, many of the mentally ill were deinstitutionalized. Thus, a large number of the residents in the nursing homes in 1980 were patients transferred from mental institutions.

Because mental illness is the most frequent diagnosis among nursing home patients, the populations of the two institutions remain unclearly differentiated.⁵²In 1986, close to 37% of the seniors admitted to nursing homes died in the nursing homes, while about 44% were subsequently admitted to acute-care hospitals.⁵

Determinants of Changes in Living Arrangements

This section will present some of the factors that influence decisions on changes in living arrangements. The literature discusses many such factors. To provide a framework for an overview of some of these factors, Lawton's Person-Environment Model⁵³ and the work of Greene and Ondrich⁵⁴ will be presented first.

Lawton's Person-Environment Model addresses the forces that instigate relocation. According to Lawton's model, changes in living arrangements are the consequences of the settlement reached between "press" and "competence." The term "press" refers to the physical and social factors that affect an individual, while "competence" refers to a person's physical, mental, and emotional capabilities. When an individual experiences a change in competence, he or she will attempt to alter press to accommodate this change. Thus, elderly people who undergo a decline in competence may change their environment in a number of ways to adjust for the decline.⁵³

For many seniors, the environmental change after a functional decline is institutionalization. Greene and Ondrich looked at the probability that a person living in the community will enter a nursing home as a "discrete-time hazard function." Using this model, Greene and Ondrich divided the variables

that predict nursing home placement into three categories: 1) factors that predispose the individual to use service, 2) factors that enable an individual to obtain service, and 3) factors that reflect the needs of the individual. Predisposing factors that lowered admission to nursing homes were ethnicity (Black and Hispanic) and being a home owner. Enabling factors which increased the risk of nursing admission were living alone, fewer visits to the physician, and higher number of beds available in nursing homes. Of the need factors, decreased functional capacity was associated with increased risk of admission.⁵⁴

Many studies have looked at risk factors for changes in living arrangements. This section will discuss the following factors in greater detail: 1) age, 2) gender, 3) marital status, 4) ethnicity, 5) functional capacity, 6) availability of social support, and 7) patient's choice.

Age

According to Speare, Avery, and Lawton, individuals aged 70 to 74 are less likely to relocate than those aged 75 to 79. However, mobility, including entering a nursing home, increased for those aged 80 and over.⁵³ Shapiro and Tate found that increased age was the factor that contributed most to an increased risk of entering a long-term care facility.⁵⁵ Persons 75 years of age and over have the highest rate of admission to institutions.³⁶ The risk of admission increases significantly after age 85 with 22% of all persons 85 years of age and over residing in nursing homes.³⁸ In Kane et al.'s study, those greater than 85 years of age discharged from acute hospitalization were ten times more likely to enter a nursing home than those aged 65.⁵⁶ The increased prevalence of physical impairment and widowhood in this age group are

highly associated with the increased rates of admission. Furthermore, prior nursing home admission is a strong predictor of institutionalization.³⁸

Gender

Elderly women with a decline in health are more likely to move in with others than elderly men. However, both genders enter institutions at approximately the same rate.³³ About 75% of nursing home residents are women. One reason is that men generally obtain more support from their wives than women from their husbands.⁵⁵

Marital Status

Shapiro and Tate found that living at home without a spouse is second to age as a significant factor in institutionalization.⁵⁵ According to Dolinsky and Rosenwaike, persons who were never married had the highest rate of institutionalization.³⁶ Almost a third of the elderly who are married and about a fifth of those who are not married have stayed one to twenty-nine days in nursing homes.³

Ethnicity

Race may be yet another factor in determining mobility. For instance, African-Americans are more likely than Caucasians to remain living alone after similar losses of functional capacity. Hispanics are less likely than other races to live alone at any level of physical disability, probably reflecting the greater likelihood of families to keep their elders at home.³³ Low income did not appear to be associated with changes in living arrangements when all other factors were controlled for.⁵³

Functional Capacity

A decline in functional capacity is highly associated with changes in residential arrangements. Among noninstitutionalized persons over age 70, a decline in the ability to perform the instrumental activities of daily living (IADLs) increase the probability of migration.⁴⁸ Changes in ADL or IADL ability were more strongly associated with changes in living arrangements than the initial scores in ADL and IADL ability.⁵³ Shapiro and Tate found that difficulty with one or more of the ADLs increased the probability of institutionalization from 40% to 67% for those between 65 and 74 years of age.⁵⁵

According to Worobey and Angel, the elderly are able to accommodate minor decreases in functional capacity without major changes in living arrangements. However, major changes in health result in changes in living arrangements.³³ Speare, Avery, and Lawton found that mobility resulted from abrupt changes rather than gradual, progressive changes in disability.⁵³

However, most of the elderly, including many who require help with three or more of the ADLs, live in the community. About 85% of the disabled elderly living in the community obtain assistance from relatives and friends. Some seniors receive additional help from paid services.³⁸

Availability of Social Support

Entrance to a nursing home is often delayed when the elderly person has children to care for them. Dolinsky and Rosenwaike found that the likelihood of admission to an institution increased with a decreased number of children-ever-born.³⁶ Individuals who have a daughter are more likely to move than individuals with no living children or only sons. This suggests that residential changes are associated with the need for help to remain in the

community. Parents who have not maintained regular contact with their children do not tend to coreside with them.⁵³ Higher education is negatively associated with the likelihood of residing with a child, while the inability to drive has a positive association.⁵⁰

For some seniors, moving in with a relative is a step towards institutionalization. In one study, individuals living with adult children were most likely to enter an institution within two years. Persons living with adults other than their children were the least likely to become institutionalized.⁵⁰

Although the needs of seniors are often seen as the determinants of changes in living arrangements, the children's needs may be significant factors as well. The availability of social support can influence significantly any housing changes for a senior. Dolinsky and Rosenwaike predict that the role of family composition in determining living arrangements for the elderly will be even greater in the future than at the present.³⁶

The Elderly Person's Choice

The majority of the elderly choose to remain independent and to live in their own homes when possible. When living independently is not an option, they typically select from two types of support networks - institutions or informal support from family and/or friends. Many elderly individuals perceive institutionalization as their last choice, to be "chosen" only when no other options are available.³⁶

Participation in Deciding a Discharge Destination

Upon discharge after hospitalization, many elderly persons must undergo a change in living arrangements due to a decline in functional

capacity. The process used to determine the discharge destination may contribute more to successful adjustment to the new home than the type of facility to which the patient relocates.⁵⁷ Persons who feel they were excluded from the decision-making process and forced into new situations will "almost always rebel against the change."⁴² Even if a patient cannot actively participate in his or her discharge planning, the patient should be allowed to listen to the discussions concerning the discharge. Some relatives find no need for discussion, believing that the patient is too confused to make any decisions. Salamon and Rosenthal claim that the patient is rarely too confused to know what is happening. Even if the patient is cognitively impaired, they are often aware that a change is occurring.⁴²

Factors Influencing the Choice of a Discharge Destination

What are the factors that influence the decision on a discharge destination? Salamon states that six factors govern the decision-making process for many families:⁴²

- 1) familiar surroundings,
- 2) fear of institutionalization,
- 3) costs,
- 4) continuity of generations,
- 5) reciprocity, and
- 6) guilt

Often the desire to remain in a familiar environment is so strong that it becomes the primary focus of the decision-making process, overpowering any other factors that may lead to a more rational decision.⁴² In addition to health,

ownership of a home and duration of residence in the home are significant determinants of mobility. Elderly persons who owned their homes and those who have lived in their current home for 15 years or more were much less likely to move than people who rented their homes or who have resided in their current homes for less than 15 years.⁵³ The fear of institutionalization and perceptions of the cost of various types of care can also influence the decisions of many patients. Relatives often feel the need to reciprocate care for an elderly person. Relatives who see nursing homes as a place where elderly people are "dumped" will feel guilty even at the thought of contacting institutions.⁴² These and many other factors can influence the choice in new living arrangements when change is necessary.

Summary

Changes in living arrangements can range from altering physical features of a home to institutionalization. The social support network, functional capacity, and preferences of an elderly person can determine whether a change is made. These factors can also influence the decision on the type of change made.

Discharge Planning

As shown above, many factors can determine changes in living arrangements when an elderly person is discharged from a hospital. What is the process used to determine these changes? Discharge planning provides guidelines for this process. "Discharge planning is defined as assessing the needs and obtaining or coordinating the appropriate resources for patients

and clients as they move throughout the health care system."⁵⁸ The four key steps in discharge planning are:

- 1) Assessment - identifying and evaluating the patient's present and expected medical needs, support network, and home situation.
- 2) Planning - pre-discharge conferences to discuss a plan for care.
- 3) Implementation - mobilizing the resources needed, discharge teaching, and making the referrals necessary to forward discharge plans.
- 4) Evaluation - making follow-up phone calls or sending forms to evaluate success of the discharge planning.⁵⁹

The responsibilities of a discharge planner include:

- 1) making assessments after gathering evaluations from a variety of disciplines,
- 2) being familiar with the patient's needs and the community services and funding sources that would benefit the patient,
- 3) assessing the patient and family's support system, and
- 4) helping the patient and family to arrive at an informed decision as soon as possible.⁶⁰

The goals of discharge planning are clearly delineated in theory, but are these goals being met in practice? This section will discuss the history and problems of discharge planning.

The History of Discharge Planning

Discharge planning, once a luxury to the health care system, is now a necessity.⁵¹ One reason is that hospitals now recognize that the cost of care depends on the level of care. For example, the cost of acute care is greater than that of nursing home care. Furthermore, the link between current health care problems and the potential for future care needs is now more widely

recognized.⁵¹ These realizations have contributed to the establishment of discharge planning at most hospitals. The Heinz-Stark Bill, part of the Omnibus Budget Reconciliation Act of 1986, required hospitals to provide discharge planning, design a needs assessment instrument, and provide a written statement of discharge rights for hospitalization and posthospitalization care.⁵⁸

Problems with Discharge Planning

Although discharge planning has been established to benefit both the patients and the hospital, the well-being of the hospital may come before that of the patients. Discharge planners often must consider the policies and terms of the institution's negotiations with other agencies and insurance companies which may compromise the quality of care for the patient.⁶¹ The increase in joint ventures has made it more difficult for discharge planners to make the most appropriate arrangements for the patients. Discharge planners may be pressured to place patients in particular nursing homes or to refer them to specific home health agencies regardless of what is best for the patients. Furthermore, the standards for discharge planning vary from agency to agency and discipline to discipline,⁵⁸ making quality control difficult.

The prospective payment system, like the joint ventures, can create ethical dilemmas for discharge planners.⁵⁸ Under the prospective payment system, the hospital stays of some patients are shortened to benefit the hospital financially. According to the New York Times [Smith, April 3, 1988], "Under the new DRG system, the sooner the patient leaves, the more the hospital earns."⁴² According to O'Hare, people "are being discharged sooner and sicker than ever before."⁵⁸

Some hospitals have developed strategies to avoid the hassle of a decision-making process. One such strategy is the "emergency room hustle" which refers to the practice of examining the patient superficially, telling the patient that the "complaint is consistent with the aging process," and sending him or her home. Another popular strategy is the "transfer game" in which patients are given a " cursory examination" and then transferred to a public hospital after being told that their complaint is due to old age. This allows hospitals to avoid patients who will have no place to go once they require a level of care that is lower than the acute care services provided at the hospital. This game could help cut hospital costs since hospitals are reimbursed at a lower rate for "dispos" or "NHPs" (nursing home placements).⁴²

Summary

There are many factors that could influence the decision on new living arrangements for a senior. The goals of discharge planning include careful assessment and consideration of many of these factors. However, some hospitals have found ways to avoid discharge planning. The extent to which the goals of discharge planning are met remains to be investigated.

CHAPTER VIII: DECIDING A DISCHARGE DESTINATION FOR FOUND DOWN VICTIMS

The patients in the study population were discharged either home to live alone again or to a skilled nursing facility. What is the process used to decide the discharge destination? Ideally, the senior's physician works with the patient, the patient's family and friends, other health professionals, and a discharge planner to arrive at a decision. In the event of a found down incident, a decision often must be reached in haste. There may not be time to consider all of the possibilities. There may not be time to contact relatives to discuss the discharge plans. The patient and family members may not have thought about living arrangements in advance due to the suddenness of the incident. Therefore, conditions under which the decisions are made may be far from ideal.

This chapter will look at the process used to decide a patient's discharge destination. The persons involved and the factors considered in the decision-making process will be discussed. The last part of the chapter examines the impact of the decisions on the well-being of the patient.

Examples of the Decision-Making Process

Before discussing different aspects of the process used to decide the discharge destination, I will provide some examples to illustrate the decision-making process. These examples were obtained from medical charts:

Case 1: He refuses placement, and at this point because of persistence of congestive heart failure, the patient could not be sent home where he stays alone...and after discussing with the patient's sister, and with Dr. Hanson, nursing home placement was finally both agreeable. ...this was approved by all physicians involved.

Case 2: (This patient has no children or relatives available to help with the decision.)

The patient had multiple falls; she probably cannot live independently anymore for her safety. Will talk to patient re [regarding] placement... The day after admission, Neurology had been consulted... Their impression at the time was that this is a 79-year-old white female with a history of stroke, hypertension, declining in ability to live independently secondary to falls with several months history of progressively worsening speech output. Although the patient had been walking and talking fine and writing with her right hand the day prior to admission and now cannot speak, write with her right hand, or walk. Neuro recommends: physical therapy, speech therapy, occupational therapy. The patient agreed and asked to be transferred to Mount Zion Hospital.

The decision-making process in determining a senior's discharge destination can be highly complicated. This case illustrates only some of the complications that may arise in the process:

Case 3:

Physician 1-Admission History:

Patient and social service will be consulted, and the patient's ability to ambulate will be assessed carefully.

Discharge plan:

Assess the availability of Visiting Nurse Association visiting home nurse for the patient.

Physician 2-Transfer Summary:

She remained weak and was clearly not able to function independently... Much of the time spent in the hospital was directed toward the social aspects of her admission and finding her a secondary care facility to which she should go. There were also financial problems with respect to choosing a nursing home which would follow her skilled nursing facility.

Discharge Plan:

The patient will be transferred to Garden Sullivan for rehabilitation/occupational therapy. From there, she will be transferred to a nursing facility as arranged by the family. Her physician, Dr. M. will return in approximately five days.

In this case, the two physicians involved had differing opinions on the discharge plan. The admitting physician's plan to assess available nursing service was either neglected or deemed unnecessary due to the second physician and the family's opinions. Furthermore, neither of the two physicians partaking in the decision-making process were the patient's regular physician. Financial status was an additional factor that complicated the decision.

As illustrated, the decision-making process can be very different for different individuals. The process may be long and involved for some patients and minimal for others. In some cases there was no mention of the steps taken to decide on the discharge destination.

Examples of No Process

Forty-one percent of the medical charts reviewed for this study made no mention of any "process" used to decide on the discharge destination. Physicians stated the discharge destination in the passive voice with no mention of how the decision was reached, as if no one were responsible for the decision. Such statements from different charts include:

- 1) "The patient is to be transferred to Laguna Honda Hospital for placement..."
- 2) "The patient is to be sent to nursing home with follow-up by nursing home doctor..."
- 3) "It is felt that he cannot live in his apartment any longer."

While the decision-making process was nonexistent for some patients, others had involvement of relatives and professionals from multiple disciplines.

Factors Involved in the Decision-Making Process

Physicians, other health care providers, the patient, and the patient's relatives and friends may be in the position to influence the decision on a discharge destination for the patient. The extent of involvement of these individuals may vary greatly from one patient to another. The following sections will discuss the role of four factors in the decision-making process: 1) the patient's opinion, 2) the physician's opinion, 3) the advocacy of relatives, and 4) pre-existing community support services .

The Patient's Opinion

Patient's Opinion Was Not Asked

In some cases, the patient was not even aware that discharge plans were being made. Ms. O. reported during an interview, "All of a sudden they told me I was going. They took me in an ambulance to San Francisco Community Convalescent Hospital on Bush and Divisadero. That was all Greek to me." Another patient, Mr. P., was also completely left out of the decision-making process. He was "discharged to skilled nursing facility to have continued physical therapy and be continually followed by the medicine service." According to his caretaker who has known him for many years, he was in the skilled nursing facility for a year before returning home. The patient, however, did not know that he was discharged from the hospital to a skilled nursing facility. He thought that he was in the hospital the entire time he was away from home. Mr. P. "couldn't wait to come home," said his caretaker. He did not know that he could have chosen to do so one year ago.

Patient's Opinion Made a Difference

When given the opportunity to voice his or her opinion, a patient can reverse the direction of discharge planning. Mrs. E. was "offered placement in a nursing home," but returned home upon refusing placement and expressing a strong desire to return to her residential hotel. Likewise, the physician and Social Work Services Team discussed possible placement for Mr. S., but he "prefers to stay at home and has already hired a home aide for additional help at home." Because Mr. S. voiced his opinion and acted in the interest of his preference, he was "offered recommendation for possible placement in the future," but was discharged home. Thus, when given the opportunity, many patients can not only clearly express their wishes, but also influence the direction of the decision-making process.

