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THE SURVIVAL OF THE CHRONICALLY-ILL ELDERLY AS A FUNCTION OF HOME CARE SERVICES presented by

SUSAN CHRISTINE HEDRICK

has been accepted towards fulfillment of the requirements for

PH.D. degree in PSYCHOLOGY

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ELDERLY AS A FUNCTION OF HOME

,

CARE SERVICES

By

Susan Christine Hedrick

A DISSERTATION

Submitted to Michigan State University in partial fulfillment of the requirements for the degree of

DOCTOR OF PHILOSOPHY

Department of Psychology

ABSTRACT

THE SURVIVAL OF THE CHRONICALLY-ILL ELDERLY AS A FUNCTION OF HOME CARE SERVICES

By

Susan Christine Hedrick

Evaluation of the patient outcomes associated with home health care services is a crucial task in the development of a more effective long-term health care system. This study was designed to evaluate the association between one type of home care and the ultimate outcome of patient survival, based on the unexpected finding that half of the studies reviewed here found a significant association between community-based services and that outcome.

The survival data analyzed here were collected in a major experimental study in which eligible patients in five sites in Michigan were randomly assigned to receive home care services or to be in a no-treatment control group (Papsidero et al., 1979). The multi-stage analysis strategy applied to these data in the present study included combinations of the following approaches: 1) a comparison of survival rates of the total experimental and control groups as well as those of those experimental group patients who actually used the services and a group of similar control group patients formed through the use of discriminant function; 2) the use of two operationalizations of survival; 3) the inclusion of 13 measures of the patients' intake health status as covariates; and4) the operationalization of the treatment variable as the number of home care visits received.

The non-significant results of these analyses provide no support for any relationship between the type of home care studied and survival. The results do underline the critical need for further research to help clarify what types of community-based services have what effects for what types of elderly patients to help qualify the oversimplistic statements on the effects of these services appearing in the policy literature.

Papsidero, J.A., Katz, S., Kroger, S.M.H. and Akpom, C.A. <u>Chance for</u> <u>change: Implications of a chronic disease module study</u>. East Lansing: Michigan State University Press, 1979.

DEDICATION

To my parents.

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First, I would like to gratefully acknowledge the guidance of my committee, Bill Davidson, Chair; Sidney Katz; Jack Condon; and Charlie Johnson. Their long-term support and encouragement was invaluable. The guidance and friendship of former and present faculty, students, and staff of the Ecological Psychology Interest Group, especially that of Deb Bybee, and Lou Tornatzky, my former Chairperson, was a great help through these years.

I also gratefully acknowledge the support and research opportunities gained over these years at the Department of Community Health Science, Colleges of Human and Osteopathic Medicine. My research was supported in part a) by a grant (HS-03760) from the National Center for Health Services Research, Department of Health and Human Services, b) by a subcontract from the Urban Institute under a contract (HHS-100-80-0158) from the Office of the Assistant Secretary for Planning and Evaluation, Department of Health and Human Services, c) by a grant (General Research Support) to the College of Osteopathic Medicine from the National Institutes of Health, and d) by a grant (DAR-782-0374) from the National Science Foundation.

A large debt of gratitude is owed to the staff of the Chronic Disease Module project, under the guidance of Sidney Katz and Joe Papsidero, for their impressive dedication and hard work in completing

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this research endeavor and to the study participants who are still contributing to our knowledge of chronic disease and its care years after the study's completion.

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Finally, I would like to acknowledge the professional clerical work by Gail Gubry and Ruth Berg.

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CHAPTER I

INTRODUCTION

A major problem in public policy today is the provision of long-term health care to the nation's chronically ill elderly in a way that most appropriately meets their needs while at the same time making efficient use of the country's finite resources. Many factors are converging at present which make increasingly crucial the investigation of modes of health care that are possible alternatives to the current system. These factors are increasing the size and complexity of the problem of providing appropriate health care services to the elderly while simultaneously decreasing the ability of the current medical care system to deal with those problems. Anne Somers (1978, 1979), in her valuable diagnosis and prognosis of the problem, cites a number of factors which will be briefly listed here. She divides the factors into those on the demand side of the equation, the health consumer side; and those on the supply side, the health care provider side.

On the demand side, first, the proportion of elderly in the population, especially of those over 85, is growing at an ever increasing rate. Secondly, environmental and behavioral threats to health care are increasing in prominence. Thirdly, the dominant pattern of illness in the population had changed from infectious acute (short-term) illnesses that could be cured with an antibiotic

to the degenerative diseases such as heart disease, cancer, or stroke that are chronic (long-term) disabling conditions that cannot be so easily eliminated. Fourth, the traditional social supports for the chronically ill elderly are less available with the decline of the extended family, the nuclear family, the traditional close-knit neighborhoods, and the increase in the number of working women. The increasing disparity in life expectancies between men and women also is a factor as it results in an increasing number of elderly widows with drastically reduced social and financial supports.

Fifth, the population has been led to have rising and unrealistic expectations of "modern medical miracles," counting on the system to provide them with "enduring youth, beauty, and emotional and social well-being" (Somers, 1979, p. 108) with no changes in their habits or lifestyles. A final factor on the demand side is the uneven removal of financial barriers. Public and private health insurance have both been skewed toward financing acute care in general hospitals and care in nursing homes, both institutional settings, and away from ambulatory and home care. Since the choice of the type of medical care sought is greatly influenced by whether the insurance company will pick up the tab, acute general hospitals and nursing homes are often chosen when other types of care would be much more appropriate for the patients' needs.

Supply side factors include the "technological imperative," found in many other fields as well, where technology becomes an end in itself. In health care, it results in an ever increasing

"intensity" of care, where more procedures, and increasingly sophisticated procedures, are being performed for each medical condition, often with no evidence of their effectiveness. This is felt by many observers to be the biggest single cause of rising health care costs.

A related factor is the continued dominance of the acute care model of medicine, in spite of the aforementioned modern pattern of illness where chronic conditions predominate. The acute care medical model has led to a medical care system that is increasingly failing to meet the unique needs of long-term care patients (Shanas and Maddox, 1976). These patients have multiple interacting dynamic medical conditions needing continuing management over time. The patient and family need education and support in dealing with their disabling conditions and their changes over time. Patients have psychosocial needs in relation to the stress of the conditions, changes in social role and economic status, death of spouses and friends and resulting social isolation, and geographic relocation. Patients also have needs for basic living supports including housekeeping, supervision for personal safety, and often need help with activities of daily living such as bathing and dressing. At the same time, it is important not to provide unnecessary services, place the person in an unnecessarily restrictive environment, cut them off from their communities, and create unnecessary dependencies. The current system is not providing the necessary mix of service, begun and ended, revised and coordinated, over time, in response to changes in needs and changes in response to the services. Dependence on the two types of care principally used today: short-term uncoordinated

stays in the acute general hospital, and long-term unmonitored stays in nursing homes, cannot adequately provide these services.

At the same time as the current system is failing to meet patient needs, it is consuming such an ever increasing amount of funds that expenditures to the elderly are the major component of all social welfare expenditure (McMillan and Bixby, 1980).

Total expenditures on health care rose from \$12 billion in 1950 to over \$160 billion in 1977, and have doubled as a percent of the GNP and more than doubled as a percent of personal income during that time. As the per capita cost of health care for elderly persons is three times as high as for younger persons, is rising faster than for younger persons, and is more likely to be paid for through public funds, expenditures for the elderly inevitably are subject to greater public scrutiny and demand for cost controls (Somers, 1978, p. 163). The unexpected and seeming uncontrollable cost experience under Medicare and Medicaid are a major factor in the continued postponement of national health insurance, in the failure to extend benefits to more adequately cover the long-term care needs of the elderly, and finally, in the reduction of the value of Medicare benefits themselves, with the elderly currently paying even more of their medical costs out-of-pocket now than they did in 1959 (Somers, 1978).

Home care, the provision of services to people in their places of residence, has been the subject of greatly increased interest because of its potential for both better meeting the needs of many chronically-ill patients <u>and</u> reducing the exponentially increasing the costs of long-term care. There is no shortage of

literature which asserts that home care services can have these benefits (Blum and Minkler, 1980; Brickner, Janeski, Rich, Duque, Starita, LaRocco, Flannery and Werlin, 1976; Colt, Anderson, Scott and Zimmerman, 1977; Comptroller General of the United States, 1977; Somers and Moore, 1976; VanDyke and Brown, 1972). A recent National Technical Information Service bibliography (no date) for the years 1964-1980 lists 229 references on home care programs. It must be noted that many studies that purport to evaluate the effectiveness of the programs, especially those done in earlier years, were very unsophisticated methodologically. Some cited isolated case studies as proof of efficacy, others presented outcome data based on estimates of treatment effects by the personnel delivering the services. Furthermore, many recent observers have agreed that, as in other fields, the more rigorously designed program evaluations have demonstrated few significant effects and have not resulted in any conclusive consistent accounting of the outcomes that might be expected from a home care program (Doherty, Segal, and Hicks, 1978; Dunlop, 1980, Iglehart, 1978; Kane and Kane, 1978, 1980; Urban Institute, 1978). Kane and Kane (1980) conclude that:

It would indeed be ironic if alternative mechanisms for care of the elderly such as a home care services network were developed only to prove more expensive than nursing home care without eliminating fraud and abuse or even improving the well-being of the elderly.

This study is designed to add to our knowledge of home care services by investigating the association between a particular type of home care service and a particular outcome, survival.

The Effects of Community-Based Services on Survival

Twelve experimental or quasi-experimental studies could be located that evaluated the outcomes of community-based services and included data on survival rates. These studies will be reviewed here.

The studies include a diversity of types of service programs studied; types of patients included; and designs, procedures, and analysis techniques used, all with obvious influence on the results and implications. Therefore, a tabular review that could highlight these differences is found in Table 1. It should be noted that several of the more recent studies, notably Skellie and Coan (1980), Hughes, Cordray, and Spiker (1980), and Weiss (1981), are still in progress and only preliminary results are presented. There are sections for each study containing the references to the major publications on the study; the study design; the sample, including the N in the experimental (E) and control (C) groups and criteria used to select the sample; and a summary description of the service program or programs studied. Data are presented for the E and C groups as a whole during the study period, expressed in number or percent, whichever is given in the original document. Results are presented for selected subgroups of patients, if such analyses were done. The probabilities of survival computed in a life table analysis done in one study, and part of the results of a multiple classification analysis of factors effecting survivorship done in another are presented.

Table l

Review of Studies Assessing Effect of Community-Based Services on Survival

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		X ² = .70	x² = .28
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** = p < .01 *** = p < .001	Treatment	Service packages con- tracted for by agency including as needed, home health aid, personal care, home management, transpor- tation, nutrition, respite care, psycho- logical support, medical and social day care, housing alternatives.	Services in the home by physician, Visiting Nurses Association, other social and health agencies as required.
•	Sample	E - 283 C - 134 Medicaid eligible, low score on functional rating scale.	 E-55 C-35 Cardiac patients discardiac patients disconsing the second to t
	Study Design	Experiment Random assignment of 1 person to control group for every 2 persons assigned to experimental group	Experiment
	Reference	Applebaum, Seidl, and Austin, 1980	Bakst and Marra, 1955

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Mortality	Non-Institutionalized One year Two years Four years Institutionalized	Une year Two years Three years Four years Expec Probal Probal	All Cases One year Two years Three years Four years One years Two years Four years	Institutionalized One years Two years Four years One years Two years Three years Four years
Treatment				
Sample				
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	ental .765 .765 .677 .558 .558 .441 ol .726 .722 .574	to Death I During <u>Control</u> 726 1006	652 652 613 900 475	llow-up 1213**
Mortality	ed Experimental .919	Number of Days from Intake to Death for Patients Institutionalized During Study. 4 Year Period. Experimental <u>Control</u> All cases 530 706 Males 537 661 Frundaers 585 725	4 05 607 635 620 520	from 6 Year Follow-up 818 1213
M	Non- Institutionalized One years Three years Four years Two years Two years Four years	Number of Da for Patients Ir Study. 4 Yea All cases Males Females	Under (2) 75 and over High physical function at intake Low physical function at intake Living alone Living with other	Partial Data 75 years or older