The Physician's Opinion

What is the physician's role in the decision-making process? "The physician's role in discharge planning in the past and, to a lesser extent, in the present, has been the gatekeeper to the health care system."⁶⁰ Today, physicians still decide when patients are admitted and when discharged. The physician's signature is still required for patients to receive reimbursements.

According to Terry, the physician's goals in discharge planning are to 1) support the discharge planning process, 2) predict the patient's medical needs, and 3) encourage the patient and the family to beginning planning for the future.⁶⁰ However, not all physicians have these goals in mind, and the ones who do may have very different concepts of the "discharge planning process." Some physicians will decide for the patient without consulting the patient, the patient's family, other health professionals, or a discharge planner. A physician who attempts to involve the patient and the family may

find them resigning the responsibility of decision-making to the physician. The physician may find himself or herself in the middle of a conflict between the patient and family members or among family members. The data from this qualitative study suggest that physicians decided on a discharge destination in three general ways: 1) unilaterally, 2) based solely on functional capacity, or 3) with involvement of other health care providers.

Decision Made Unilaterally

According to Silverstone and Hyman, "even when the patient is unable to contribute, the decision should not be a dictatorial one."⁴² Yet, from the medical charts reviewed, many decisions appeared to be made solely by the physicians with no mention of participation from the patient, family, or other health professionals:

Example 1: It was decided by _____, M.D. and _____M.D., that the patient would benefit from a stay in the skilled nursing facility.

Example 2: It was the opinion of _____M.D. and also myself [another M.D.] that she required skilled nursing care for rehabilitation.

Yet, are there occasions when the medical professional is justified in making a decision without encouraging patient involvement? Here is the story of a patient who complicates the issue of patient involvement:

Jan. 22, 1993: Discharged to home after admission for... pneumonia because refused placement.

Jan. 24, 1993: Called 911, oxygen hookup trouble while at home, left against medical advice on Jan. 29, 1993.

Jan. 30, 1993: Patient fell, unable to walk, admitted for placement...left against medical advice on March 25, 1993 after refusing placement.

Mar. 26, 1993: found cyanotic, admitted.

April 1, 1993: It is felt that patient will need twenty-four hour attendance/close observation for the rest of his life, if he is free to move from his bed or chair. The patient is to be transferred to Laguna Honda Hospital for placement.

As demonstrated, the job of "bringing the patient and the family to an informed decision as soon as possible"⁶⁰ may be difficult, if not impossible.

Patient Wants Physician to Decide

Another complication is the patient who wants the physician to make the decisions for him or her. Beisecker and Beisecker found that the participants in his study perceived that physicians had greater authority than patients in making medical decisions. Although patients wished to be informed in all areas of medicine concerning their health, many do not wish to take responsibility for making decisions in those areas.⁶² Mrs. C., a found down victim, exemplified this. When asked how it was decided that she should enter a nursing home, Mrs. C. replied, "It was up to Dr. Z." Dr. Z. is not the doctor Mrs. C. had been seeing for many years, which further complicates the picture. Her regular doctor had passed away and Dr. Z. was the doctor she had acquired just prior to coming to the nursing home.

In the case of Mr. I., the physician's familiarity with the patient's medical history may have played a role the discharge home. Mr. I. needed assistance with monitoring his blood sugar. His nurse had written that home or a senior citizen home was to be the discharge destination. Yet, Mr. I. was discharged home with the following note in his chart written by his physician:

[The patient] is known to me over a number of years...[The patient was last seen by me in my office on Jan. 12, 1993 at which time he was in splendid spirits, had no complaints...He was seen in the ER two days ago and was examined and sent home in view of the fact that his physical finding were unremarkable.

Knowing the patient for many years may give a doctor the privilege of knowing the patient's ability to manage at home and his or her satisfaction with living at home. Such information may enable the physician to better predict the patient's ability to return home.

Decision Made Solely Based on Functional Capacity

The physician may base his or her discharge decision entirely on the patient's physical and mental needs with limited knowledge of the patient's family situation. Here are two examples of decisions that appear to be made solely on the basis of physical and mental function:

Case 1:

AO x 3 [alert and oriented to name, place, and time], forgetful at times...needs help with ADL. Anxious to return home...walking distance improving with walker and supervision. Postoperatively, the patient has been relatively afebrile and has had no complications... She is ready for transfer at this time [to a skilled nursing facility].

Case 2:

Over the subsequent three days, the patient's mental status gradually improved with nearly complete resolution of his agitation and improvement in his mental status such that he is now completely oriented and capable of following commands and participating in physical therapy...The patient is being transferred to [skilled nursing facility].

There was no mention of a "process" used to decide these patients' discharge destination other than the physician's assessment of the patient's physical and cognitive function.

Involvement of Other Health Care Providers

In some cases, physicians consulted other health care professionals before deciding on a discharge destination. For instance, one patient was

found to be independent by an occupational therapist and a physical therapist before she was discharged home. Psychiatry was consulted for another patient regarding the question of depression before he was discharged to a rehabilitation facility. Although some decisions were not made solely by the physician, there was no participation from family members or non-medical disciplines such as social work.

The Opinion of Relatives

What role do family members play in the decision-making process? A family member may serve as an advocate for a patient's placement or return home. The next section provides examples of the involvement of relatives in deciding a discharge destination. The problems with involvement and lack of involvement of relatives will also be discussed.

A Relative Advocates for the Patient's Institutionalization

One patient's chart stated that the patient "has been living alone and taking care of herself and very reluctant to give up her independence." Meanwhile, her daughter has been working on placing her mother in a nursing home:

Patient's daughter has been trying to place her mother in a nursing home or retirement community for one year. She had put the patient on a waiting list for a retirement center near her home in Los Angeles and a spot recently opened up...Patient's daughter will discuss with patient and patient's primary doctor.

Thus, the daughter had the primary role in deciding her mother's institutionalization and has mobilized her plan prior to discussing it with either the patient or the patient's doctor.

Relative Advocates for the Patient's Return Home

On the other hand, the involvement of a relative in the decision-making process could postpone, if not prevent, a patient's entrance to a nursing home. For instance, one patient, Mrs. F., said:

St. Mary's Hospital made recommendations as well as the social worker, and physical therapist and the doctors. They were advocating that perhaps I should go to a nursing home or convalescent home to recuperate, but fortunately I have a daughter who said, "No, Mom is going to go home and we will get help at home."

Mrs. F. was subsequently discharged home with 24-hour help for about three to four months while she recovered.

The presence of a relative who is available to provide home care may increase a patient's options after discharge, but not necessarily a patient's freedom to choose his or her discharge destination. Mrs. F. admitted that if the decision were up to her, she would have chosen to go to a convalescent hospital. She did not want to trouble her daughter to take care of her. She said, "Anybody would want to go home, but you do have to think of your family." If her daughter had not insisted on her mother's return home, the patient would have entered a nursing home. Thus, a family member may increase the number of possible discharge destinations for a patient, but not necessarily the patient's freedom to choose.

The option of placement may not even be discussed if the patient has a relative who can provide help at home. For example, Mrs. J. required a visiting physical therapist, visiting nurses, and infusion service for an indwelling central line for medication. Yet, she was discharged home with no mention of placement in her medical chart. Her physician did write that Mrs. J. has a daughter who takes care of her with the help of another caretaker. The

availability of pre-existing home help may make discharge home seem the simpler and more natural choice when the best choice is not obvious. Thus, the family's role and extent of involvement in the decision-making process varies from individual to individual, as does the role of the physician.

Problems with Relatives As Advocates

As demonstrated, a family member can have a dominating role in deciding the patient's discharge destination. Yet, a family member may not know the patient or the patient's situation well enough to make an accurate assessment of the patient's needs. For instance, Mr. N. has two nieces who "aren't aware of his medical problems and [who] have left presently [when the physicians were deciding the patient's code status.]" The physicians eventually decided the patient's code status on their own:

Due to the morbidity/mortality in patients this age who undergo cardiopulmonary resuscitation, Dr. ___ and Dr. ___ think it would be medically futile to code this patient. Will, therefore make patient DNR and inform family if able to find them. Patient unable to discuss these issues now.

The nieces were ultimately consulted in deciding the patient's discharge destination, despite their unfamiliarity with their uncle's situation. A means of assessing the relatives' competency in deciding what is best for the patient would be one way to improve the decision-making process.

The Lack of Relative Support

Many patients have no family members who can provide the extra care needed when recovering from a found down incident. Because more women are waiting longer before starting a family, many seniors will have children who are less than 35 of age, not yet secure in their careers, and thus unlikely

to be suitable candidates to be caretakers for their parents.⁴² With no caretaker available, many of these individuals feel that they have no choice, but to agree to the physician's decision on placement. One patient who has not been happy living in a convalescent hospital said that she came to the institution because she had no means to stay home. She had no relatives who could take care of her and her housekeeper would not have been able to provide the level of care she needed. Likewise, another patient, when asked how it was decided that she enter a nursing home, said, "It was up to Dr. _____. I was sure I couldn't come home. Look when you just think about it, think how you have to shop, cook, all that sort of thing..." Without the support of family members, many seniors with a decline in functional capacity feel they have no choice but to enter an institution.

The Role of Pre-Existing Community Services

As with family members, the availability of community services and support may also have a role in the decision-making process. The presence of pre-existing community support exempts the physician from finding or mobilizing community support prior to the patient's discharge. For instance, Mrs. U. had a caretaker who provided two to three hours of help each day. The physician felt that Mrs. U. was "capable of managing at home with her attendant" and discharged her home. Likewise, Mr. M. was "evaluated by the Geriatric Service, who felt that he should be returned home as soon as possible." He was admitted multiple times for worsening congestive heart failure prior to this most recent admission and was in his "usual poor health at home." However, prior to admission, he had a visiting nurse who came to his home once a month and a friend and neighbor who attended to his needs. Therefore, he was discharged home.

Mrs. P., on the other hand, had no established help from the community. The physician decided that she is "going to the rest home, because of her inability to care for herself at home...Social history shows that she lives alone..." Mrs. P.'s condition could have been worse than either Mrs. U. and Mr. M.'s conditions to account for her institutionalization. However, the medical charts do not indicate this. The differences in discharge destinations suggest that pre-existing community support may influence the decision on a patient's discharge destination.

Summary

The number and the degree of involvement of each participant in deciding a discharge destination vary from case to case. How can a patient be assured that all efforts to arrive at an informed decision have been taken? To what extent should the decision-making process be standardized?

The Consequences of the Decisions

Whether one person or multiple persons were involved, decisions on discharge destinations were made. Some patients returned home despite recommendation of placement in a nursing home. Others entered nursing homes feeling that they had no other choice. This section will discuss some of the consequences of returning home against medical advice and of institutionalization.

Returning Home Against Medical Advice

Of the patients who returned home against medical advice after discharge, some were eventually institutionalized. Other patients managed without major difficulties after returning home. Examples of each category of patients is provided in the next section.

Eventual Institutionalization

Many patients who originally refused placement later experienced found down incidents that convinced them or forced them to be institutionalized. One patient's chart read:

...refused board and care, or nursing home placement in the past... initially very interested in going home, however given the fact that she seems to have poor ability in her own ADL, physical therapy saw her as well as social work, and felt that placement would be requested, and the patient finally agreed to placement at Laguna Honda Hospital without difficulty.

Another patient, Mrs. V., convinced the physician that she was ready to go home. Her physician wrote:

reports that she's in her usual state of health and wishes to go home...I have asked her a variety of questions about how she would respond to various urgent situations which might arise at home, she is able to articulate a plan, suggesting that her decision to go home is most likely a competent one. We will attempt to contact her social worker and neighbor, and hopefully to increase her home aide support upon discharge.

This patient was readmitted three days after discharge for injuries sustained during a mechanical fall. She was found in pain, covered with feces, and "scattered verbally" three hours after her fall. With this hospitalization, her chart read: "presents now with failure to thrive...The patient doesn't know why she is here and wants to go home." Despite the patient's persistent wish to

return home, she was discharged to a skilled nursing facility this time. The decision was reached in the following manner according to the physician's notes:

Psychiatry came by to assess her and found that she was unable to care for herself, and recommended probate conservatorship and placement in a supervised nursing care...We will proceed with work up to rule out reversible cause [of dementia] and if none are apparent, we will need to proceed with obtaining conservatorship for the patient so that she can be placed in a skilled level facility. She is incapable of caring for herself.

Although originally discharged home, Mrs. V. was forced to enter an institution three days later.

A home may not be as well-equipped as a nursing home to accommodate a patient's needs. One patient in the study returned home under the care of her sister only to be hospitalized a month later and discharged home with the help of a home health agency. In another case, the patient's brother and sister took care of her at home. She was reportedly unable to cook for herself or clean her home. Her brother and sister went to Reno for a few days and left food in the refrigerator for her. During their absence, she spent three days on the commode, unable to get up. The visiting nurse found her dehydrated, emaciated, weak, and hypokalemic. The patient was subsequently admitted to a convalescent hospital. Seniors who were originally discharged home with relatives often become institutionalized when family members are forced to recognize that they are unable to provide adequate care.

Successful Management After Returning Home

The decision to go home despite the physician's recommendation for placement does not always lead to disastrous consequences. In some cases, patients are highly successful at recuperating at home and continuing to live

independently. One patient, Mr. W., tells the story of how he was discharged home contrary to his physician's advice:

It wasn't decided at all that I should to a nursing home. I made up my mind that I was going to go home...It was pretty tough. I had a hard time getting out...I tried to have Social Service do something for me, but they said they couldn't...The nurse said they couldn't get anything; it would cost \$15 an hour.[for a home aide] I couldn't do it, you see. I said, "I'll go home."...Very nice man [his physician], but he was very strict. I didn't think I was going to get out of the hospital. But this man [another physician] who came in the day I was getting out of the hospital - I wasn't feeling well either...When the doctor came in to take my blood pressure, it was good. He said, "How would you like to go home?" I said, "I'll go now then. And I never saw the guy before. He said, "Okay. Get going." And I went.

Since his discharge, Mr. W. has been able to continue with his hobbies - photography, baking, and woodwork with no regrets about coming home. Mr. W.'s case illustrates the difficulty in predicting the outcome of a decision on a patient's discharge destination.

Institutionalization

While some patients chose to return home against medical advice, others entered institutions. This next section presents some of the consequences of institutionalization. The relationship between participation of the patient in deciding the discharge destination and the satisfaction or dissatisfaction with the decision will be examined as well.

Mrs. C., who felt that it was up to her physician to decide her discharge destination, was content to be in a nursing home one year after the incident: "Everybody is nice to me. And plenty of activities...So it's quite adequate really." In contrast, Ms. O., who did not even know that she was being transferred to a convalescent hospital, was discontent in a nursing home. She described her stay in the convalescent hospital:

They [the staff] were very nice, but I have this hearing problem and I can't get too acquainted and it's embarrassing to keep saying, "I can't hear you"...[The food] was murder at the convalescent hospital.

Another patient, Mrs. L., is not at all happy with her present living arrangements. She felt that she had no choice but to go to a nursing home:

I've been here for over a year. I don't know how much longer I will live. It's hard for me here. First of all, I can't get used to living here. Secondly, there aren't very many people who can speak Chinese and I'm not used to the food here...It's hard. It's difficult is all I can say. At home, there's no one to bother you. I can take as long as I want about anything.

Thus Mrs. L. was discontent with her discharge plans, but felt that she had no choice except to be institutionalized.

Summary

As illustrated, the degree of satisfaction with the discharge arrangements varied widely from patient to patient. With the small number of patients interviewed, the relationship between the patient's role in the decision-making process and his or her success at adjusting to the new living arrangements remains unclear. However, those who felt that they chose their own living arrangements appear to more content.

CHAPTER IX: THE IMPACT OF THE FOUND DOWN SYNDROME

An elderly person may be forced to confront many changes in his or her life as a result of being found down. These changes may be transient or permanent. The following section will discuss five areas of the impact of the found down syndrome on the lives of the seniors: 1) living arrangements, 2) functional capacity, 3) social support, 4) psychological well-being, and 5) financial status.

Impact on Living Arrangements

The found down syndrome can have a dramatic effect on a senior's living arrangements. Data from the interviews and efforts to contact patients showed that one year after the found down incident, 21% of the study population have died and 44% no longer had the same living arrangements as they had prior to the incident. Twenty-six percent of the seniors did not undergo any permanent changes in living arrangements. These seniors were either discharged home directly after hospitalization or returned home within one year. Forty-four percent of the population had more permanent changes in living arrangements. One year after being found down, some of these patients never left the nursing homes to which they were discharged. Others were no longer living in their former homes and have been lost to follow-up. A summary of the living arrangements one year later is provided in Table 9.1.

Table 9.1: Living Arrangement One Year Later (n=58)

Type of Living Arrangement One Year Later	Discharge Destination	
	Home	SNF†
Home Alone	10 (17)	5 (9)
With Relative	0	3 (5)
Skilled Nursing Facility	1 (2)	5 (9)
Hospital	1 (2)	0
Deceased	4 (7)	8 (14)
Not Original Home, New Living Arrangements Unknown	5 (9)	10 (17)
Unknown	5 (9)	1 (2)
Total	26 (45)	32 (55)

†Skilled Nursing Facility

In general, patients who were discharged home had greater capacity to remain independent and a lower mortality rate one year after being found down. Thirty-eight percent of patients discharged home were living home alone one year later, compared to 16% of those who were discharged to nursing homes. The mortality rate at one year after the found down incident was 21%. Twenty-five percent of those discharged to nursing homes have died. Half of these patients died while still in the nursing home. A lower portion, 15%, of those discharged home, have died.