Treatment

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Study Design

Reference

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1	N
	x ² = 5.7
	8 8 8 8 8 8 8 8 8 8 8 8 8 8 8 8 8 8 8
Mortality	py only
M	Home care - 84 Physical therapy only - 36 36
	Home care Physical th
	nurse, home social
Treatment	visiting and occr des, and orkers.
Tre	Visits by visiting nurse, physical and occupa- tional therapists, home health aides, and social service workers.
	s youly - denta we lenta we lenta we denta we denta de denta de therapy therap
Sample	Home care - 25 Physical therapy only - 25 Home care patients were stroke patients admitted to St. Luke's Hospital in 1971 who met following criteria: 1. Physician requested home care and made plan of care 2. Patient medically ready for transfer from hospital to home a. Patient must require one or more of following home health services: skilled nursing physical therapy social service occupational therapy physical therapy speech therapy tinhalation therapy speech therapy physical therapy physical therapy hysical therapy by speech therapy tinted to St. Luke's Hospital who did not receive home care but did receive
	Home care Physical ti Home care stroke pati stroke pati stroke pati to home ci of care to home ci or more home home shill spea occulantia physical ti home care physical ti
	nt tients and or 9 period
Study Design	
De	Quasi-experiment Comparision patients matched on age and extreme cases of stroke eliminated. Record review for 9 month follow-up peri
Reference	Bryant, Candland, Lowenstein, 1974
Ref	Bryant Lowen

	x² = .06	X ² = 1.31 or
Mortality	Home health care - 12 Home delivered meals - 11	25 X C - 36 X Non-significant differences for 71 subgroup comparisons
Treatment	Physician visita, nurse/ social worker joint case management, home health aid/homemaker personal care and chore services, telephone reassurance, volunteer friendly visiting.	Home visits by visiting nurses.
Sample	Home Health Care = 122 Home Delivered Meals = 123 Home health care patients 1. aged 60 years and older 2. residing in geo- graphical area served 3. homeboundedness 4. medically underserved 5. in need of combination of medical and social services 6. not in need of 24 hour supervision in the absence of an informal	 E - 150 C - 150 Patients discharged from Benjamin Rose chronic disease rehabilitation hospital: 1. To a home setting 2. Who were 50 years old or older 3. Who had a hospital stay of at least a week 4. Who did not leave the hospital against advice
Study Design	Quasi-experiment Comparison group of consecutively accepted clients of Home Delivered Meals Program. Assessed at intake and nine months later. In progress.	Experiment Followed for 2 years after intake.
Reference	Hughes, Cordray, and Spiker, 1980	Katz, Ford, Downs, Adams, and Rusby, 1972

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Mortality	M&10 0040 00 40 40	ol
W	Total Group Subgroups Subgroups <u>Fracture</u> Arthritis Stroke Other Yes No <u>Age</u> Yes No ZT5 years 275 years 275 years Female	B Concurrent control Terminal control
Treatment	Home aide services under supervision of paraprofessionals under supervision of social worker and nurse.	Services provided in the home by public health nurses and consultative and diagnostic services of other specialista. Services offered for 18 month period.
Sample	 B-50 C-50 Patients discharged from chronic disease rehabilitation hospital who: I. Were over 60 years of age 2. Did not require intensive skilled nursing or custodial care 3. Had a non-institutional place of abode 4. Were not already receiving home aide, homemaker, or visiting housekeeper services from a community agency 	E=100 Concurrent control = 60 Terminal control = 40 All persons discharged from Geriatric Rehabili- tation Service of Gold- water Memorial Hospital during three year interval from January 1, 1958 and December 31, 1960 who re- ceived some rehabilitation training and were 60 years old or older.
Study Design	Experiment Assessed at intake, 2 weeks after dis- charge and 6 and 12 months after intake	Experiment Stratified random assignment to experi- imental, concurrent control groups. Experi- mental and concurrent controls assessed at intake and at 4, 12, 18 and 24 months after intake. Terminal controls assessed at intake and 24 months
Reference	Nielsen, Blenkner, Bloom, Downs and Beggs, 1972	Posman, Kogan, LeMat, and Dahlin, 1964

	itial	<mark>x² 6.08</mark> * .33 1.43
	ge, tri dedt	25 29 6 35 13
	livinaç ex, an	19 25 15 18
Mortality	Adjusted $\bar{\pi}$ E13 C29 p = .029* Analysis of covariance with age, initial activities of daily living, living arrangements, disease, sex, and education as covariants.	For 12-24 month period Total group Subgroups <u>Recommended</u> <u>ADR</u> ALS HDS
Treatment	Non-skilled nursing care in home including personal and environ- mental care provided by aide, LPN, and RN. Maximuun of 12 hours of service a week by health assistanta, viaita by RN and LPN as needed, and telephone supervision at a skilled level on a 24 hour basis.	Alternatives prescribed: Adult day rehabilita- tion (ADR) = ambula- tory health care within an adult day care center. Alternate living services (ALS) = 24 hour residen- tial care through
Sample	 E = 64 C = 60 Persona who: Persona who: Persona who: Persona who: Persona who: Persona who: Could be maintained at home with periodic at home with periodic distance of the nonskilled level Have chronic or disabiling conditions Wishes to remain in own home and would benefit from services of Health Maintenance Team Can himself or has responsible person who is capable and willing to provide care during mights, weekends, and holidays Has a telephone available for use by himself or responsible person Can obtain food, abelter, clothing, medicines, and equipment. 	E = 208 C = 59 Medicaid-eligible, 50 years of age or older, either meet medical nursing home preadmission acreening criteria or be nursing home resident.
Study Design	Experiment Assessed at intake; 2, 4, and 6 months after service began; and 3 months after termina- tion of care for patients under care at end of study.	Experiment Random assignment of 1 person to control group for every 3 persons assigned to experimental group. Assessed every 6 months up to 4 years. In progress.
Reference	Selmanoff, Mitchell, Widlak, and Mossholder, 1979	Skelile and Coan, 1980, and Skelile, Mobley and Coan, 1980

			congregate living. foster				
			bome care, or board and	HDS/ADR ALS/Other	19	5 89 5 89	1.71 .35
				Living Arrangement	02	15	c
			social services provided under supervision of nhysician, along with	others ental			9.28**
			meals, supplies, equip-	Activities of Daily Living More independent	12	24	1.21
			help.	More dependent	11		2.63
				Activities or Daily Living Most independent (-1	13	18	31.
				2-3	9	11	-02
				Most dependent 4-6	2		3.57
				Regular Medicaid Home			
				Users	6	20	0
				Non-users	16	30	4.27*
				Nursing Home	12		96
				Von-users	15	56	3.38
				Number of Days Survived	न्त्र।		
			•	ULL OL FIRST 330 Days	335	318*	*
				For Nursing Home Recipients	ients		
				Number of Days Survived E	ط 338	\$262	*
Weiss, 1981 Experiment Assessed at	Experiment Assessed at intake and	K = 200 C = 100	Service packages contracted for by	Preliminary results for 2-24 months	F 2-		
6 month intervals up 30 month period. In progress.	tervals up to eriod.	Any person 65 years of age or older who 1) has Medicare Part A	project including as needed, traditional medical and health	₩ 	ײ	χ ² = 1.06	90
		and B	services, preventative				

			ľ	0			
		c C % 21 21 21	24** 17	21 20	19 28	16 22 *	27 12 29 29 22
		ECC %%%% Total Group 1321 Subgroups	18 8	15 11	13 13	16 12	15 11 19 12
Mortality	·	. Day Care Study Sample	<u>Age</u> Under 75 75 or older	<u>Sex</u> Male Female	Race White Nonwhite	Living Arrangement Alone With others Primary	
Treatment	services provided through monitoring and and assessment, social services provided through multi-purpose senior centers, and in- bome support services.	Day Care - 13 services available on site: nursing podiatry patient activities	social services personal care nutrition services	meals transportation physical therapy	occupational therapy speech therapy eye examination	hearing examination Homemaker services consisted of following services provided in person's home:	home management- cooking, cleaning, laundry personal care services- assistance in bathing, dressing, walking, skin care supportive activities
Sample	 cesides in specified areas of San Francisco has health or social needs that make it difficult to live or function in- dependently 	Day Care E = 313 C = 239 Homemaker E = 276	C = 326 Both Day Care and Homemaker	E = 132 C = 10 4 Excludes invalid,	missing, and contaminated cases.	Patients who were: 1. Medicare eligible 2. (for sites offering homemaker services) hospitalized for at	least three days during two weeks prior to study period 3. judged to need health care services to restore or maintain functional ability, not merely custodial care
Study Design		Experiment Assessed at intake, and at 3, 6, 9 and 12 months past intake. 2 sites offered day care	services, 2 homemaker services and 1 both.				
Reference		Weissert, Wan, and Livieratos, 1979; Wan, Weissert, and Livieratos, 1980;	Weissert, Wan, Livieratos, and Katz, 1980;	Weissert, Wan, Livieratos, and Pellegrino, 1980.			

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		23	20		35*		30	40**	C J		ŝ	34*	41		27	43*		38	12	65		25	29	43 * *		21		\$\$
		13	13		26	4	28	25	00	500	2	5 26	35		23	31		24	0	69		10	31	58		16		10
Mortality	<u>Hospitalized Before</u> Intake	Yes	No		Total patients	Age	Under 75	75 and over	Sex	Male Femalo	Race	White	Nonwhite	<u>Living</u> Arranoement	Alone	With others	Primary Diamosis	Circulatory	Injuries	Cancer	Physical	<u>Uependency</u>	Moderate	Severe	Patients Who Were Not	Hospitalized During Study	Day Care and Homemaker	study sample Total Patients
Treatment	outside home such as shooning	health care manage-	ment services-	accompanying	patient to nealth care services																							
Sample	4. judged as not requiring 24-hour a day gunar-	vision																										
Design																												
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ļ	27*	30	40	22	28*	36		27	20		33	17		44*	18	29*		Beta	.064	.155**
		15		œ		10		ء و			11	0		~	19	2	alysis of	orship Eta	.150*	.186**
Mortality	Age Under 75	75 and over	<u>Sex</u> Male	Female	Race White	Non-white	Living Arrangement	Alone	With others	<u>Primary</u> Diagnosis	Circulatory	Injuries	Physical	Minimal	Moderate	Severe	Multiple Classifiction Analysis of	Factors Affecting Survivorship Eta	Day Care Use	Homemaker Care Use
Treatment																				
Sample																				
Study Design																				
Reference																				

These results are presented both to indicate the findings in the literature regarding the effect of community-based services and to illustrate the varied approaches taken to the analysis of this type of data. Tests of the significance of the differences in outcomes between the experimental and control groups were reported in some studies and are presented in the results column of the Table. No significance tests were reported for the data in other studies. The statistical significance of the differences in outcomes in these studies was computed for this review using the chi-square procedure. These results were then entered in the Table. The levels for all tests are given as *=p < .05, **=p < .01, and ***=p < .001.

The information in Table 1 will be discussed in the following manner. First, the characteristics of the twelve studies will be summarized. Next, a summary of the published results of the comparisons made of the total service and comparison groups will be presented. A meta-analysis performed to further explore the results of the studies will then be described. The next section will describe the examination made of the characteristics of the studies to determine if the design, or sample size, or follow-up period, etc. seemed to be related to the results. Finally, the results reported from those studies that analyzed the results separately for subgroups of subjects will be presented.

Study Characteristics

Ten of the twelve studies reviewed in Table 1 were true experiments, with subjects randomly assigned to groups. The studies

by Bryant, Candland, and Lowenstein (1974) and Hughes, Cordray, and Spiker (1980) were quasi-experiments, comparing the subjects receiving the experimental services with matched comparison groups. Subjects in the studies were assessed at prescribed intervals after the initiation of services with the follow-up periods lasting from nine months for some studies (Bryant et al., 1974; Hughes et al., 1980; Nielsen, Blenkner, Bloom, Downs, and Beggs, 1972) to five years for Blenkner, Bloom, Nielsen, and Weber (1974), with most having a one or two year follow-up period. The length of the follow-up period was not reported for two studies (Bakst and Marra, 1955; Applebaum, Seidl, and Austin, 1980). The number of subjects ranged from 50 for Bryant et al. (1974) to 417 for Applebaum et al. (1980). Subjects were selected from populations of patients discharged from specified institutional settings in five of the studies (Bakst and Marra, 1955; Bryant et al., 1974; Katz, Ford, Downs, Adams, and Rusby, 1972; Nielsen et al., 1974; Posman, Kogan, LeMat, and Dahlin, 1964) and in the rest of the studies from community residents who were referred to or referred themselves to the service program studied. Most studies had criteria for admission to the study sample which included 1) being at least a certain age, 2) having a need for service defined in terms of having a chronic condition and/or being unable to perform daily tasks and/or meeting the Medicare/Medicaid nursing home admission eligibility requirements, and 3) not having a need for the intensive skilled nursing services or 24-hour a day supervision not provided in most community-based service programs.