Studies have shown that altering features of a home such as installing handle bars or emergency alert systems can be an alternative to relocation after a change in functional status.^{18,63} However, none, except for one, of the found down victims interviewed had special accommodations in the home prior to the found down incident. Mrs. F. was the senior who had some pre-existing safety features which she described:

My home was pretty well safe-guarded before the accident, because of the two total knee replacements. My shower, lavatory, all have the bars and all. I had wall-to-wall carpeting put in so that there's no scattered rugs. Because when I was recuperating from knee surgery I had to take all those safe guards.

After the found down incident, Mrs. F. installed an emergency alert system in her home, but did not add any other features. She used the electric chair that brought her up and down the stairs which she originally had installed for her mother. None of the other persons interviewed had considered making physical changes to their homes either as an alternative to relocation or as a means of preventing found down incidents. Many patients stated that the idea never occurred to them.

Thus, a large percentage of patients experienced a change in living arrangements as a result of being found down. For most of these seniors, the relocation was permanent (at least one year). Although the literature suggests that adding safety features to a home was one alternative to relocating after a decline in functional capacity, none of the seniors interviewed had considered this option.

Impact on Functional Capacity

Examples of the Impact on Functional Capacity

This section provides a description of the impact of the found down event on the functional capacity of the study population. First a few examples of how the event has affected patients' ability to perform the activities of daily living (ADLs) will be presented. Following will be a comparison of the functional capacity of persons who returned home with those who were discharged to nursing homes. The functional capacity both at the time of discharge and one year later will be compared.

Information gathered from reviewing medical charts showed that 14% of the population were unable to perform the ADLs independently prior to being found down. At the time of discharge, 58% of patients required

assistance with their ADLs. Information gathered from interviews and efforts to contact patients showed that one year after being found down, 24% of the patients required assistance with the ADLs .

One found down victim, 79-year-old Mrs. F., said, "Prior to the accident, I drove my own car. I led a very active life. I did my own shopping. I was in Bridge groups, domino groups, on different boards at the hospitals, charities - I was out everyday." The cause of her found down incident was a fall that led to a leg fracture. She underwent surgery to insert a nail in her femur bone. After the surgery, she was unable to get out of bed without assistance. One year after the incident, she regained most of her independence, but remained house-bound due to her leg injury.

Another patient, Mrs. C., had a car which she used almost everyday prior to being found down. She went to the grocery store, the bank, and even to a gym to exercise. Her medical chart stated that a "cardio-embolic event" caused the incident. She became hyponatremic while down and consequently underwent mental status changes. She was very weak and unable to walk at the time of discharge. She showed minimal improvement during physical therapy. Her mental status improved, although she "never completely normalized." After hospitalization for the found down incident, Mrs. C. spends most of her day in a wheelchair in diapers in the nursing home. One year later, she remains wheelchair-bound in a nursing home. Although she is adapting well to her new home, she feels she has left behind her active life in the community.

The two examples illustrate the changes in functional capacity resulting from a found down event. The following section will focus on changes in functional capacity at the time of discharge and one year later.

Patients discharged home and will be compared to those discharged to nursing homes.

Functional Capacity At the Time of Discharge

ADL Capacity

Studies have shown that a decline in functional capacity is associated with changes in residential arrangements (See Chapter VII). Data gathered from the medical charts of found down victims showed that 76% of the patients who did not regain their previous level of ADL function were discharged to skilled nursing facilities compared to 13% of those who had no change in ADL function (See "Impact on Living Arrangements"). Over five times as many of the patients who required assistance with four or more of the ADLs were institutionalized than discharged home. Sixteen percent of the study population were reported to be incapable of performing any of the ADLs at the time of discharge and were all discharged to an institution (Fig. 9.1).

Ambulating

One ADL, the ability to ambulate, was frequently described in detail in the medical charts. At the time of discharge, 16% of those discharged home and 22% of those discharged to nursing homes had difficulty walking without some type of assistance, which may be a cane, a walker, or aid of another person (Table 9.2). For example, Mrs. S. was able to move all four extremities and ambulate well without assistance when she was discharged to an institution. In contrast, when Ms. O. was discharged to a skilled nursing facility, she had poor gait and required a cane to walk. Her discharge form read:

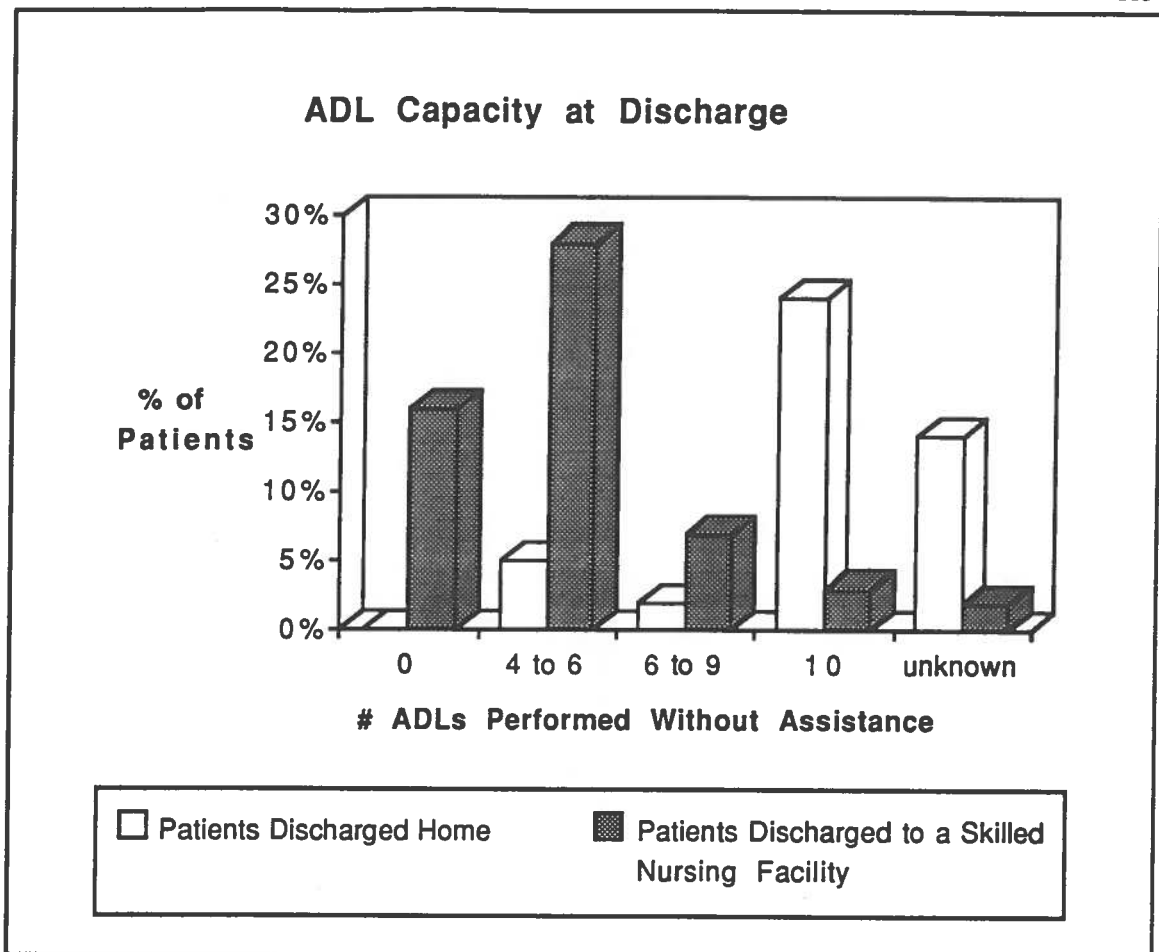


Figure 9.1

Postoperatively, the patient progressed extremely slowly with physical therapy and occupational therapy. Secondary to this, it was decided by Doctor _____ and Doctor _____ that the patient would benefit from a stay in the skilled nursing facility here...in an attempt to increase her ability to ambulate and perform her activities of daily living.

Although the ability to ambulate was described in detail in many medical charts, there are cases in which it was not a determinant of whether a patient was discharged home.

Table 9.2: Weakness, Limitations on Mobility, and Difficulty with Ambulating* At the Time of Discharge (n=58)

	Discharge Destination	
	Home	Skilled Nursing Facility
	# of Persons (%)	# of Persons (%)
Weakness	3 (5)	7 (12)
Limitations on Mobility	4 (7)	4 (7)
Difficulty Ambulating	9 (16)	13 (22)

*includes individuals requiring a cane, walker, or staff assistance with standing or walking

Cognitive Capacity

Descriptions of the cognitive capacity of the patients at the time of discharge were also present in many of the medical charts. Nineteen percent of the individuals who were discharged home had no known cognitive deficits, compared to 16% of those discharged to a nursing home. However, an almost equal percentage of patients who were described as confused or having altered mental status were discharged home as to a nursing home. None of the patients who returned home were described as being depressed, compared to 3% of those institutionalized (Fig. 9.2). A decline in cognitive capacity may be a better predictor of institutionalization than the level of cognitive ability. However, the cognitive capacity prior to being found down was not assessed.

Summary

To summarize, patients who required assistance with their ADLs tended to be institutionalized rather than discharged home. More patients without cognitive deficits were sent home than to nursing homes. However, these generalizations did not hold true in many cases, suggesting that factors other than physical and cognitive capacity were considered in deciding the discharge destination (See Chapter VII).

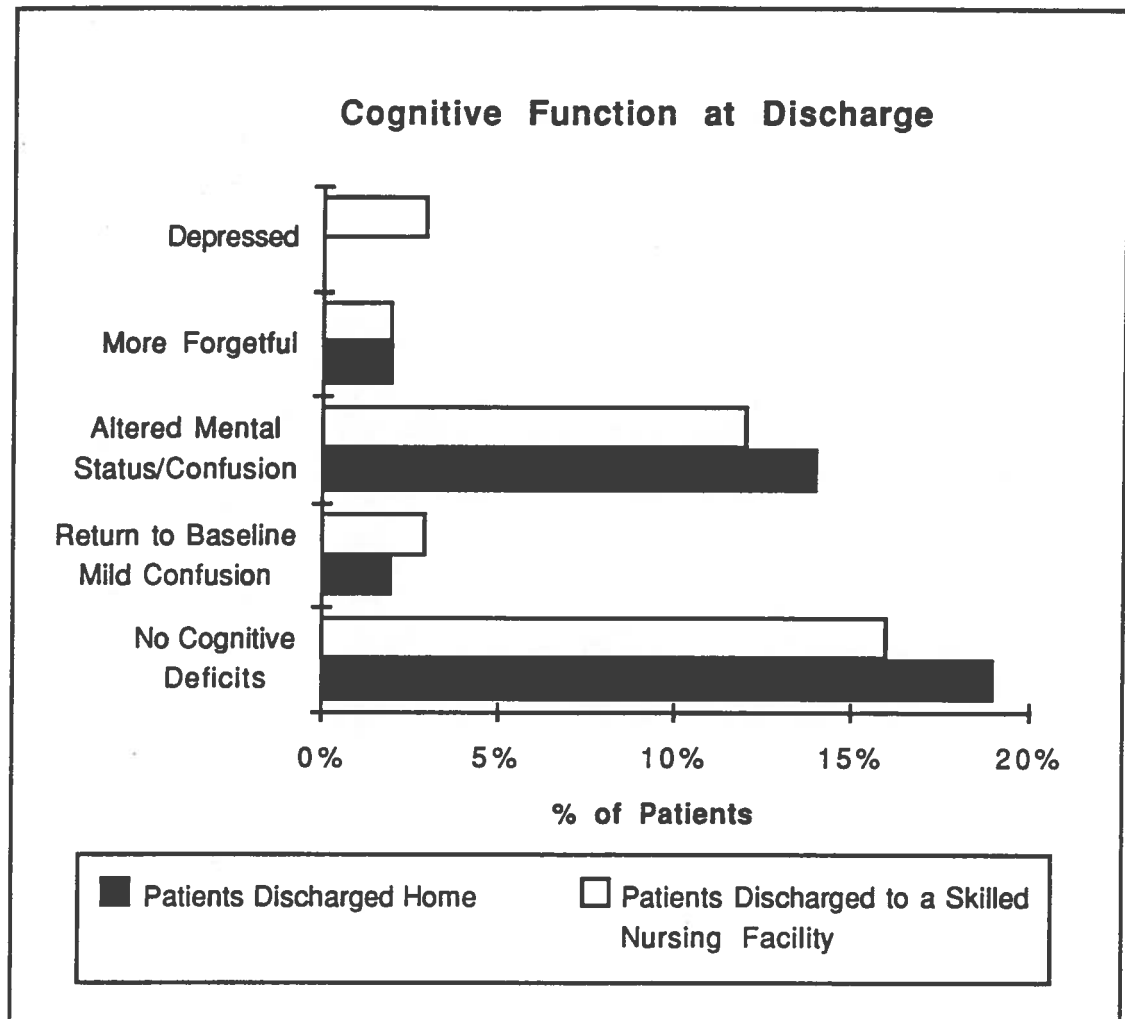


Figure 9.2

Functional Capacity One Year Later

Patients Who Were Institutionalized

Data gathered from interviews and efforts to contact patients were used to determine the change in physical capacity of the study population one year after the found down incident. Fourteen percent of the patients who were discharged to a nursing home have moved home. Half of these individuals are living independently at home. Four of the patients who were discharged to

nursing homes were still institutionalized. Three of these four seniors were able to perform the ADLs independently, while one is reportedly in his "last stretch." Seven percent of the study population have died in the nursing home after being discharged there, while three percent have died after moving out of the nursing home (Fig. 9.3).

Patients Who Returned Home

The majority of the patients who returned home with or without community support services are reportedly managing well at home. However, four of the seniors who are at home are unable to perform the ADLs independently. Mrs. Z., for example, is bedridden and unable to talk. She receives 24-hour home care after having had several strokes and falls. Her daughter said, "My mother is "getting weaker and doesn't want to get up and I don't know what we are going to do with her." Twelve percent of the persons discharged home have died in their homes (Fig. 9.3).

Summary

Patients who were institutionalized generally had poorer functioning capacity at the time of discharge and one year later. Surprisingly, a larger percentage of patients with no cognitive deficits were discharged to skilled nursing facilities than home. Perhaps the decline in cognitive capacity, which was not assessed, would have a positive correlation with institutionalization. Persons discharged home have a lower mortality rate than those discharged to nursing homes.

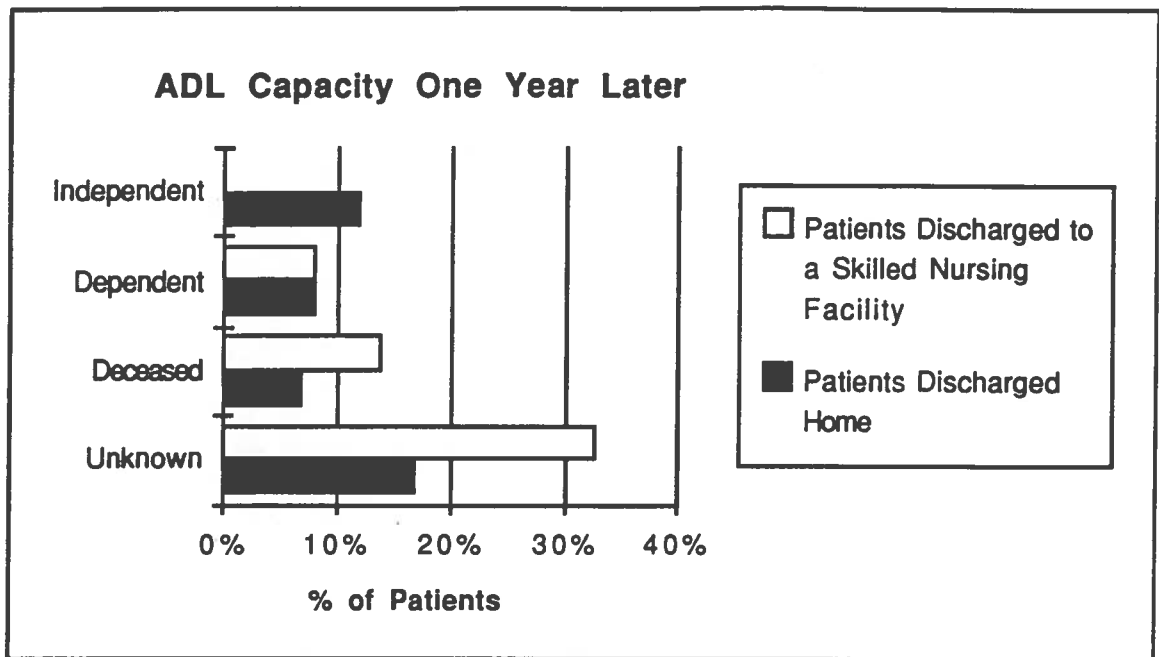


Figure 9.3

Impact on Social Support

How has the social network of these seniors changed after the found down incident? Some of the seniors experienced a decline in physical capacity and required community support after returning home. The relocation of some individuals forced them to leave former social networks behind. Others who were institutionalized not only had to relinquish former social support groups, but also had to adjust to an entirely different sense of community. Following is a description of the impact of the found down syndrome on social support.