The types of community-based services evaluated in these studies could be divided into three groups although these groups can serve only as a very basic scheme for categorizing service programs that undoubtedly differ on many dimensions. The first type is services provided in the home by a paraprofessional home health aide or homemaker. This type of service was studied by Applebaum et al., 1980; Nielsen et al., 1974; Selmanoff, Mitchell, Widlak, and Mosshandler, 1979; and in the homemaker study by Weissert, Wan, and Livieratos, 1979. (It should be noted here that the Weissert et al. study actually consisted of evaluations of three types of service modalities studied simultaneously at different sites, making the total number of studies reviewed here 14.)

The second type of services are those provided in the home by a registered nurse. Bakst and Marra (1955), Bryant et al. (1974), Katz et al. (1972), and Posman et al. (1964) studied this type of care. The rest of the studies evaluated various other types of community-based care including intensive social work case management (Blenkner et al., 1974), services in an adult day care center (the day care study of Weissert et al., 1979) and a "channeling" type service where a central staff arranged for and coordinated a wide variety of community-based services (Hughes et al., 1980; Skellie and Coan, 1980; Weiss, 1981).

Total Group Comparison Results

The results of these fourteen studies can now be examined. The results for the comparisons of mortality rates for the total experimental and control groups indicates that six studies found that the experimental groups had a significantly lower mortality rate than the control groups (Bryant et al., Selmonoff et al., Skellie et al., and all three studies of Weissert et al.). Skellie et al. (1980) found a significant difference favoring the experimental group not only in the number of patients who survived to the followup time but also in the number of days subjects survived from the beginning of the study. Weissert et al., (1979) performed a multiple classification analysis and found that the use of day care and the use of homemaker services were significant factors affecting survivorship.

One study found that the experimental group had a significantly <u>higher</u> mortality rate than the control group (Blenkner et al.). Seven studies found no significant difference between the groups (Applebaum et al., Bakst and Marra, Hughes et al., Katz et al., Nielsen et al., Posman et al., Weiss). It would seem that these results (six positive, one negative, and seven no difference) can be summarized at this point as indicating that community-based services do have significant effects on survival in at least some situations. Further explorations of these results were conducted to help clarify the findings.

Meta-Analysis

A very basic attempt at meta-analysis (Glass, 1981) was made by combining the data from all fourteen studies where data were available into one analysis. The number of subjects in all fourteen experimental groups who were dead at the end of the study period was

summed as was the number of deceased control group subjects, and the number alive in each group. This resulted in a 2 x 2 table which yielded a chi-square of 22.36, $\underline{p} < .0003$. This finding could help support a general conclusion that community-based services do have a positive effect on survival rates.

Study Characteristics Review

The characteristics of the studies were examined to see if any pattern could be seen that could indicate in which situations the significant effects were most likely to be seen. For example, if most of the studies in which significant differences were found were those with relatively long follow-up times and most of those in which significant differences were not found were those with relatively short follow-up times, then this could indicate that the length of the follow-up time was important and possibly that differences would have shown up in more studies if the follow-up times had been longer. However, clear evidence for this kind of situation was not found. The studies in which significant differences were reported had short, medium, and long follow-up times. Some evidence for a follow-up time effect could be derived from the Blenkner et al. study, where the differences for the total group were not significant until the third year of follow-up. Likewise, the design of the study did not seem to influence the findings as the two quasi-experimental studies included one with a significant difference and one with a non-significant difference. The number of subjects involved did not seem to be related to the findings as some studies with differences

used relatively small numbers of subjects and others relatively large numbers of subjects. The source from which the subjects were sampled --institutions or the community--did not seem to be associated with the results.

For an examination of the type of services studied--home health aide, registered nurse, or other--another basic meta-analysis was performed. The data were combined for just those studies evaluating the home health aide type of service and the experimental and control group mortality figures were compared. This process was repeated for the studies evaluating the other two types of service. For the home health aide studies, 16% of the patients in the combined experimental groups were dead compared with 26% in the combined control groups. In the other service studies, 16% were dead in the combined experimental groups compared to 23% in the combined control groups. In the registered nurse studies, 27% were dead in the combined experimental groups and an equal 27% in the combined control groups. An examination of the differences in mortality rates for the three types of service indicate that the home health aide service may most warrant further study.

A more sophisticated meta-analysis of these studies could be performed with more detail about the designs of the studies, the samples obtained, and with process data about the characteristics and intensity of the services actually rendered. Unfortunately, this information is not often available in the study publications.

Subgroup Analyses

As a final approach, the mortality findings for various subgroups of subjects within each study can be compared across studies. This approach could help to indicate the type of person for whom community-based services could have the greatest potential survival effects. Separate data analyses for subgroups of subjects were performed in the studies by Katz et al., Nielsen et al., Blenkner et al., all three studies of Weissert et al., and Skellie et al. The Katz et al. study analyzed the results separately for subjects divided into 71 subgroups or "intake classes" that had been formed based on subject's scores on various combinations of demographic, physical health status, and psychosocial health status measures. The resulting statistics were not published but it was stated that there were no significant differences in mortality for patients in any of the subgroups.

The other studies performed separate comparisons for a smaller number of subgroups that had been formed based on scores on single variables. As the same subgrouping variables were used in more than one of these studies, these results can be compared profitably across studies. Different combinations of eight different variables were used to form subgroups in these studies: age, sex, race, living arrangements (availability of a potential care giver in the home), diagnosis, functional status in the activities of daily living (ADL) (level of independence in performing such activities as bathing, dressing, feeding, and continence), functional status in the instrumental activities of daily living (level of independence in

performing such activities as laundry, housecleaning, telephoning, paying bills, taking medication), and placement in nursing home at any time during the study. The subgroup comparisons using these eight variables will each be discussed in turn, and then the results will be summarized.