Patients Who Returned Home

As stated above, many of the seniors lost the ability to perform some or all of the ADLs after being found down. Consequently, those who returned

home required more assistance than before, especially during the first few months after the incident. Providers of these services increased the number of social contacts of the patients during the period in which extra home help was needed. The following section describes the services utilized by patients requiring home support (Table 9.3). For example, Ms. R. had someone who shopped and cleaned for her come twice a week. She also had meals delivered to her apartment for a month after the incident. Mrs. F. had 24-hour help in addition to visits from her daughter three nights per week for three to four months. Mr. W.'s friend helped him manage at home for five days a week. His two sons came to see him every night that he was in the hospital. Presently they visit him once or twice per week and call him frequently.

Table 9.3: Community Support Utilized After Discharge Home

Type of Support	Number of Patients (%)
Home Health Agency	7 (12)
Caretaker/Housekeeper	6 (10)
Visiting Nurse	6 (10)
Relatives	3 (5)
Social Worker	3 (5)
Friend	2 (3)
Occupational Therapist	1 (2)
Physical Therapist	1 (2)
No Help Required	1 (2)
Unknown	7 (12)

*Patients who had more than one type of support were counted more than once.

In contrast, one of the seniors, Ms. A. W., had no extra help after being found down. The recent death of her husband and her worsening glaucoma despite thirteen eye surgeries were areas of concern for Ms. A.W., in addition

to the recent found down event. Furthermore, she had to look after her two grandchildren until her son finds a new job. Thus, the need and availability of support after hospitalization varied from patient to patient. However, most of the individuals interviewed had extra support for a period after the incident.

Patients Who Were Institutionalized

A decline in physical capacity often temporarily increases the social contacts of a patient. However, seniors who have moved are physically further away from some of the friends, relatives, and neighbors who once lived nearby. For example, Mrs. K. moved to Los Angeles. She misses the friends she had known all her life. Although she is making new friends in the nursing home, they are not the "life-long cherished friends" she once had. Another senior, Mrs. C., who used to exercise regularly at the gym near her home, is now in a nursing home. When asked if her friends come to visit her, she replied:

Well, the gang [from the gym] still drops by and that's about it. You know, it [the visits from her friends] drops off as time goes on, but they come every now and then and tell me their griefs.

Mrs. C. attempts to make new friends at the nursing home, but is not always successful at initiating a conversation: "If they feel like talking fine, if not, it's all right with me." Mrs. L. was also institutionalized after being found down. She feels lonely living in a place where none of the staff members speak her language, except for a couple of janitors who do not have regular schedules. Because she cannot understand what any of the activity leaders are saying, she often resigns to reading the Bible in her room.

Conclusion

Thus, of the patients interviewed, most who were discharged home had increased social contact either in the form of community services or support from family members. The support, however, was temporary for patients who were able to regain prior functional capacity. Patients who were institutionalized lost their former support networks and were attempting to form new networks one year after being found down.

Psychological Impact

Found down victims may be living in fear - fear of falling, fear of another found down incident, fear of living alone. Victims who become institutionalized must move abruptly to an entirely foreign environment. The psychological impact of a found down incident may hinder recovery and influence the choice in living arrangements. This section will describe the psychological impact of the found down incidents in terms of the fears of falling, of another found down event, of living alone, and of institutionalization. Changes in life perspective resulting from being found down will also be presented.

Fear of Falling

Several of the seniors interviewed mentioned the fear of falling after being found down. Studies have shown that the fear of falling can lead to self-imposed restrictions on physical activity and may hinder progress during rehabilitation.^{15,18} One senior's fear of falling was alleviated by placement in a nursing home. She felt safe from falls when strapped to her wheelchair.

Another patient, Mrs. F., describes her progress in regaining ambulatory function: "Now I'm just trying to walk and not be afraid of falling with the eyesight practically gone...And the fear of falling. I don't think I could ever forget that cracking sound" [when she fell during the found down incident].

Fear of Another Found Down Incident

In addition to being afraid of falling, Mrs. F. is fearful of having another found down incident. To alleviate her and her concerned daughter's anxieties, she decided to enroll in an emergency contact system at a local hospital. She described how pleased she was with the system:

So I wear it at all times so if I fall or if anything happens, I just push this button and it gets help immediately. I pay thirty dollars a month, but it's a sliding scale. It gives my daughter great peace of mind; it gives me peace of mind, because I know that if this ever happens again, I just press this and the machine is up by my bed there. And it takes minutes and they'll be calling and asking if I need help. The neighbor next door is the first one they would call. Then the one across the street. They'll call and if they can't get either neighbor then they call 911. So you do have help within reach.

Another patient's fear of being found down again made her insecure about her decision to return home. When asked if she was excited to come home after leaving the convalescent hospital, Ms. O. stated that she was both "excited and not excited." She wanted to come home, yet she felt secure at the convalescent hospital. She explained that she had slipped while attempting to reach the commode during her stay in the convalescent hospital. Although the accident occurred in the middle of the night, six people ran in to the room to help her up. She was unsure of the consequences if the accident were to occur at home. Although the fear of another found down event did not prevent these two women from returning home, they returned with fear and anxiety.

Fear of Living Alone

Found down incidents have also affected the victims' perspectives on living alone. One victim's desire for the comfort of her own home overcame any fear of living alone. When asked if she was afraid to live alone, this patient responded: "No. I've been here since 1948, so I know this house and neighborhood very well." Despite her fear of living alone, another patient, Ms. R., also decided to return home:

Ms. R: I was scared coming home but nevertheless I wanted to.

Interviewer: Why were you scared?

Ms. R: Being alone - you know, for the time being and that sort of thing, but I got over that. Now it's okay.

Mr. W. had no fear of living alone again after the incident, but became depressed while alone. His wife's death may have contributed to the depression. Another patient lost her appetite and stated that medications did not help her depression.

Fear of Institutionalization

For some individuals, the fear of institutionalization was greater than any fears of living alone. Mr. W. expressed his fear of being institutionalized:

My daughter-in-law says, "Maybe you should sell the place and move into a retirement home." That would kill me and be the end of me. I says, "I'll stay here until I die and then you could put the house up and what you get from the house, you can split between the three of you." So they don't say anything no more...I'm not happy, but at least I can work down in the basement [woodwork was his hobby].

Seniors who were institutionalized did not face the fear of living alone. Instead, they had to confront the emotional impact of sudden institutionalization. When an individual has anticipated placement in a nursing home, he or she may have time to prepare for the transition. However, for a found down victim, the transition to a nursing home may be far from gradual (See Chapter VIII).

Changes in Life Perspective

Continuing with Life

How has the found down incident affected the seniors' views of their lives? Two of the seniors interviewed said that the found down incident has not changed their life perspectives. They continue to live their lives as if death were not any closer than it was before the incident. When asked whether the event has affected her view of life, one patient replied:

Accidents will happen. Nobody likes them, but you can't prevent them. It was an unfortunate accident. You can't foresee when a washer will give under the sink there, and you and the kitchen gets flooded.

Similarly, when asked to describe her feelings about the found down event last year, Ms. R. responded: "Oh, nothing. It's behind me. I always feel you get sick, then you get better. I'm okay now."

Death

Death, however, may be on the minds of many of the found down victims. Two of the seniors mentioned that they sense that their time is limited:

Mr. W.: Just trying to keep myself busy. That's the main thing. You know when you get old. I know I haven't got much time left because I'm on borrowed time....I don't care anymore, you know...I guess my family will divide these [precious possessions in his basement] when I'm gone.

Mrs. L.: I've been here [in a nursing home] for a year. I don't know how much longer I will live.

Another senior, Mr. P., is living in hopes of a better afterlife. He says, "Life is horrible. Troubles all the time. I can only wait for a better life after death. I just hope that tomorrow won't be any worse than today." Death is also on Ms. O.'s mind: "I don't know what's going to happen to me. I'll probably end up in Potter's Field." She wonders what her niece will do with all her photographs once she is gone.

Suicide

Not only death, but suicide may be on the minds of many of these people. The feeling of helplessness from being found down may instigate suicidal thoughts or magnify any suicidal tendencies. The two persons who mentioned suicide at length during the interviews were living at home one year after being found down. Both seniors cited religion as a reason not to commit suicide:

Mr. W.: My whole thing after the accident was I was pretty depressed. I even considered suicide, I was so depressed, but I thought of my sons. I know how I felt when my father committed suicide and then my brother did, you know. It's against my religion too on top of it.

Mr. P.: I'm an old man and very sick...I can't commit suicide, because my religion is very strict...The worse thing you can do is commit suicide. Once you do that it's kaput. You end life here and life up there. My religion won't allow it.

Summary

According to the patients interviewed, being found down can have a major impact on a person's psychological well-being. Some victims are able to continue their lives as before, without any permanent changes in their perspectives on life. Others sense that death is approaching much more rapidly after being found down and have even considered suicide. The psychological well-being of these patients prior to being found down was not assessed, but would be useful for comparison with present life perspectives.

Financial Impact

Major Impact

One major component of a found down incident is the financial burden. The cost of hospital and posthospital care had a major financial impact on many of the patients. One patient was in the hospital for six days. When discharged home, she had 24-hour help for about four months. This was her comment about the financial impact of the accident:

My daughter had to loan me money. Thank God I have been able to pay her back. It did hit me hard financially. It's care at home that's so costly, but if you enter a convalescent hospital, you'd still be paying about the same. It's the care after an accident, because Medicare and the supplementary insurance will take care of the hospital and the doctor's fees, but the care after you leave the hospital is really expensive. My daughter had to come to my rescue then.

Another patient was hospitalized for eight days and placed in a convalescent hospital for three weeks. She said this about the financial costs of being found down:

It burns me to think I used to stash some of my salary aside for my old age, but I have to give it to the medical profession. You fall apart and you wind up bankrupt. It's enough to make anyone depressed!

Mr. W. spent about six weeks in the hospital and hired a friend to take care of him during his recovery at home. Mr. W. felt fortunate that he had medical insurance:

...if I didn't have my butcher's insurance, it would've been terrible. I think they spent over \$50,000 on me. I had three CAT scans.

Two of his sons paid for the care at home. However, his sons eventually asked their father if he could manage with only three days of help instead of five due to financial restraints.

Minimal Impact

In contrast, two of the seniors were not financially affected by the found down event. Mr. P., who was in the custody of the court, did not worry about the financial component of being found down. He explained that he gets a few dollars of pocket money from the government, but has had no income since he became physically incapable of working. The government paid for his stay in the nursing home and presently pays his rent.

Like Mr. P., Mrs. C. also felt that the found down incident had no significant impact on her financial status. Mrs. C. has been in a nursing home for over a year. When asked how much she paid for staying in the nursing home, she stated: "About \$100 per day, but if you look at it from a different angle, even hotel rooms are around that much these days." Mrs. C. had saved a large sum of money for retirement. In addition, her husband left money for

her when he passed away. Therefore, Mrs. C. did not feel the financial impact of the found down event.

Summary

Most of the seniors interviewed stated that the financial impact of being found down was of major concern. Some seniors mentioned that the financial considerations influenced the amount and type of posthospitalization care they received. Others commented on the negative impact of the financial burden on their psychological well-being. However, the financial costs of hospitalization and posthospitalization care did not impact the patient who had large retirement funds and the patient who was in the custody of the court.

CHAPTER X: PREVENTION OF THE FOUND DOWN SYNDROME

Strategies to prevent the found down syndrome will greatly benefit elderly persons at risk and their communities. Reducing the number of found down events will decrease the number of persons who suffer the physical and mental consequences of being found down. Furthermore, prevention would benefit both the patient and the community financially. Many of the seniors interviewed stated that the found down event had a major impact on their financial status. Gurley et al. estimated the cost of care for found down patients to be \$13,069,875 per year for the city of San Francisco.¹¹

Methods of preventing found down incidents should be available to all persons at risk. Due to the limited resources and the growing elderly population, prevention strategies targeting persons who are at greatest risk for being found down may be necessary. This chapter will first summarize the demographic, social, and medical risk factors for being found down. Following will be a discussion of prevention strategies.

Risk Factors for Being Found Down

Demographic Risk Factors

Gurley et al.'s study has identified a number of potential demographic risk factors for being found down. Gurley et al. showed that the rate of found down events increased exponentially with age. The rate of increase escalated rapidly after age 60 with the most dramatic increase after age 85. The peak incidence occurred among men living alone who were aged 85 and older.¹¹ Thus, increased age is a significant risk factor for being found down.

Gurley et al.'s study also showed that incidence rates varied among ethnic groups and income levels. The rate of found down events for African-Americans was approximately double the rates for Caucasians, Asians, and persons of Hispanic origin. The African-American patients in the study tended to be in the low community income levels, while the Asian patients were mostly either in the lowest or the middle income level. The majority of the Caucasian patients were in the middle to high income levels. Thus, African-Americans at low income levels seem to be at greatest risk.¹¹

Based on these demographic results, the people at highest risk for being found down are males over the age of 85 who live alone. Elderly African-American men in the low community income levels are at particular risk. However, anyone living alone over the age of 60 is at much greater risk than those under age 60.

Social Risk Factors

In addition to demographic risk factors, characteristics of a patient's social network may place him or her in a high risk group. Data from the medical charts and interviews with patients show that almost half of the seniors in the qualitative study are widowed. This is a higher percentage than that found in the community-dwelling elderly population of the U.S.³ The increased number of widows and widowers may be due to the selection of persons who live alone for the study. Nonetheless, a widow or widower is more likely to live alone than a person with a living spouse and thus, would be at greater risk for being found down.

Although over half of the study population had relatives living within two hours' drive, only 12% were known to have regular visits from relatives. The majority of persons who had regular visitors were visited by employees of

home maintenance or home health services. Almost 9% of the patients have authorized a friend or neighbor to have their power of attorney. These statistics indicate that elderly persons who live in relative or complete social isolation are at increased risk for being found down. The need for community home support services is another risk factor.

Medical Risk Factors

A person's health status may be a strong indicator of the risk for being found down. Almost half of the population in the qualitative study had multiple medical problems with cardiac condition, a history of falls, and hypertension being the three most common conditions. A history of multiple emergency room visits or hospitalizations may also be indicative of persons at risk. Although most of the seniors were managing well at home prior to the found down event, over one-third of the study population were utilizing at least one source of community help. Thus, from this study, the increased number of medical problems and the need for home aid are risk factors for found down incidents.

The assessment of the risks for falls and pressure ulcers during hospitalization may be a strong indicator of persons at risk for found down incidents. Half of the seniors were evaluated to be at moderate or high risk for falls. Forty percent were found to be at risk for pressure ulcers.† Thirty percent of the patients were at risk for both falls and pressure ulcers. Although these assessments were made after the patient had been found down, previous assessments recorded in a patient's chart may be useful in evaluating the present risk. Further research is necessary to investigate this possibility.

†This was determined nursing assessment using scales that measured the risk for falls and pressure ulcers.

Summary

In summary, there are demographic, social, and medical risk factors for being found down. Demographically, elderly males who live alone are at high risk. Elderly African-American males at low income levels are at highest risk. The risk increases with age. Social risk factors include widowhood and lack of regular visitors. Multiple medical conditions, need for community services, and multiple hospital admissions or emergency room visits are among the medical risk factors.

Areas to Target Prevention

Based on the demographic, social, and medical risk factors discussed above, prevention strategies can be targeted at four groups of people: 1) the persons at risk, 2) the social network of these persons, 3) the health care providers, and 4) the government. Each group of people will need education and organization before a plan for prevention can be activated. The following section will elaborate on suggestions for prevention for each of the four groups of people.

Prevention Strategies for the Person at Risk

First, the patient needs to acknowledge the potential for a found down event and be aware of the consequences. The senior should learn how to assess his or her own risk for being found down. After determining the risk, he or she should learn about the means of reducing the risk. Means to reduce the risk can target three main areas of their lives: 1) their homes, 2) their health, and 3) their social networks. Each of these three areas will be discussed next.

The Home of the Person at Risk

•Primary Prevention

Means of primary prevention of the found down syndrome can be applied to the home of a potential victim. Because falls is the leading cause of found down incidents among the elderly, strategies to prevent falls would be useful in preventing the syndrome. However, many seniors in the study have neither thought about the safety of their homes prior to being found down nor added any safety features after being found down. One way to decrease the number of falls at home is to alter features of the home that can lead to falls. Josephson et al. discuss a list of steps that can be taken to reduce the hazards in each room.¹⁸ General guidelines for home safety that can be applied to any part of a home include: 1) removing or relocating objects or furniture that may cause a senior to trip, 2) improving lighting or using special lighting to increase visibility, 3) placing possessions in convenient places to avoid physical maneuvers that may lead to falls, and 4) adding handrails or grip bars in locations where falls frequently occur, such as in the shower, near the toilet, or by the stairs.

•Decreasing Down Time

The study on the found down syndrome has shown that the length of down time is correlated with the outcome. Patients who had a shorter down time were more likely to return to their prior ADL capacity. Secondary methods of prevention would involve educating the person at risk on ways to reduce the amount of down time. Adding more telephones to a home would increase the likelihood of a senior reaching a telephone after being down. More expensive means of arriving at the same goal include purchasing a cordless telephone and ensuring that it is within reach at all times.

Home emergency alert systems are being used more extensively in many urban areas. According to one patient interviewed, the home emergency alert system has reduced her and her family's anxieties concerning a second found down event. A home emergency alert system is also called by many other names, including personal response system, medical alert service, and community alarm. The alert system is a signaling device that summons help during an emergency. It has three components: 1) electronic hardware in the home that includes portable and installed sensors and a control console, 2) a response center which is either provider-based or manufacturer-based, and 3) means of dispatching assistance.⁶³ The alert system allows a person to activate a call for urgent help by pushing a button kept either around the neck or on the wrist.

Redd et al. found that the primary users of alert systems are women in their seventies or eighties who live alone. Many of these women have cardiac and musculoskeletal problems which make them prone to falls.⁶³ A similar device designed for use in the hospital setting has decreased falls by 45% in a general medical unit.⁶⁴

No studies have been done on reasons for the absence of such a system in many hospitals. Perhaps more research on the cost-effectiveness of the systems will increase their utilization. Lack of education seems to be the reason many seniors are not using the systems. Some seniors were not aware they were at risk for being found down. Others thought that the system was too expensive. Disseminating information about the found down syndrome and the various alert systems available may be ways to increase the number of people benefiting from the systems.

•Minimizing Negative Consequences

Although reducing the down time is the best strategy for decreasing the negative consequences of being found down, other ways to improve outcome exist. Persons at risk can learn to avoid some of the complications that can arise from being in a certain position for a long period of time. For instance, elderly persons could learn how to shift positions while down or in pain to minimize the risk of developing decubitus ulcers. Placing bottles of water in strategic places could reduce the amount of dehydration when a victim is waiting for help. Similarly, carpeting and good insulation in the home could reduce the risk of hypothermia. Furthermore, blankets could be placed where a down person could easily reach them to decrease the risk of hypothermia.

The Health of the Person at Risk

One way to decrease the chance of being found down is to avoid the health-related causes of found down events. An important health factor is the risk for falls. Hazards in the home environment that can lead to falls have been addressed above. Seniors could be taught to avoid risky behaviors such as using a stepping stool to reach overhead items.⁶⁵ Falls can result from one or more health factors such as weakness, poor vision, and side effects of medications which should be addressed by medical providers. Persons at risk for the found down syndrome should be advised about the significance of regular physical and eye examinations. Teaching seniors to ask about the dosages and side effects of medications, especially drug interactions, is important. Guidelines for good nutrition, adequate exercise, and other health maintenance issues provided by health care providers can greatly reduce the risk for many of the causes of found down incidents.

The Social Network of the Person at Risk

Persons at risk can increase the chance of being found when down by building a strong social network and learning techniques to minimize down time. Living with another person or a group of people can greatly reduce the down time. Acquaintances can be asked to be vigilant of a senior's absence from regular social functions. The senior could ask a neighbor or friend to call daily to ensure the senior's well-being. The senior should consider giving a neighbor or friend a key to the home to hasten any attempts to help in the event of a found down incident. Churches and other community organizations have already established telephone networks run by volunteers in the community. Persons involved in the network call elderly persons daily to ensure their well-being. Many more simple and economical techniques for increasing the chances of being found could be devised both by and for persons at risk.

Means to Develop Prevention Strategies Aimed at the Person at Risk

Education of persons at risk is the foremost method of preventing found down incidents. Workshops, television programs, and literature to inform seniors of the ways to make their homes safer is one step in preventing found down tragedies. Affordable and easily accessible groups established to help seniors assess the safety of their homes and make the necessary alterations would be the second step. Alterations for some seniors may include grip bars and special toilet features, although routine maintenance of homes are needed by many elderly persons. As discussed above, many prevention strategies could be easily and economically implemented. Motivation of community members to implement these strategies is necessary.

Prevention Strategies for the Social Network of the Person at Risk

Relatives, friends, and neighbors can learn to identify persons at risk and help prevent the found down syndrome. Social contacts of persons at risk can play a role in making homes safer. They can act as liaisons with community service providers to help seniors find the help they need.

Neighbors and friends can learn to be vigilant of the absence of a senior at a regular social function. They could make note of typical times when a person at risk leaves his or her home. An attempt to contact the person when he or she fails to leave home at the usual time can greatly reduce a found down person's down time. Being wary of the signs of being found down, such as mail or newspapers piling up in front of the house, is another way for friends and relatives to help. Informing the persons delivering the mail or newspaper of the persons at risk in the neighborhood would increase the chances of discovering a found down victim. A senior's social network could engage in these and many other simple methods to help prevent found down events.

*Prevention Strategies for Health Care Providers*Education of the Health Care Providers

All health care providers who work with persons at risk for the found down syndrome should be aware of the risk factors and consequences of the syndrome. Establishing groups responsible for giving seminars to health care workers about the syndrome is one way to disseminate the information. Another means of sharing information involves distributing literature to health care providers throughout the United States.

Developing Means to Measure and Document Risk

An efficient and effective way to measure and document a patient's risk for being found down is a crucial step towards reducing the number of found down events. Questions concerning the patient's living arrangements and social network should be included in all medical history forms. Physicians should ask those questions routinely when taking medical histories. A scale that considers the risk factors and degree to which they contribute to found down events would be helpful in identifying a large number of persons at risk. Further studies are required to develop such a scale. Meaningful usage of the scale would require education on standardized ways of assessing and interpreting the score. Health care systems would also need to ensure the routine and proper usage of the scale.

Assessment of the Home

Physician visits to a patient's home would be ideal, though unrealistic, for gathering information about a person's living arrangements and health maintenance ability. Such knowledge would enable the physician to treat the patient as a whole person. In assessing a found down patient's condition in a hospital, the physician sees and addresses only a small fraction of a much larger problem. Information gleaned by a home visit enables a physician to consider the possible causes and remedies of found down events. Unless the underlying cause for the person's presentation in the emergency room is addressed, the same person may have multiple emergency room visits. When confronted with a purely medical diagnosis, the underlying cause of a symptom or sign is always sought as a standard of care. When a diagnosis is as much medical as environmental and social, the medical conditions may be

treated, while the environment and social pathologies remain undiagnosed and unresolved.

Given the present organization of the health care system, home visits by a physician are not feasible. More thorough history-taking is one way to find out more about a patient's home environment. An alternative could be to establish a group dedicated to making home assessments. Such a group would help an elderly person find the means to make the necessary changes in the home. This group would also be responsible for sharing with a senior's physician the knowledge obtained from the home visits. Cost is one factor which would hinder efforts to establish groups to assess the patients' homes. Training social workers to perform these tasks may be less costly than establishing a new group of people. Pilot studies that show the cost-effectiveness of such measures would be necessary to convince policy-makers to allot funds for this project.

Referrals

Resources for the elderly abound in San Francisco and in the Bay Area. One way to prevent the found down syndrome is to help seniors utilize these services. For instance, paramedics often find seniors who need help with cooking and cleaning, but who did not need to be transported. In such cases, the paramedics could contact a senior service agency or provide resource information to help meet the patient's needs. Such referrals could play a major role in preventing found down incidents. Physicians are also often in the position to make referrals. However, referrals are often nonspecific or absent due to the lack of knowledge of the resources available. The resources are numerous and difficult to keep track of. A handbook of resources for seniors tailored to meet the needs of health care providers would greatly facilitate the

referral process. The following chapter discusses a project to publish such a handbook for emergency care providers.

Improving the Outcome of a Found Down Event

• *Physical Recovery*

Once a found down event has occurred, a health care provider could do a number of things to maximize the extent of physical and psychological recovery. The patient should have thorough discharge instructions and be evaluated for comprehension of the instructions. The necessary home help services should be provided if the patient is discharged home. Follow-up evaluation to ensure the patient has received the needed services is important. Proper management of the physical condition of a found down victim includes providing physical therapy when needed and follow-up medical appointments.

• *Psychological Recovery*

The psychological needs of the patient should also be assessed carefully. One strategy for increasing patient satisfaction and compliance with discharge plans is to ensure that he or she has a role in deciding the plans. A standard process for arriving at a decision should be established. For instance, the relatives or friends to contact and the role of their opinions in the decision-making process need to be considered. Physical therapists and other health care providers working with the patient should be included in the process. Meetings of all persons involved should be conducted routinely using a standardized procedure to ensure that all persons and factors are considered in the interest of the patient's well-being.

The patient's well-being includes a thorough assessment of the patient's psychological well-being. The fear of falling may hinder progress in physical

therapy. Fears of living alone, of another found down incident, or of institutionalization may influence a patient's adaptation to changes in living arrangements. By being aware of these fears, health care providers, friends, and relatives can ease these fears with words as well as action. For instance, if a senior is fearful of another found down incident, installation of a home alert system may decrease the fear. Allowing time for a senior to become familiar with a nursing home and the residents before moving in may be one way of reducing the fear of institutionalization. Although these are not primary methods of preventing the found down syndrome, they can play a large role in increasing the quality of life and degree of life satisfaction for a victim.

Prevention Strategies for the Government

The government can play a role in these areas of prevention:

- 1) ensuring the establishment and adherence to prevention guidelines and
- 2) providing financial resources. A bill could mandate the development of scales to assess the risk of being found down. Hospitals could be required by law to create and enforce guidelines for prevention. Financial resources to develop and implement prevention methods are also needed. Groups dedicated to obtaining such resources may be crucial in prevention of the found down syndrome.

CHAPTER XI: A HANDBOOK OF SERVICES FOR THE ELDERLY IN SAN FRANCISCO

A Practical Approach to Providing Referral Information to Emergency Health Care Providers

Background

The great number and variety of resources available to the elderly in San Francisco are amazing. However, the inaccessibility of information regarding these resources to emergency health care providers is even more bewildering. Emergency health care providers serve a large elderly clientele, yet have very minimal means of linking many of those who are in need of social services with appropriate agencies available in the city. Paramedics, and other emergency care providers, have little to no access to social work or case management services for clients during non-office hours. In addition, paramedics have essentially no portable resources for making at-home referrals for patients who they feel are only marginally self-supporting.

The ideas and resources for this proposal arose from the found down study. One reoccurring and important theme which arose from conducting the study was the paramedics' sense of frustration in trying to assess and refer many of these patients who they felt were at risk prior to such an event. The seniors requiring emergency care are often the ones who have no access to social services or preventive care. They are frequently socially or economically isolated. Such persons are in need of social services that may prevent medical emergencies such as home repairs to prevent falls, transportation to help seniors get to medical facilities, and visiting nurses to ensure medication regimens are followed. Social workers are not available at many emergency care facilities. After hours, the paramedics are faced with

the unpleasant choice of transporting a patient for social reasons when no social worker is available, or essentially doing nothing to address the underlying problems. The emergency care provider becomes the only potential link to desperately needed services for these isolated seniors.

However, for most emergency care personnel, the time commitment necessary to acquire the knowledge for making appropriate referrals efficiently is not feasible, given the wide array of services, the variety of problems encountered in patients' homes, and the need to update information. Complicating the issue is the fact that the population of seniors in San Francisco requiring emergency care (as identified by Gurley's study) varies greatly in ethnicity. This diverse population requires services that incorporate a large variety of cultural values and languages. The diversity of resources available in San Francisco matches the diverse needs of the community's seniors, but often remains inaccessible to the paramedics, and potential clients.

For many paramedics, one of the most frustrating and challenging encounters is that of discovering a patient who is only marginally functioning or failing at home. Paramedics often need to evaluate home situations and make referrals on the spot. Results thus far from a questionnaire distributed to the paramedics of the San Francisco Department of Public Health show that the majority of the paramedics believe that information on resources would be "very useful." One paramedic wrote: "We in many cases end up being the resource person/social worker etc. and we have no answers to give in too many cases." Emergency health care providers can be the bridge between what is needed and what is available with the proper knowledge of the community's resources open to their clients.

This bridge between needs and resources can be a primary means of preventing medical emergencies involving seniors in the community. Prevention should be the most cost effective and humane means of decreasing the number of medical emergencies. A referral for a required service would take perhaps a minute, but may prevent medical emergencies that can cause hours or even days of physical pain and psychological trauma for the client.

In summary, many of the elderly in the San Francisco community are in dire need of social services that can help decrease the number of medical emergencies. A reduction in medical emergencies would not only spare many seniors physical pain and psychological suffering, but also benefit the community economically. Emergency health care providers are often the only link of these socially isolated individuals to the city's resources, but lack the knowledge necessary to make the appropriate referrals.

Project Description

There is a notable absence of a portable handbook of services available to the elderly in the community that is easily accessible to emergency care providers. Dr. Jan Gurley and I are working on a project that entails designing, publishing, and distributing a handbook of services for the elderly in San Francisco that will facilitate emergency health care workers in making referrals. In addition, a pamphlet containing information concerning resources will be designed and translated into several languages for emergency health care providers to give to their clients as needed.

A guide entitled *A Resource Guide of Services for Seniors in San Francisco* has been compiled by the City and County of San Francisco Commission on the Aging-Senior Information and Referral. Social workers

and referral agencies are the primary users of this guide. According to the Senior Information and Referral division of the Commission on the Aging, most health care workers have not been using the guide that exists. The large number of entries and detailed information in the guide make it difficult for emergency health care providers to locate services in the guide and may account for the low utilization rate by health care workers.

Because the Commission on the Aging has already published a resource guide for seniors, reorganizing and editing this guide would be the most economical and efficient way to produce a new handbook for emergency health care providers. The Commission of the Aging Senior Information and Referral has agreed to provide an updated version of the guide on diskette for us to edit and re-design into a handbook for emergency care providers. In addition, the Paramedic Division at the San Francisco Department of Public Health, which works with a large percentage of elderly clients, is interested in this handbook of services for the elderly and will contribute significantly to the production of the handbook.

Methodology

Questionnaire for Health Care Providers

A questionnaire concerning the format and types of entries and indices for the handbook was designed in October 1993 and presented for distribution at the San Francisco Public Health Research Oversight Committee meeting on October 12, 1993 (See Appendix E for a copy of the questionnaire). A captain of the paramedic division distributed the questionnaire to all two hundred paramedics of the San Francisco Department of Public Health. The results from the questionnaire will be analyzed and will serve as the basis for designing and formatting the handbook.

Editing and Updating the Handbook

The Resource Guide of Services for Seniors in San Francisco prepared by the City and County of San Francisco Commission on the Aging will be edited and reformatted based on the results of the questionnaire. Various indices, including categorization by type of service provided and languages spoken, will be compiled to ease searches for the resources included. The completed handbook will then be formatted for desktop publishing.

Publishing and Distributing the Handbook

Once the handbook has been prepared for publication, either the publisher used by the Commission on the Aging or another suitable and economical publisher will be hired. Upon publication, the handbook will be distributed to the health care providers in the city free of charge. Depending on the needs of rotating emergency staff at each institution, each health care agency may be given multiple copies. An estimation of the distribution of approximately 400 copies of the handbook is as follows:

Agency Receiving Handbook	Number of Copies Provided
Paramedics in the Paramedic Division in the San Francisco Department of Public Health	200
Hospitals in San Francisco receiving ambulances	120
Veterans' Hospital not receiving ambulances, but providing care to indigent elderly	10
Neighborhood health centers	50
Free clinics	20
TOTAL	400

Pamphlets for Patients

Those present at the San Francisco Public Health Research Oversight Committee Meeting on October 12, 1993 suggested that a handbook would be useful for health care providers, while pamphlets with resource information in different languages would be useful for distributing to patients. Thus, such a pamphlet will be designed, based on some of the results of the questionnaire for the handbook and translated into various languages including Spanish and Chinese. Upon completion, a total of 1000 copies of the pamphlet will be produced and distributed. An estimation of the distribution of approximately 1000 copies of the pamphlet is as follows:

Agency Receiving Pamphlets	Number of Copies Provided
Paramedics in the Paramedic Division in the San Francisco Department of Public Health	500
Hospitals in San Francisco receiving ambulances	200
Veterans' Hospital not receiving ambulances, but providing care to indigent elderly	40
Neighborhood health centers	200
Free clinics	60
TOTAL	1000

Future Updates and Distribution of Revisions

The database for the completed handbook and pamphlets will be designed to easily accommodate revisions and additions. Copies of the database will be given to appropriate personnel of the San Francisco Department of Public Health and arrangements will be made with the department for updating the information every two years. The possibility that the agencies receiving the pamphlets will be responsible for restocking their own supplies will be discussed with each agency.

This project is extremely economical and practical. Firstly, it arose from a recognized need expressed by the population for which it will serve. Secondly, the design of the handbook will be tailored by those who will use it. Thirdly, this project uses exemplary resources and databases which already exist, but need to be edited and formatted for the purpose at hand. The primary costs of the project are those of publication and distribution.