<u>Age</u>.--Age was used as a subgroup variable in five of the six studies and significant differences were found in four. In three of these studies (Blenkner et al., for the first, second, and third years of follow-up; and the day care and day care plus homemaker study of Weissert et al.), younger subjects, those less than 75 years of age, had different mortality rates in the experimental group while the Blenkner et al. study found higher rates.

On the other hand, the Weissert et al. homemaker study and Blenkner et al.'s six-year follow-up analyses reported that the subjects 75 years of age and older, rather than the younger subjects, were those who had a different mortality rate. As usual, the Weissert et al. study found lower rates in the experimental group while Blenkner et al. found that group to have higher rates.

<u>Sex and Race</u>.--Groups were classified by sex in five studies. In no case were there differences between groups for males or females (Blenkner et al., Nielsen et al., and all three studies reported in Weissert et al.). The three Weissert et al. studies used race as a subgroup variable. The homemaker and homemaker plus day care studies found that white subjects had significantly lower mortality rates in

the experimental condition while non-white subjects showed no such differences. The day care study found no differences for either subgroup.

Living Arrangement and Diagnosis.--Five studies used the subjects' living arrangements as a subgroup variable. In three of these studies there were differences. In each case, the subjects who lived with other persons had lower mortality rates in the experimental group than in the control group while no such differences were found for those who lived alone (Skellie et al., the day care and homemaker studies in Weissert et al.). Diagnosis was not a useful subgrouping variable in these studies as none of the four studies using it found subgroup differences.

<u>Physical Functioning</u>.--Initial level of physical functioning in the activities of daily living (ADL) interacted with the treatment condition in two of the five studies using this measure. The Weissert et al. day care plus homemaker study found that both those with the lowest level and those with the highest level of functioning were likely to have lower mortality rates in the experimental group, while the homemaker study found that only those in the lowest functioning group had such a result. Only Skellie et al. used the level of functioning in the instrumental activities of daily living (laundry, etc.) as a subgroup variable, reporting no differences.

<u>Nursing Home Placement</u>.--The final subgroup variable used in these studies was the patient's placement in a nursing home during

the study period. Skellie et al. found no difference in the number of patients who survived until follow-up but did find that nursing home service recipients in the experimental group survived a greater number of days. Blenkner et al. found a difference for those subjects who did spend time in nursing homes, with the experimental group having a higher mortality rate than the control, in line with the direction of the other findings in that study.

<u>Subgroup Results Summary</u>.--One could conclude from these subgroup results that certain of the variables included in these studies are more important than others in defining subgroups of subjects that show different mortality effects from community-based services. These variables are the subject's age, race, living arrangements, ADL, and use of nursing homes. In general, the subjects that were likely to have lower mortality rates in the experimental conditions were those who were younger, white, not living alone, with initially high levels or low levels of physical functioning in ADL. The Blenkner et al. study found that the subjects who were likely to have a higher mortality rate in the experimental condition were younger patients that had been admitted to nursing homes during the study period.

Summary and Rationale

Higher survival rates have not been seen as a realistic goal for any community-based service program for chronically-ill elderly populations. The research studies evaluating the effectiveness of home care services that have reported data on patient survival have

often done so more as a way of tracking subject loss than because of any real expectation that this type of intervention could affect patient survival. Improved physical function is even often seen as an unrealistically high goal and a slower rate of deterioration, avoidance or postponement of institutionalization, and improved patient and/or family morale are often the actual stated goals. The studies reviewed above very seldom found that significantly more experimental than control group subjects achieved even these goals. The fact that six of the fourteen studies above reported higher survival rates in the service groups--and that one reported lower rates in the service group--is thus quite significant. A recent government report designed to "help frame policy deliberations regarding longterm care" (Health Care Financing Administration, 1981, p. iii) concluded that "community-based services appear to have a positive impact on survival rates" (p. 46), citing the Bryant et al., Skellie et al., and Weissert et al. work. This strong interpretation of the literature in this type of report illustrates the need for further research to help clarify the relationship of community-based services to survival, and the policy significance of that research.

An intensive analysis of survival as an outcome variable in data sets from other evaluations of community-based services would seem to be useful in beginning to assess the types of services, situations, and patients in which the effects on survival rates can take place. There are data sets from rigorously designed experimental studies of home care services including survival data that have not yet been fully exploited.

The advantages of secondary analysis, "the reanalysis of data for the purpose of answering the original research question with better statistical techniques or answering new questions with old data" (Glass, 1976, p. 3), have been explored by Boruch and Reis (1980), Bryant and Wortman (1978), Cook (1974), and, in the area of long-term care research, by the Inter-agency Statistical Committee on Long-Term Care for the Elderly (1980). The use of secondary analysis is an especially cost-effective research strategy in these times of increasing concern over patient privacy and fiscal constraints.

This dissertation will be conducted using data previously collected in an experimental study of home care services described in Papsidero, Katz, Kroger, and Akpom (1979). This data set has several features which make an intensive analysis of survival data especially worthwhile. First, there are several characteristics of the study that would seem to allow a reasonable assessment of the benefits of home care services. The study was a true experiment with random assignment of a large number of subjects. These 935 subjects were followed in regularly scheduled assessments for a period of up to 24 months using a large number of carefully developed measures with a long history of use. Extensive administrative procedures were instituted to ensure data quality.

A second feature of this data set that supports its use in secondary analysis is the availability of documentation on study procedures and the data set itself. The unavailability or incomprehensibility of documentation on the studies of interest has been cited

as a major problem in secondary analysis (Hedrick, Boruch, and Ross, 1978). In contrast, voluminous records are available on the Papsidero et al. study. Funding proposals, early progress reports, interviewers manuals, coders manuals, internal memos, minutes of meetings, and the actual data collection forms for each patient are all available locally, some on microfilm for easy access. The availability and interest of the original principal investigators and other staff members also helps assure access to information about study procedures, treatments, measures, etc.

A third rationale for this analysis is the opportunity to apply alternative multivariate analytic approaches to the data. The original analysis of the data set in the Papsidero et al. study reported only one analysis of survival data. The chi-square performed on differences in survival rates between groups was not significant. Papsidero et al. report that the chi-square test was selected for this analysis to provide data comparable to an earlier study (Katz, Ford, Downs, Adams, and Rusby, 1972), and that more advanced multivariate techniques were being explored (p. 74). To date, the survival data have not been reanalyzed. Further opportunities for fruitful reanalysis stem from the fact that the Papsidero et al. analysis included only data from the first 12 months of the 24-month follow-up period, and only one of the two control groups.