Budget

Budget Categories	Amount
Personnel: Administrative Assistant (10% time)	\$250
Supplies: General Office (including postage for distributing handbooks and surveys stamps)	\$625
Printing and Reproduction	\$4107
TOTAL	\$4982

Project Timeline

Objective 1: To produce 400 copies of a handbook of services for the elderly in San Francisco to be used by the emergency care providers in San Francisco for making referrals.

* implementation of schedule begins when funding has been obtained

Activity/Task	Evaluation Methodology	Resources Needed	Implementation Schedule	Outcome
1.1 Questionnaire for paramedics to obtain information regarding handbook content and design	Present results to S.F. Public Health Oversight Committee for comments and additions	Required resources already provided by the S.F. Department of Public Health	Done	Information on which resources to include in handbook and how to format entries
1.2 Edit database provided by the Commission on the Aging	Present edited version to Commission on Aging for comments	10 computer diskettes	Month 1 through Month 4	A revised database of resources to be included in the handbook
1.3 Publish handbook	Approval of quality of publishing by S.F. Department of Public Health	Publication costs	Month 5	A product that is useful & easily accessible to emergency health care providers
1.4 Distribute 400 copies of handbook according to schedule given in "Project Description" section	Response to survey of handbook value enclosed in handbook	1. Shipping costs of handbook 2. Stamps for return of survey	Month 6 through Month 7	Handbooks available to emergency health care providers in San Francisco free of charge

Objective 2: To design and produce a total of 1000 copies of a pamphlet in several languages containing information on services for the elderly which emergency health care providers can give to clients.

* implementation of schedule begins when funding has been obtained

Activity/Task	Evaluation Methodology	Resources Needed	Implementation Schedule	Outcome
2.1 Use information on questionnaire for handbook to select services to include in pamphlet	Present list of selected resources to S.F. Public Health Oversight Committee and Commission on Aging for approval	Required resources already provided by the S.F. Department of Public Health	Month 4	Revised database with only selected resources to be included
2.2 Design and format pamphlet	Present draft to S.F. Public Health Oversight Committee and Commission on Aging for approval	none	Month 5	Pamphlet in English that is useful to emergency care clients ready
2.3 Translate pamphlet into several languages including Spanish & Chinese	Verification of translation accuracy by showing pamphlet to agencies serving those who speak the language in question	Assistance in translation	Month 6	Pamphlets in several different languages providing resource information for elders
2.4 Produce a total of 1000 copies of pamphlet to distribute to emergency health care agencies in San Francisco according to schedule given in "Project Description" section	Telephone agencies to confirm arrival and use of pamphlets	1. Duplication costs 2. Colored paper 3. Shipping costs	Month 7	A pamphlet containing useful information on resources for the elderly in San Francisco in several languages that emergency care agencies can hand out to clients

Progress Report

Dr. Jan Gurley and I are working on editing *The Resource Guide of Services for Seniors in San Francisco* prepared by the City and County of San Francisco Commission on the Aging. Funding for the handbook by the Emergency Medical Services Authority of the City and County of San Francisco is being processed at the present.

CHAPTER XII: CONCLUSION

With the help of the paramedics of the San Francisco Department of Public Health and the seniors who generously shared their experiences, my understanding of the found down syndrome has increased. I deeply appreciated the opportunity to talk at length with found down victims. Medical students rarely have the valuable experience of visiting patients in their homes. The seniors I interviewed added tremendously to my medical school education, both in terms of knowledge of social concerns and of communication skills. I was most inspired by the energy and desire of some of the seniors to continue to live their lives in the fullest. Such energy should be kept alive as long as the person is alive.

Of course, this research project had its share of difficulties. This section will discuss the difficulties encountered during this project in hopes of facilitating further research in this area. Ideas for further research projects will be presented in the following section.

Difficulties Encountered During the Study

Attempts to Obtain Interviews

Many of the difficulties confronted during the study occurred during attempts to obtain interviews. The first attempt to contact potential study subjects was a letter introducing the study with a return card to be filled out by those interested. Although the letter was printed in large letters, many of the patients were unable to read the mail due to poor vision or frailty. Relatives who read the patient's letters may have thrown the letter away, assuming that the senior would not be interested. Many of the letters were returned with no forwarding address.

The second step was a follow-up telephone call to ask if the senior had received the letter and if he or she were interested in participating in the study. Some of the persons who were sent letters did not recall receiving the letter. Some of the seniors were hard of hearing and had trouble comprehending the content of the telephone call. Often, no one answered the call. Perhaps these seniors were too frail to answer the telephone or perhaps they had moved or were in the hospital. On a few occasions, a home service provider or relative answered the telephone and stated that the senior was not well enough to participate without first asking the senior. However, nurses in nursing homes were cooperative and made extra effort to explain the study to patients.

The third attempt to increase the number of interviews involved writing to the emergency contact persons listed in a patient's medical charts. The letter asked the emergency contact person for the patient's new address and if the addressee or another friend or relative is willing to participate in an interview. The low response from this attempt may have resulted from the complicated nature of the letter and consent forms, designed to comply with the restrictions from human subject committees. Telephone calls to these contact persons were not allowed by the human subjects committee.

Potential solutions to the problems of contacting patients include beginning with a larger population and providing an incentive for the interviews. An alternative to these approaches is to hire interviewers to wait in emergency rooms for found down victims. Patients who are not in serious condition can be interviewed while they wait in the emergency room. Names of patients who will be admitted can be placed on a list to be contacted at a later date during hospitalization. Persons who are found dead or not transported can be identified through the paramedics as was done during this study.

Nonresponse Bias

Inherent to the study methodology is nonresponse bias. The patients interviewed represent only the found down victims who were well enough physically and emotionally to participate in the study. However, information on the experiences of individuals who were not well enough to respond or who have died would add to our understanding of the more drastic effects of the syndrome. One way to obtain this data would be to interview close relatives or friends of these victims.

Inconsistent Record-Keeping

Health care providers may not be consistent in the information they record on the paramedic pre-hospitalization forms and medical charts. A potential strategy to overcome this problem is to design a standard, succinct form for a small number of paramedics and physicians to fill out for each patient. Other options include having researchers accompany the paramedics to the homes of potential found down victims or observing physicians at work.

Recall Bias

The interviews were conducted approximately one year after the found down event. Recall bias may have entered some of the descriptions of the incidents. Furthermore, the more immediate psychological impact of being found down is difficult to elicit one year later. A possible way to circumvent the recall bias is to conduct the interviews either during hospitalization as suggested above or soon after discharge. An alternative would be to have the person who discovered the patient present to remind the patient of details of the incident. A third possibility would be to interview the persons who discovered the victims in addition to the victims themselves.

Implications of the Study

Despite these shortcomings, much has been discovered about the found down syndrome. The mortality rate in the study population was over 20%. Many of those who survived suffered physical and mental trauma. The consequences of a found down event may be devastating. With the increasing number of elderly persons in the world, the number of found down victims will increase unless prevention strategies are developed and implemented.

The data from this study will help guide the development of prevention plans. Three components of the found down syndrome have been investigated in this study: 1) the backgrounds of the victims prior to being found down, 2) descriptions of the found down events, and 3) the impact of the syndrome. The information on the demographic, medical, social, and financial backgrounds of the victims prior to being found down indicated risk factors for being found down. The risk factors include increasing age, social isolation, and multiple medical conditions. Knowledge of the risk factors could be used to target prevention strategies toward groups at high risk. Removal of the risk factors is another goal of prevention. The data on the found down experiences and discovery will help develop secondary prevention methods, including means to decrease the down time. The study showed that the syndrome may alter the lifestyle of a victim, including his or her functional capacity, living arrangements, financial stability, and psychological well-being. Information gathered on the impact of the incident enables the community to examine means of diminishing the negative consequences of the syndrome. Methods of improving hospital and posthospital care and maximizing life satisfaction may help prevent tragic outcomes.

The data indicate that the found down syndrome results from a combination of environmental, medical, and social problems. Therefore, the

collaboration of service providers in all three fields may be necessary to design and implement the most efficient and effective prevention methods. Further research on the syndrome will also contribute to efforts to prevent the found down syndrome.

Areas for Further Studies

This research has raised many issues for future studies. Topics yet to be explored can be divided into the following categories: 1) medical aspects, 2) the psychological impact, 3) family members, and 4) institutionalization. The following is a list of topics for future investigation.

Medical Aspects

- a comparison of diagnoses before and after found down incidents
- medications used by found down victims, including possible side effects and drug interactions
- direct observations of the dynamics of deciding on a discharge destination
- variation in documenting information on medical charts
- correlation of previous assessments of the risk for falls and pressure sores with found down incidence rates
- development of a scale to assess risk

Psychological Impact

- possible correlation of patients' thoughts while down with the psychological impact
- effects of the psychological impact on physical and emotional recovery

Family Members

- reaction of family members to found down incidents
- financial impact of the found down syndrome on family members
- changes in living arrangements of family members as a result of a found down event

Institutionalization

- factors which determine temporary versus permanent institutionalization
- adaptation to institutionalization two or three years after being institutionalized and factors of the found down event which may have played a role

Concluding Remarks

I am grateful to everyone who contributed to this research, especially the elderly found down victims who shared their experiences. Much knowledge has been obtained from this project. I hope that this knowledge will help make the "golden years" in our futures less frightening. However, this research also uncovered unexplored areas that may have significant roles in the prevention of found down tragedies. It is my hope that these areas will not remain unknown for long. Voices such as these have inspired me to do this work and I hope they will continue to inspire others:

"It is weariness of all pursuits that creates weariness of life."

Cicero⁶⁶

"The way I look at it, old age is actually a reward for not getting run over by a truck or dying of a terminal illness."

Arthur Marx- The son of Groucho Marx⁶⁷

"An aged man is but a paltry thing
A tattered coat upon a stick, unless
Soul clap its hand and sing, and louder sing
For every tatter in its mortal dress."

Yeats⁶⁸

"I am all too aware that the old computer under my scalp has blown fuses; that the television, through which I look out at life, has loose screws; that all my machinery is breaking down. If I were to cry over it, the parts would only rust sooner."

Dame Hyacinthe Hill, an American poet⁶⁸

"As for myself, I have always preferred not merely the Pursuit of Happiness, but the Happiness of Pursuit."

Jerome Lawrence, an American playwright-director⁶⁹.

"At the age of seventy-five I am not yet old, and I hope to grow much, much older. But I am determined that come what may I shall die before I become old."

Lee Loevinger, legal theorist, judge, and attorney.⁷⁰

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APPENDICES

Appendix A: Medical Chart Review Form

Patient study #: _____ Date of review: _____

Social Conditions Prior to Accident:

Does the patient have a regular medical provider? yes no unknown
 If yes, specify:
 Agency: _____ Physician: _____

Has the patient received help from any community agency?

yes no unknown

If yes, which one(s)?

Source of information:

home health agency

paramedic run sheet

meals on wheels

physician's hx

visiting nurse

nurse's notes

homemaker

MS notes

other:

other:

Is the patient a widow/widower? yes no unknown

If yes, for how long? _____ unknown

Source of information:

paramedic run sheet physician's hx nurse's notes MS notes

other:

Does someone visit the patient regularly? yes no unknown

If yes, fill in the available data:

<u>Name</u>	<u>Age</u>	<u>Relationship</u>	<u>Frequency of Contact</u>
-------------	------------	---------------------	-----------------------------

Source of information:

paramedic run sheet physician's hx nurse's notes MS notes

other:

Patient's Functional Status Prior to Accident

Physician's opinion: information unavailable

Nurse's opinion: information unavailable

<u>Activity</u>	<u>Independent</u>	<u>Need Assist</u>	<u>Unable to do</u>	<u>Explain/U=unable to det.</u>
bath/shower				
dressng				
toileting				
moving to/from bed / chair				
walking				
eating				
meal preparation				
household chores				
oral hygiene				
bladder mgt.				
bowel mgt.				

other notes from nurse:

information unavailable

Friend/relative's opinion:

information unavailable

Source of information

Name:

Address:

Phone:

Relation:

information unavailable

Patient's opinion:

- information unavailable

Patient's Medical History Prior to the Accident:

- hx unknown cardiac condition
 angina asthma/emphysema
 pneumonia diabetes mellitus
 ID II periph. neur.
 seizure disorder CVA
 obesity hypertension
 alcoholism presently history of no hx of
 smoking presently history of no hx of
 psychological disorder-specify:
 at high risk for falls
 history of falls
 most recent fall:
 rate/# falls prior:
 other - specify:

Circumstances of the Accident

Who called for help? unknown

<u>Name</u>	<u>Relationship</u>	<u>Phone # &/or Address</u>
-------------	---------------------	---------------------------------

Discovery of patient was:

- unknown
 an accident
 a result of noticing newspapers piled at front door / stuffed mailbox
 due to person's failure to emerge from home at familiar times
 during a scheduled meeting with patient
 preceded by warning from patient (i.e. patient said he/she wasn't well)
 patient called for help

- heard patient fall
- patient used home emergency alert system
- due to person's failure to answer the phone
Who attempted to call the patient?

<u>Name</u>	<u>Relationship</u>	<u>Address</u>	<u>Phone</u>	<u>Reason for calling</u>
-------------	---------------------	----------------	--------------	---------------------------

- information unavailable

Was forced entry necessary? yes no unknown

Where was patient found?

- | | |
|--|--------------------------------------|
| <input type="checkbox"/> bedroom | <input type="checkbox"/> living room |
| <input type="checkbox"/> kitchen | <input type="checkbox"/> bathroom |
| <input type="checkbox"/> while showering/bathing | <input type="checkbox"/> yard/porch |
| <input type="checkbox"/> other: | |
| <input type="checkbox"/> information not available | |

Patient was found

- | | |
|--|---|
| <input type="checkbox"/> prostrate on the floor | <input type="checkbox"/> lying on the bed |
| <input type="checkbox"/> sitting on the floor | <input type="checkbox"/> sitting in a chair |
| <input type="checkbox"/> in urine/feces | |
| <input type="checkbox"/> other: | |
| <input type="checkbox"/> information unavailable | |

Condition of patient upon discovery by paramedics:

- | | |
|--|--|
| <input type="checkbox"/> AO x 4 | <input type="checkbox"/> ambulatory after assistance to feet |
| <input type="checkbox"/> AO x 3 | <input type="checkbox"/> dehydrated |
| <input type="checkbox"/> AO x 2 | <input type="checkbox"/> weak |
| <input type="checkbox"/> AO x 1 | <input type="checkbox"/> starving |
| <input type="checkbox"/> unresponsive | <input type="checkbox"/> confused |
| <input type="checkbox"/> unable to speak | <input type="checkbox"/> violent |
| <input type="checkbox"/> difficulty speaking | <input type="checkbox"/> depressed |
| <input type="checkbox"/> unconscious | <input type="checkbox"/> short of breath |
| <input type="checkbox"/> in pain - specify: | <input type="checkbox"/> other-specify: |

Apparent reason for accident:

- mechanical fall - 2° to _____
- dizziness seizure
- suicide heart attack
- unable to get up after sitting down or lying down
- other:

Briefly describe circumstances of incident:

- information unavailable

Condition of home upon discovery:

- emergency alert system available unkept
- malodorous no running water
- no electricity no food/little food
- spoiled food cold
- cockroach infested
- other:

- information unavailable

Patient's Functional Status After the Incident**Physician's opinion:**

- information unavailable

Nurse's opinion:

<u>Activity</u>	<u>Independent</u>	<u>Need Assist</u>	<u>Unable to do</u>	<u>Explain/U=unable to det.</u>
bath/shower				
dressing				
toileting				
moving to/from bed/chair				
walking				
eating				
meal preparation				
household chores				
oral hygiene				
bladder mgt.				
bowel mgt.				

information unavailable

other notes from nurse:

information unavailable

Friend/relative's opinion:

information unavailable

Source of information same as previous source new source

Name:

Address:

Phone:

Relation:

information unavailable

Patient's opinion:

information unavailable

Cognitive Function

Physician's opinion: information unavailable

Nurses' opinion:

Cognitive Screen Scale information unavailable

Recall:

Orientation:

Attention:

Memory:

Total Score:

other notes by nurse: information unavailable

Relative/friend's opinion: information unavailable

Source: same as previous source new source-see last pg. for details

information unavailable

Hish Risk for Falls Assessment

information unavailable

score calls for falls protocol

SFGH	UCSF	Mt. Zion	PMC
55 or older	65 or older	65 or older	age >70
mental limits	mental limits	mental limits	confusion<70
hx of falls...	hx of falls	hx of falls	confusion>70
mobility limits	mobility limits	mobility limits	depression
elim. needs	elim. needs	elim. needs	elim. needs
	medications	comm. barrier	fall hx <70
		multisys. dx	fall hx >70
			mobility limits
			surgery
			temp. increase
			weekness
			medications
			unstab. hemo.
total	total	total	total

What was the patient's pressure sore risk assessment? unknown

SFGH/UCSF

St. Mary's

Mt. Zion

PMC

physical cond.	chronic dis.	sensory percep.	sensory percep.
mental status	health factors	fric.& shear	
activity	activity status	activity	activity
mobility	mobility stat.	mobility	mobility
incontinence	bowel&bladder	moisture/incon.	moisture/incon.
	nutritional	nutrition	nutrition
	skin integrity	skin breakdown	
total	total	total	total

score calls for initiation of pressure ulcer protocol

risk category from score: low moderate high

Patient's Discharge Plans:

Destination:

- home convalescent home
 rehabilitation center with a relative
 skilled nursing facility other:

Specify name of agency/relative and address & phone #:

If discharged to home, are discharge services needed?