This analysis can take advantage of the large number of measures of the subject's demographics and health status at intake used in the Papsidero et al. study. These measures include those used in the twelve studies reviewed above to form subgroups of

subjects and assess the types of subjects who were most likely to have significantly different survival rates. The present study will go beyond the univariate analysis reported in the studies above to examine the joint relationship of these variables and home care use with survival.

This study can also take advantage of several features of the data set to apply alternative analytic approaches to a problem encountered in the course of the Papsidero et al. study. After originally agreeing to be in the study, 60% of the subjects assigned to the experimental treatment group subsequently found themselves unable or unwilling to participate in the treatment. These patients received no actual home care visits or only one such visit and were considered non-service users in the present study. The non-use of services by experimental group subjects is a common concern in program evaluation studies conducted in "real world" field settings. It may be an especially serious problem in studies of community-based services. Applebaum et al., reviewed above, found that 25% of their experimental group subjects did not use services. Weissert et al. found that 25% of the day care study subjects, 20% of the homemaker study subjects, and 49% of the homemaker plus day care study subjects did not use the assigned services. Gerson and Hughes (1976), in a study of post-hospital home care for surgical and short-term medical diagnoses, found that 56% of the experimental group patients did not use the home care services.

Dunlop (1980) cites the non-use of services in the Weissert et al. studies as possible evidence of a "natural" limitation on the

demand for these services. Barney, in a 1977 article entitled "The Prerogative of Choice in Long-Term Care", discusses the difficulties found in reaching the frail chronically-ill elderly needing these programs in spite of massive outreach efforts. Many of the elderly avoid the health and social services available to them because of a perceived connection with charity or welfare; and concern over loss of privacy, loss of independence and possible institutionalization. The patients, families and private physicians can also be suspicious of outside services, feeling that the offer of services reflects badly on their own treatment of the patient or will usurp their positions.

There are several analytic approaches that can be taken when a large percent of the experimental group patients refuse the treatment. The first is to compare the outcomes of all subjects assigned to the experimental services, whether they used them or not, with those of the total control group. This approach, the first of those to be used in the study, is the most conservative as the inclusion of large numbers of subjects who did not use the services dilutes their effect. The second approach, that most commonly used in the studies that attempted to deal with the problem, compares the outcomes of those experimental group subjects using the services with those of the total control group. This approach compares the experimental group service users with a larger group of subjects that likely contains many subjects who would not have used the services if they had been offered to them and who are likely to differ from the service users in important respects.

A third approach, that to be used in this study, attempts to achieve greater precision through comparing the experimental group service users with a group of control group subjects who are as similar as possible to the service users in the demographic and health status characteristics measured at intake to the study. The opportunity to evaluate the use of several approaches to this common problem of service refusal should serve as a methodological contribution to the field.

To summarize, in light of the findings from the twelve studies reviewed above, the presence of unanalyzed study data, and the availability of multi-stage multivariate analytic approaches not used in the original analysis, further analysis of this data set that required five years and two and a one-half million dollars to collect is clearly warranted.

Research Questions

The major research question to be studied is whether there is an association between home care services and survival. Several different analytic approaches to this question will be used. First, several different methods will be used for forming the groups of subjects whose survival will be compared. The first comparison will be the true experimental test of the research question. All subjects assigned to the experimental group will be compared to all subjects assigned to the control group.

The fact that many of those assigned to the experimental group did not actually use the home care services indicates that a

quasi-experimental approach could contribute to the understanding of the research questions. One extremely useful feature of the Papsidero et al. study was the use of many different measures of the subjects' characteristics at intake into the study. It is expected that these data will allow the formation of an equation predicting use of home care services in the experimental group. This equation will then be applied to the control group, resulting in the identification of a smaller group of control group subjects who are more comparable to the experimental group service users at intake into the study. A comparison of survival will then be made of the experimental group services users and the "user-like" control group subjects.

Another approach to the association of the home care services and survival concerns the intensity of service use. The experimental subjects who did use the home care services differed in the number of home visits they received. Survival will therefore be analyzed for these experimental group service users as a function of the number of visits received.

Still another approach will be used to obtain a more precise estimate of the relationship between home care services and survival. Measures of the subjects' characteristics at intake to the study will be used as predictors or covariates in some analyses.

Finally, survival will be operationalized in two ways, to be called survivorship and length of survival. Survivorship is the simple dichotomous variable assessing whether the person was still alive at the end of the study. In this operationalization, a subject who dies in the first week of the study is counted the same as a

subject who dies two years later, a week before the end of the study. In a long-term follow-up study, the assessment of survival should also examine the length of survival of those people that do die during the study period.

Combinations of all the above approaches will yield many different but related tests of the association between home care services and survival.

One other subsidiary research question will be addressed in this study. The twelve research studies reviewed above found many significant differences in survival rates for subgroups of patients, indicating the types of patients for whom community-based services seem to have the greatest potential survival effects. In this study, exploratory tests of the interactions among subject characteristics and home care services in their relationship with survival will be conducted.

CHAPTER II

METHODS

Subjects and Setting

The Papsidero et al. (1979) study, known as the chronic disease module study, was conducted in Michigan between 1973 and 1977. All persons who were either patients in selected ambulatory care facilities or who were about to be discharged from selected hospitals were screened for eligibility for referral to the project by personnel of the referring facilities. Table 2 presents the five locations in which the home care service teams, called chronic disease modules, were established, the sources of patients in each location, and the number of patients screened in each site, totaling 18,638. Patients who met the following criteria were considered eligible for the study:

- 1. forty-five years of age or older,
- discharged to a non-institutional setting within geographic access to module service unit from selected hospitals in area or living in a noninstitutional setting within geographic access to module service,
- in need of assistance for at least 3 months with respect to either the activities of daily living, (bathing, dressing, toileting, transfer, continence, or feeding), cardiopulmonary condition or arthritis,
- 4. not in need of skilled nursing service, 24-hour-aday supervision or on kidney dialysis (Papsidero et al., p. 28).

	(Office of Healt	th Services Educat	of Health Services Education and Research, 1976, p. 37).	1 <u>976, p. 3</u> 7).	
Sources of Patients	Grand Rapids	Cass County	Gratiot County	Saginaw	Manistee
 General Acute St. Mary's Care Hospitals (10,885) 	St. Mary's Hospital (10,885)	A. Lee Memorial A. Gratiot Com Hospital (579) Hospital (1,38 B. Pawating B. Carson City Hospital (1,811) Hospital (572)	2). 2)	A. St. Mary's Hospital (1,638) B. Saginaw General Hospital (239)	A. West Shore Hospital (454) B. Onekema Hospital (108)
				C. Saginaw Comm. Hospital (18)	
2. Ambulatory Clinics	A. Comprehensive Health Center (410)		A. Gratiot Family Health Center (142)	A. Saginaw Comm. Clinic (39)	Health Main- tenance Clinic for Elderly
	B. Family Health Center (49)		B. Ithaca Clinic (19)	B. Family Health Center (3)	(134)
			C. Alma Clinic (2)		
3. Other		Cass County Public Health Department (90)	District Health Department (3)	Private Prac- tice, Dr. Buttman (52)	Department of Social Services (9)
Total	11,344	2,480	2,120		705

Number of Persons in Referral Process and Referral Sources of Health Services Education and Research 1976 n 37

TABLE 2

Not all patients found to be eligible for the study were asked to participate. Various times during the study were designated as "non-sampling" periods where no new patients could be admitted to the study because the service modules were serving the number of patients that had been set as the maximum allowable caseload. Patients screened in during these times were not allowed to participate. Other patients refused study participation when they were contained. No figures are available on the number of patients in these categories.

Of the eligible patients who were contacted, 1,183 agreed to take part in the study. Patients admitted during the first three months at each site were used to test interview and treatment procedures and were termed the baseline subjects. These 249 subjects were eliminated from the present sample as not being comparable to the later subjects in data collection or service procedures. The beginning sample to be used in the present study is thus 934 subjects.

Design

Subjects were assigned randomly to either the experimental treatment group or to a no-treatment control group, stratifying on age and sex. The treatment group was offered the experimental home care services while the control group was not offered these services but were not restrained from access to any services they were normally eligible for in their communities. The modules were phased in over a four-year period, and all modules continued to operate until the end of the study. The study report indicated that Grand Rapids

served patients for 35 months, Cass County for 30 months, Gratiot County for 39 months, Saginaw for 22 months, and Manistee for 18 months. With the exception of one group, subjects were assessed at their intake into the study and at 6 month intervals thereafter until the end of the data collection period. At each site, the data collection period ended before some subjects who entered the study toward the end of the collection period were able to have their twelve-months assessments, though all were in the study at least six months. The group of subjects that did not follow the usual interview schedule was in Grand Rapids, the first module to be established. To reduce costs by reducing the number of subjects who would have to be interviewed every six months over the several years of the project, the subjects at Grand Rapids were assigned randomly to either the experimental group or one of two control groups. The "concurrent" control group was interviewed following the regular schedule while the "final" control group was interviewed only at intake, at six months, and at the end of the study period which was twelve, eighteen, or twenty-four months, depending on when a person entered the study. These sixty final control group patients were not included in the Papsidero et al. (1979) analysis, as that study used only the six and twelve-month follow-ups, and the final control group did not have the twelve-month interview. Data on patient deaths were collected throughout the study and up to 15 months after the end of the regular data collection period.

Service Delivery Procedures

The home care services were delivered by a newly developed type of paraprofessional provider, termed a health assistant, working with an interdisciplinary team consisting of a physician and a nurse or social worker. One team, or module, was set up in each of the five study sites. The characteristics of each module and host agency in which it was established are described as follows:

The Grand Rapids module was set up in a general care acute hospital. The module physician was the medical director of the family-oriented primary care clinic at the hospital where the module was located. A Master's level social worker was the other module professional. The module health assistants included one with partial prior training as a licensed practical nurse and one who had completed two years of college.

The Cass County module was established in the county health department which was already a certified home care provider. The members of the team included a local physician in private group practice, a Master's level public health nurse, a health assistant who was also a licensed practical nurse, and a health assistant who had previously been a nurse's aide.

The Gratiot County module was housed in an ambulatory clinic in this rural area. The team included the physician of the family health center where the module was located, a Master's level nurse, who was later replaced by a Bachelor's level social worker who had extensive experience in rehabilitation, and the health assistants.

Both of these health assistants had B.A. degrees, one in psychology and one in sociology.

The Saginaw module was set up in an ambulatory clinic. The module professionals were a registered nurse and a family physician in private practice who had formerly been associated with the clinic where the module was located. Both of the health assistants had had training in licensed practical nurse programs, and both spoke Spanish.

The module in Manistee was first set up in a clinic in a housing unit for the elderly and subsequently moved to the county medical care facility. The team members included a physician who was chief of staff at a local hospital, a nurse with rehabilitation expertise, and two health assistants. One health assistant was a licensed practical nurse, and the other had previously received some practical nurse training.

The teams met at regular intervals to identify patient problems, prepare a care plan, and define service activities. The roles of the team members were outlined as follows by Papsidero et al.:

- (1) Physician
 - (a) Assessment
 - 1. Evaluated adequacy of medical information.
 - 2. Relayed orders for medications and treatment regimen from attending physician.
 - 3. Assessed with social worker or nurse the behavioral skills required for medical management.
 - 4. Assessed the type of instruction necessary for family members or others responsible for care.
 - 5. Discussed general condition of the ill person and assisted in developing a problem list.

(b) Management

- 1. Provided information on disease condition, underlying physiology, effect of care on prognosis, and secondary prevention.
- 2. Gave medical approval of team proposal for care and management.
- (c) Referral
 - 1. Evaluated any specialized health care needs in management of the disease and referred to appropriate medical channels.
- (d) Follow-up/Follow-through
 - 1. Provided continuing channel of communication to specialized medical referral to assess adequacy of referral care.
- (2) Nurse or Social Worker
 - (a) Assessment
 - 1. Performed initial assessment of ill person.
 - 2. Assisted in team assessment and understanding of significant social, emotional, and economic factors related to person's care.
 - Assisted in organizing person's module service record for continuing assessment of the case management