- information unavailable
 yes family able to continue care patient able to care for self

If yes, what skilled services are required?

- information unavailable RN
 PT OT
 HHA MSW
 Sp. Ther. other:

Who had a role in deciding the discharge destination? info. unavail.

- physician
 relative(s)-specify:
 friend(s)-specify:
 nurse
 other:

Description of decision process:

information unavailable

Source of information:

physician's hx nurse's notes MS notes other:

Contact Persons/Family Members Who Are Alive: none

1. Name:

Relation:

Address:

Phone:

Contact Freq.:

source: M.D. hx M.S. hx paramedic in-pt. record

other-specify:

2. Name:

Relation:

Address:

Phone:

Contact Freq.:

source: M.D. hx M.S. hx paramedic in-pt. record

other-specify:

3. Name:

Relation:

Address:

Phone:

Contact Freq.:

source: M.D. hx M.S. hx paramedic in-pt. record

other-specify:

Patient's phone number:

Appendix B: Interview Guides

In-Person Interview Guide

Patient Study #: _____

Date of interview: _____ Time began: _____ Time completed: _____

I. Introduction

My name is Nancy Lum. I am a second year student in the U.C. Berkeley-UCSF Joint Medical Program and I am working on this project for a Master's thesis. I would like to thank you first of all for agreeing to talk to me. I am here today, because I would like to gather information about people who, while living alone, had an accident which left them unable to get help. A study has shown that over a course of three months, there were over 350 people who have had such accidents. I would like your help in gaining a better understanding of what it is like to have such an accident and what happens to people after they have had the accident. The information that you share with me will be very useful in figuring out ways to prevent these accidents and to provide better medical and community services to people who have had such accidents. I would like to start out by asking you some questions about the accident that you had in your home in (month) last year. Then I would like to ask about your health and living arrangements before the accident and now. This interview will take about two hours of your time. You have the right to end this meeting at anytime and you do not have to answer any questions which you do not feel comfortable answering. Your name will not mentioned along with any information that you share with me. (Explain consent form and have interviewee sign form)

Do you have any questions before we begin?

II. Description of the Accident

1. Do you recall the accident at your home last (month) that left you unable to get help? (A more precise description from chart reviews will be given on an individual basis to ensure that the interviewee has the correct episode in mind.)

yes

no

If no, go to section III.

If yes,

2. Could you describe the accident to me?

Probe questions for interviewees who would like more specific questions :

a. Where were you when you fell (had the accident)?

b. What were you in the middle of doing?

c. Did you lose consciousness at any time during the accident?

yes

no

d. For how long?

e. Many people recall being in pain while waiting for help. Do you remember being in any kind of pain?

yes

no

f. Could you describe the pain to me?

g. Did you feel any other discomfort besides (the pain) while you were down?

h. About how long do you think you were unable to get help?

i. Did you call for help yourself?

yes

no

If yes, go to question k.

If no:

j. Who found you?

k. What went through you mind while you were unable to get help?

l. How did you feel when you knew that help was on the way?

III. Description of the Decision-Making Process

Right now, I would like to find out about how it was decided that you should go home after leaving the hospital. Sometimes the doctor tells the patient where he or she should go after being in the hospital and the patient agrees. Sometimes relatives and friends discuss with the patient the options and decide together the best place for the patient to go. Social workers and other service providers such as occupational therapists and rehabilitation specialists may also have been important in making the decision. Now I would like to ask you about how it was decided that you return home after you left the hospital and what you thought of the decision making process.

1. Can you tell me how it was decided that you should go home?

Probe questions for interviewees who would like more specific questions :

a. Do you recall who decided that you should go (discharge destination) after leaving the hospital?

b. Who else was there to help make the decision? (Relatives? Friends? Social worker? Other health professionals?)

- c. Where did the doctor who saw you after the accident say you should go after leaving the hospital?
- d. Did anyone ask you where you wanted to go?
- e. Did you tell anyone where you wanted to go (destination desired)?

IV. Reaction to the Decision-Making Process and Decision

1. How did you feel about the way in which it was decided that you should return home?

Probe questions for interviewees who would like more specific questions :

- a. Did you want to be involved in deciding where you would live after leaving the hospital?
- b. Did you feel you were given the opportunity to help decide where you would live?

2. How did you feel about the decision?

Probe questions for interviewees who would like more specific questions :

- a. After the accident, did you want to go back to living at home by yourself?

If yes, go to question c.

If no,

- b. Where did you want to go?

c. What is the most important reason why you did (didn't) want to live alone in your home again?

d. What other reasons made you want (not want to) go back to living alone in your home?

e. Right now, do you feel that the decision for you to go (discharge destination) was the right one?

V. Psychological Impact

Now I would like to learn about your feelings concerning the accident.

- 1. How do you feel about the accident now?
- 2. Have you thought much about it?
- 3. Do you feel that you are managing as well, not as well, or better than you were before the accident? Why?
- 4. Are afraid of having another accident like the one you had last year?
 - yes
 - no

5. Did the accident increase, decrease, or not affect your fear of living alone?

6. Can you think of anything good about having had the accident?

7. Has the accident changed your view of life?

yes

no

If no, go on to question 9.

If yes,

8. How has the accident changed your view of life?

9. Is there anything you would like to add about how you feel about the accident?

VI. Effects of the Accident

Now I would like to ask you some questions about the effects of the accident, including any changes in physical capacity, living arrangements, and financial status. Let's start with some questions about physical capacity.

Effects on Physical Capacity

The Multidimensional Functional Assessment Questionnaire ADL Section (for before and after the accident)

Effects on Living Arrangements

After such an accident, some people change their living arrangements. Changes may involve living with someone else, having someone come to do house chores, moving to another home, or making physical changes in the home. Some people did not make any changes.

1. Did you make any changes in living arrangements after the accident?

yes

no

If no, go to question 3.

If yes:

2. Can you describe the changes to me and tell me why they were made?

3. Are you a widow? How long have you been a widow?

4. *Just before the accident, who has done the following tasks for you? (Q. 258, p.74)

1=yes 2=no

9=DK

	Housekeeping	Meals	Grocery Shopping	Money Mgmt.
self				
spouse				
other household member				
other friend/relative				
paid assistance				
religious/private charitable organization (specify)				
City or county social service agency (specify)				

5. Was additional assistance needed in getting the tasks done?

1=yes 2=no

	Housekeeping	Meals	Grocery Shopping	Money Mgmt.

6. After you left the hospital, did you live alone at home?

yes

no

If yes, go to question 11.

If no:

7. Who lived with you?

8. Why did this person move in with you?

9. Is this person still living with you now?

10. Was there anyone else who lived with you that you haven't mentioned?

11. Did you move since living at the (discharge destination)?

yes

no

If no, go to question 17.

If yes:

12. Where?

13. Why?

14. Did you move again after going to _____?

yes

no

If no, go to question 17.

If yes:

15. Where?

16. Why?

17.*Now who does the following tasks for your household?

1=yes 2=no

9=DK

	Housekeeping	Meals	Grocery Shopping	Money Mgmt.
self				
spouse				
other household member				
other friend/relative				
paid assistance				
religious/private charitable organization (specify)				
City or county social service agency (specify)				

18. Is additional assistance needed in getting the tasks done?

1=yes 2=no

	Housekeeping	Meals	Grocery Shopping	Money Mgmt.

19. Did you make any changes to your house since the accident because of your physical condition or health problems?

20. What kind of changes?

21. *Which of the following have you made? (Q.088, p.26)

1=Yes 2=No 9=DK

Installed "grab"/handbars (anywhere)	-----
Installed ramps (anywhere)	-----
Installed stairway chair device	-----
Widened hallways/doorways	-----
Lighting improvements	-----
Special bathroom equipment (i.e. raised toilet seat; seat in shower/bath, etc.)	-----
Special kitchen equipment, (i.e., utensils appliances)	-----
Uses hospital-type bed	-----
Removed rugs or installed non-skid pads	-----

Effects on Finances

1. How has the accident affected you financially?

a. *Before the accident, have your assets and financial resources been sufficient to meet your daily needs? What about now, after the accident? (Q. 296, p. 84)

b. *Are you doing as well financially as you expected to do, at your present age? (Q. 297, p. 84)

Effects on Social Contact

1. Do you think that the accident has affected your social life in terms of the number and types of social contacts?

yes

no

If no, go to question 3.

If yes,

2. How?

	Prior	Now
3.* In general, how many relatives do you have that you feel close to? (People you feel at ease with, can talk to about private matters, and can call on for help?) (q. 237, p.70) <i>If no one, Skip to question 6.</i>		
4. How many of these close relatives live in places that can be reached from your home in one hour or less by car?		
5. How many of these close relatives do you see at least once a month?		
6. *In general, how many close friends do you have that are not relatives? (Friends you feel at ease with, can talk to about private matters, and can call on for help?) <i>If no one, go to question 9.</i>		
7. How many of these close friends live in places that can be reached from your home in one hour or less by car?		
8. How many of these close friends do you see at least once a month?		

9. Before the accident, how often did you leave the house each week, on average? And now? Why are you leaving the house more (less)?

If reason is physical limitations and interviewee used to leave the house prior to the accident, go to question 11.

If reason is not physical limitations:

10. How much do the following contribute to why you don't go out as much as you used to (don't go out at all)? (A card reminding the interviewee of the answer choices will be provided.)

A lot	1
Somewhat	2
None at all	3
Don't know	9

- a. street noises -----
- b. crime -----
- c. heavy traffic -----
- d. no sidewalks or poorly
maintained sidewalks -----
- e. trash or litter -----
- f. inadequate lighting at night -----
- g. difficulty finding people to
hire to run errands
or do odd jobs around
the house -----
- h. no public transportation
nearby -----
- i. no grocery store or
supermarket nearby -----
- k. other: -----

If interviewee had left the house prior to the accident:

11. Name the three most frequent places that you went to when you left the house prior to the accident.

- 1)
- 2)
- 3)

If interviewee does leave the house currently:

12. What are the three most frequent places that you visit now?

- 1)
- 2)
- 3)

13. Is there anything concerning social contacts that you would like to add?

VII. History of Found Down Incidents

1. Have you ever had another accident like this one while you were living alone?

yes

no

If no, go to section VIII.

If yes,

2. How many such accidents have you had?

3. When was the most recent one (not counting the one last _____)

4. How long have you been having recurrent accidents such as these?

VIII. Conclusion

1. Is there anything else that you would like to add?

2. Do you have any questions?

*Questions borrowed from the Study of Physical Performance and Age-Related Changes in Sonomans (SPPARCS) Questionnaire

Guide for Telephone Interviews

(Identical to the approved guide for in-person interviews with the pronouns changed and some questions deleted)

Patient study #: _____ Date: _____
Interviewee's relationship to patient: _____

I Introduction

Hello. My name is Nancy Lum and I had contacted you earlier about a telephone interview concerning [the patient's name]. Thank you very much for agreeing to answer some questions about the health and living arrangements of [the patient's name]. Before I begin, I would like to inform you that you may refuse to answer any question that makes you uncomfortable. You are also free to end this interview at any point. Any information that you give me will be kept confidential and [the patient's name] name will not be mentioned with any of the information you provide. I understand that some of the questions may be difficult for you to answer, since you are not the patient. However, I would appreciate your help in answering the questions to the best of your knowledge. Do you have any questions before we begin?

1. How are you related to [the patient's name]?
2. *If friend:* How long have you known the patient?
3. How frequently did you visit the patient prior to the accident?

II. Description of the Accident

1. Do you recall the accident that [the patient's name] had at home last (month) that left him/her unable to get help? (A more precise description from chart reviews will be given on an individual basis to ensure that the interviewee has the correct episode in mind.)

yes

no

If no, go to section III.

If yes,

2. Could you describe the accident to me?

Probe questions for interviewees who would like more specific questions :

- a. Where was the patient when he/she fell (had the accident)?
- b. What was he/she in the middle of doing?
- c. Did he/she lose consciousness at any time during the accident?

If yes:

d. For how long?

e. Was the patient in pain?

yes

no

If yes:

f. What kind of pain?

g. About how long do you think he/she was unable to get help?

h. Did he/she call for help him/herself?

If no:

i. Who found the patient?

j. Did the patient mention anything else concerning the circumstances of the accident?

III. Description of the Decision-Making Process

Right now, I would like to find out about how it was decided that the patient should go home after leaving the hospital. Sometimes the doctor tells the patient where he or she should go after being in the hospital and the patient agrees. Sometimes relatives and friends discuss with the patient the options and decide together the best place for the patient to go. Social

workers and other service providers such as occupational therapists and rehabilitation specialists may also have been important in making the decision. Now I would like to ask you about how it was decided that [the patient's name] return home/go to a nursing home after leaving the hospital and what he/she thought of the decision making process.

1. Can you tell me how it was decided that the patient should go home?

Probe questions for interviewees who would like more specific questions :

- a. Do you recall who decided that he/she should go (discharge destination) after leaving the hospital?
- b. Who else was there to help make the decision? (Relatives? Friends? Social worker? Other health professionals?)
- c. Where did the doctor who saw the patient after the accident say he/she should go after leaving the hospital?
- d. Did anyone ask the patient where he/she wanted to go?
- e. Did the patient tell anyone where he/she wanted to go (destination desired)?

IV. Reaction to the Decision-Making Process and Decision

1. How did the patient feel about the way in which it was decided that he/she should return home?

Probe questions for interviewees who would like more specific questions :

- a. Did he/she want to be involved in deciding where he/she would live after leaving the hospital?
- b. Did he/she comment on the decision-making process? If so, what were the comments?

2. How did he/she feel about the decision?

Probe questions for interviewees who would like more specific questions :

- a. After the accident, did he/she want to go back to living at home by him/herself?

If yes, go to question c.

If no,

- b. Where did he/she want to go?
- c. What do you think is the most important reason why he/she did (didn't) want to live alone in your home again?
- d. What other reasons made him/her want (not want to) go back to living alone at home?
- e. Right now, does he/she feel that the decision for him/her to go (discharge destination) was the right one?

V. Psychological Impact

Now I would like to learn about his/her feelings concerning the accident.

1. How does he/she feel about the accident now?
2. Does he/she mention it? How often?
3. Does the patient feel he/she is managing as well, not as well, or better than he/she was before the accident? Why?
4. Is he/she afraid of having another accident like the one last year?
5. Is the patient afraid of living alone?
6. How has the accident changed the patient's view of life?
7. Is there anything you would like to add about how the patient feels about the accident?

VI. Effects of the Accident

Now I would like to ask you some questions about the effects of the accident, including any changes in physical capacity, living arrangements, and financial status. Let's start with some questions about physical capacity.

Effects on Physical Capacity

The Multidimensional Functional Assessment Questionnaire ADL Section (for before and after the accident)

Effects on Living Arrangements

After such an accident, some people change their living arrangements. Changes may involve living with someone else, having someone come to do house chores, moving to another home, or making physical changes in the home. Some people did not make any changes.

1. Did the patient make any changes in living arrangements after the accident?

yes

no

If no, go to question 3.

If yes:

2. Can you describe the changes to me and tell me why they were made?
3. Is the patient a widow? How long has he/she been a widow?
4. Just before the accident, who cooked for the patient?
5. Who did the grocery shopping?
6. Who managed the patient's finances?

7. Did the patient receive any community services?

8. Did the patient move since living at the (discharge destination)?

yes

no

If no, go to question 14.

If yes:

9. Where?

10. Why?

11. Did the patient move again after going to _____?

yes

no

If no, go to question 14

If yes:

12. Where?

13. Why?

14. Just after the accident, who cooked for the patient?

15. Who did the grocery shopping?

16. Who managed the patient's finances?

17. Did the patient receive any community services?

18. Did the patient make any changes to his/her house since the accident because of his/her physical condition or health problems?

19. What kind of changes?

20. *Which of the following has he/she made? (Q.088, p.26)

1=Yes 2=No 9=DK

Installed "grab"/handbars (anywhere)	-----
Installed ramps (anywhere)	-----
Installed stairway chair device	-----
Widened hallways/doorways	-----
Lighting improvements	-----
Special bathroom equipment (i.e. raised toilet seat; seat in shower/bath, etc.)	-----
Special kitchen equipment, (i.e., utensils appliances)	-----
Uses hospital-type bed	-----
Removed rugs or installed non-skid pads	-----

Effects on Finances**1. How has the accident affected the patient financially?**

a. *Before the accident, has the patient's assets and financial resources been sufficient to meet his/her daily needs? What about after the accident? (Q. 296, p. 84)

b. *Is the patient doing as well financially as he/she expected to do, at his/her present age? (Q. 297, p. 84)

Effects on Social Contact**1. Do you think that the accident has affected his/her social life in terms of the number and types of social contacts?**

yes

no

If no, go to question 3.

If yes,

2. How?

3. How many people visited the patient regularly prior to the accident? How many after the accident?

4. Before the accident, how often did the patient leave the house each week, on average? And now? Why is he/she leaving the house more (less)?

If the patient had left the house prior to the accident:

5. Name the three most frequent places that he/she went when he/she left the house prior to the accident.

1)

2)

3)

If the patient does leave the house currently:

6. What are the three most frequent places that he/she visit now?

1)

2)

3)

7. Is there anything concerning social contacts that you would like to add?

VII. History of Found Down Incidents

1. Has the patient ever had another accident like this one while he/she was living alone?

yes

no

If no, go to section VIII.

If yes,

2. How many such accidents has he/she had?
3. When was the most recent one (not counting the one last _____)
4. How long has he/she been having recurrent accidents such as these?

VIII. Conclusion

1. Is there anything else that you would like to add?
2. Do you have any questions?

*Questions borrowed from the Study of Physical Performance and Age-Related Changes in Sonomans (SPPARCS) Questionnaire

Appendix C: Letters to Potential Subjects

Introduction Letter to Patients

[letter head]

Dear _____

My name is Nancy Lum and I am a second year student in the U.C. Berkeley-UCSF Joint Medical Program. I am conducting a study about how your health can cause changes in living arrangements and how decisions concerning living arrangements are made. Your name was identified when we were reviewing medical records of people who had used an ambulance because of something that had happened in their home. I would like to ask you some questions in an in-person interview. These questions will be about such things as your living arrangements and your experience with accidents at home. If you agree to have an interview, you can refuse to answer any question that makes you feel uncomfortable. Your name will not be mentioned with any of the information that you share with me. The interview will take about two hours. You will not be paid for participating, but you will help people in the community learn about how health can affect living arrangements in order to improve medical and community services for elderly persons. If you would like to participate, please return the enclosed stamped postcard. If I do not receive the postcard in a week, I will call you to see if you have received the letter and to ask you whether you would like to participate.

If you have any questions about this study, please call Nancy Lum at (510) 843-5524. Thank you!

Sincerely,

Nancy Lum

Enclosure card:

The enclosure card will have a designated study number in the upper right hand corner. The outside of the card will have a stamp and a return address. The opposite side of the card will state:

I wish to participate in the research study. I understand that my participation will not affect my care or medical records in any way.

My current address and phone number where I can be contacted is:

Address: _____

Phone number: () _____

Consent Form to Patients

[letter head]

CONSENT TO BE A RESEARCH SUBJECT**A. PURPOSE AND BACKGROUND**

Nancy Lum, a second year medical student in the U.C. Berkeley-UCSF Joint Medical Program, is conducting a research study to help understand how circumstances of my health and life may have affected my living arrangements. My name was identified when the researchers were reviewing the medical records of people who had used an ambulance because of something that had happened in their home.

B. PROCEDURES

If I agree to be in the study, the following will occur:

1. I will be asked some questions in an in-person interview. These questions will be about such things as my living arrangements and my experience with accidents at home. This should take approximately two hours.
2. An audiotape will be made of this discussion.

C. RISKS/DISCOMFORTS

1. Some of the questions I am asked may cause me to worry or to have other questions. My questions will all be answered as fully as possible at the close of the interview.

2. Some of the questions may make me uncomfortable, but I am free to decline to answer any questions I do not wish to answer or to stop the discussion at any time.

3. Confidentiality: Participation in research may involve a loss of privacy; however, my records will be handled as confidentially as possible. Only Nancy Lum and her co-investigators will have access to my study records or audiotapes. After the discussion has been transcribed from the tapes, the tapes will be destroyed. No individual identities will be used in any reports or publications that may result from this study.

D. BENEFITS

I will not be paid for participating in the study. However, the information that I provide may help doctors and health care providers better understand how the problems that come from being alone when something happens to you can be prevented or better treated.

E. COSTS

There will be no costs to me as a result of taking part in this study.

F. PAYMENT

I will not be paid for participating in the study.

G. QUESTIONS

I have talked to Nancy Lum about this study and have had my questions answered. If I have further questions, I may call her at (510) 843-5524.

If I have any comments or concerns about participation in this study, I should first talk with the investigator. If for some reason I do not wish to do this, I may contact the Committee on Human Research, which is concerned with the protection of volunteers in research projects. I may reach the committee office between 8:00 and 5:00, Monday through Friday, by calling (415) 476-1814, or by writing: Committee on Human Research, Box 0962, University of California, San Francisco/San Francisco, CA 94143.

H. CONSENT

I will be given a copy of this consent form to keep.

PARTICIPATION IN RESEARCH IS VOLUNTARY. I am free to decline to be in this study, or to withdraw from it at any point. My decision as to whether or not to participate in this study will have no influence on my present or future status as a patient at UCSF.

If I agree to participate I should sign below.

Date

Signature of Study Participant

Date

Signature of Person Obtaining Consent

Letter to Emergency Contact Persons

[letter head]

Dear _____

My name is Nancy Lum and I am a third year student in the U.C. Berkeley-UCSF Joint Medical Program. I am conducting a study about how health is related to accidents at home and to changes in living arrangements. [The patient's name] was identified when I was reviewing medical records of people who had used an ambulance because of something that had happened in their home. I have been attempting to reach [the patient's name] to introduce the study to him/her and to ask if he/she would like to participate in an in-person interview. The interview will occur at a place and time convenient for the patient. The questions asked during the interview will be about such things as the patient's experience with accidents at home and ability to obtain help after an accident. Unfortunately, I have been unable to reach [the patient's name] to ask if he/she would like to participate in the study. I was wondering if you could provide us with [the patient's name] new address so that we could contact him/her.

In the event that [the patient's name] is unavailable for an interview, I would like to conduct a telephone interview with one of his/her closest relatives or friends.

If you are available and agree to be interviewed by telephone, I will arrange for a time that is convenient to call you. If you are unavailable to be interviewed by telephone, I would like to conduct a telephone interview with another friend or relative of the patient who agrees to be interviewed. During the interview, you (or another friend or relative) may end the interview at any time. You (or another friend or relative) may refuse to answer any question that makes you (or him/her) feel uncomfortable. Your name (or the name of any friend or relative) as well as the name of the patient will not be mentioned with any of the information provided. The interview will take about half an hour.

Participants will not be paid for participating, but the information they provide will help people in the community learn about how health can affect living arrangements in order to improve medical and community services for elderly persons. I would like your help in supplying the means for me to contact consenting participants. **Please return the enclosed form in the stamped return envelope provided.**

If you have any questions about this study, please call Nancy Lum at (510) 843-5524. Thank you very much for all of your help!

Sincerely,

Nancy Lum

Response form:

[The response form will have a designated study number in the upper right hand corner. The form will come with a stamped envelope with a return address. The form will read as follows:

I understand that any information I provide will not affect the care or medical records of the patient in any way.

Please check all that apply:

The patient can be contacted to be introduced to the study. The current address of the patient is:

Number and street	Apt. #
City	State
	Zip Code

The patient is unable to participate in the study, because:

He/she is in poor health

He/she is deceased.

Other: _____

Either I or one of the patient's close relatives or friends is willing to participate in a telephone interview. I or this relative or friend will be called to schedule an appointment for the interview. My name and phone number (or the name and phone number of the other friend or relative) are:

Name: _____

Relationship to the patient: _____

Telephone number: () _____

Best time(s) to call: _____
 _____ Day _____ Time
 _____ Day _____ Time

Thank you very much!

Consent Form for Emergency Contact Persons

[letter head]

CONSENT TO BE A RESEARCH SUBJECT**A. PURPOSE AND BACKGROUND**

Nancy Lum, a third year medical student in the U.C. Berkeley-UCSF Joint Medical Program, is conducting a research study to help understand how health may have affected accidents at home and changes in living arrangements. When the researchers were reviewing the medical records of people who had used an ambulance because of something that had happened in their home, the names of some persons were identified. I have been asked to participate in this study because I am the relative or friend of such a person.

B. PROCEDURES

If I agree to be in the study, the following will occur:

I will be asked some questions in a telephone interview. These questions will be about such things as the patient's experience with accidents at home and changes in living arrangements. This should take approximately one hour.

C. RISKS/DISCOMFORTS

1. Some of the questions I am asked may cause me to worry or to have other questions. My questions will all be answered as fully as possible at the close of the interview.
2. Some of the questions may make me uncomfortable, but I am free to decline to answer any questions I do not wish to answer or to end the interview at any time.
3. Confidentiality: Participation in research may involve a loss of privacy; however, the patient's records will be handled as confidentially as possible. Only Nancy Lum and her co-investigators will have access to the study records. No individual identities will be used in any reports or publications that may result from this study.

D. BENEFITS

I will not be paid for participating in the study. However, the information that I provide may help doctors and health care providers better understand how the problems that come from being alone when something happens to you can be prevented or better treated.

E. COSTS

There will be no costs to me as a result of taking part in this study.

F. PAYMENT

I will not be paid for participating in the study.

G. QUESTIONS

I have talked to Nancy Lum about this study and have had my questions answered. If I have further questions, I may call her at (510) 843-5524.

If I have any comments or concerns about participation in this study, I should first talk with the investigator. If for some reason I do not wish to do this, I may contact the Committee on Human Research, which is concerned with the protection of volunteers in research projects. I may reach the committee office between 8:00 and 5:00, Monday through Friday, by calling (415) 476-1814, or by writing: Committee on Human Research, Box 0962, University of California, San Francisco/San Francisco, CA 94143.

H. CONSENT

I will be given a copy of this consent form to keep.

PARTICIPATION IN RESEARCH IS VOLUNTARY. I am free to decline to be in this study, or to withdraw from it at any point. My decision as to whether or not to participate in this study will have no influence on the patient's present or future status as a patient at UCSF.

If I agree to participate I should sign below.

Date

Signature of Study Participant

Date

Signature of Person Obtaining Consent

Appendix D: Scales for the Assessment of the Risks for Falls and Pressure Sores

Examples of Scales for the Assessment of the Risk for Falls

Assessment Form - Identification for Patients at High Risk for Falls (from Mount Zion Medical Center of University of California, San Francisco)

	<u>Score</u>
A. <u>Age 65 or older</u>	(1)
B. <u>History of:</u>	
• Previous falls	(5)
- Pre-Admission (home or community)	
- Previous Admissions	
• Seizure Disorder	
C. <u>Communication Barrier</u>	(2)
(e.g. monolingual - language other than English)	
D. <u>Mental Status Limitations</u>	(5)
• Altered level of consciousness	
• Routine use of narcotics and/or Anti-psychotic medications and/or Sedatives/Hypnotics	
• Disoriented/Hallucinating	
• Forgetful	
• Anxiety/Agitation	
E. <u>Mobility Limitations</u>	(4)
• Unable to ambulate	
• Independence altered by impaired vision	
Requires another person and/or assisting device to ambulate	
F. <u>Elimination Needs/Problems</u>	(4)
• Frequency/Urgency	
• Incontinence	
• Bowel preparations	
• Diuretics	
• Fluid intake volume (Oral/NG/IV)	
• Nocturia	
G. <u>Multi System Diagnoses</u>	(3)
• (i.e., CVA, cardiac, (CHF), with hip fracture)	

Total Score:

For score of six or greater, initiate plan

High Risk for Falls Assessment
(from the University of California, San Francisco Medical Center)

65 or older	-1-
Mental status limitations (see Cognitive Screen)	-5-
History of falls	-5-
Mobility Limitations	-4-
Elimination Needs	-2-
Medications	-1-
TOTAL SCORE	----

Initiate nursing care problem for score of 6 or more.

Examples of Scales for the Assessment of the Risk for Pressure Ulcers

Pressure Ulcer Risk Assessment Scoring Scale:
(from California Pacific Medical Center)

Sensory Perception	Moisture/ Incontinence	Activity	Mobility	Nutrition
1 No impairment	1 Rarely	1 Walks Freq.	1 No Limitations	1 Excellent
2 Slightly Limited	2 Occasionally	2 Walks Occasionally	2 Slightly Limited	2 Adequate
3 Very Limited	3 often	3 Chair Fast	3 Very Limited	3 Probably Inadequate
4 Completely Limited	4 Constantly	4 Bed Fast	4 Completely Immobile	4 Very Poor

Skin Risk Assessment
(from St. Mary's Hospital and Medical Center)

Activity Status

- 0 Ambulatory Independent
- 1 Ambulatory with Assist
- 2 Chairbound
- 3 Bedbound

Mobility Status

- 0 Fully mobile (turn self)
- 1 Limited assistance
- 2 Immobile or restrained

Bowel & Bladder Status

- 0 Continent bowel & bladder
- 1 Incontinent of urine
- 2 Incontinent of stool
- 3 Incontinent of both

Nutritional Status

- 0 Good (eats/drinks 75%) or TPN/Tube feeding
- 1 Fair (eats/drinks 50-75%)
- 2 Poor (unable/refuses; eats/drinks less than 50% of meal)
- 3 IV fluids only

Chronic Disease Status

COPD, CHF, ASVD, PVD, Diabetes, motor/sensory, liver/renal disease, HIV, dementia, cancer

- 0 Absent
- 1 One present
- 2 Two present
- 3 Three or more present

Assess every 5 days -

Score: 0-5 Low Risk

- 6-10 Moderate Risk - initiate prevention protocol & care plan
- 11+ High Risk - initiate high risk prevention and/or appropriate treatment protocol & care plan

Influencing Health Factors

- 1 Hematologic Disorders
- 1 Infection
- 1 Edema
- 1 Obesity
- 1 Fever
- 1 Dehydration
- 1 Steroid Use
- 1 Radiation Therapy
- 1 Fidgety/restless
- 1 Other: _____
- Total factors present: _____

Skin Integrity

- 0 Intact with good turgor
- 1 Intact with decreased turgor (Stage I, dry, red or thin)
- 4 Superficial break (Stage II)
- 10 Full thickness (Stage III,IV)

Appendix E: Survey for Senior Resources Handbook

What would be the most convenient size for the handbook?

- smaller than a 3"x5" index card
 - breast pocket size
 - clipboard size
- other suggestions:

About what percentage of your clients need the following types of medical services?
psychiatric counseling

- >75%
- 50-75%
- 25-50%
- 10-25%
- <10%

alcohol/drug abuse

- >75%
- 50-75%
- 25-50%
- 10-25%
- <10%

case management

- >75%
- 50-75%
- 25-50%
- 10-25%
- <10%

dental service

- >75%
- 50-75%
- 25-50%
- 10-25%
- <10%

nutrition counseling

- >75%
- 50-75%
- 25-50%
- 10-25%
- <10%

care for dementia patients

- >75%
- 50-75%
- 25-50%
- 10-25%
- <10%

vision care

- >75%
- 50-75%
- 25-50%
- 10-25%
- <10%

others-please specify:

- >75%
- 50-75%
- 25-50%
- 10-25%
- <10%

What percentage of your clients need referrals for the following home support services?**in-home care**

- >75%
- 50-75%
- 25-50%
- 10-25%
- <10%

adult day health centers

- >75%
- 50-75%
- 25-50%
- 10-25%
- <10%

respite care

- >75%
- 50-75%
- 25-50%
- 10-25%
- <10%

caregiver support

- >75%
- 50-75%
- 25-50%
- 10-25%
- <10%

home-delivered meals/meal sites

- >75%
- 50-75%
- 25-50%
- 10-25%
- <10%

home visitors/companions

- >75%
- 50-75%
- 25-50%
- 10-25%
- <10%

transportation/escort

- >75%
- 50-75%
- 25-50%
- 10-25%
- <10%

legal support

- >75%
- 50-75%
- 25-50%
- 10-25%
- <10%

financial support

- >75%
- 50-75%
- 25-50%
- 10-25%
- <10%

home repair

- >75%
- 50-75%
- 25-50%
- 10-25%
- <10%

other-please specify:

- >75%
- 50-75%
- 25-50%
- 10-25%
- <10%

What percentage of your clients would you refer to the following social services?**multipurpose community centers**

- >75%
- 50-75%
- 25-50%
- 10-25%
- <10%

recreational organizations (clubs, outdoor trips)

- >75%
- 50-75%
- 25-50%
- 10-25%
- <10%

adult education

- >75%
- 50-75%
- 25-50%
- 10-25%
- <10%

volunteer opportunities

- >75%
- 50-75%
- 25-50%
- 10-25%
- <10%

other-please specify:

- >75%
- 50-75%
- 25-50%
- 10-25%
- <10%

What percentage of your clients would benefit from the following support services?**homeless shelters/services**

- >75%
- 50-75%
- 25-50%
- 10-25%
- <10%

gay/lesbian agencies

- >75%
- 50-75%
- 25-50%
- 10-25%
- <10%

agencies on elder abuse

- >75%
- 50-75%
- 25-50%
- 10-25%
- <10%

support for widows/widowers

- >75%
- 50-75%
- 25-50%
- 10-25%
- <10%

other-please specify:

- >75%
- 50-75%
- 25-50%
- 10-25%
- <10%

Which indices would be most useful to include in the handbook? Please rank them 1 to 5 with 1= the most useful and 5=the least useful.

types of services provided

areas of the city

languages available

ethnic groups

funding source

others-please specify:

How many pages do you think would be a good number for this handbook?

<50

50-100

101-200

>200

Would a handbook of resources for the elderly be useful to you?

very useful

somewhat useful

not useful

Other comments/additions: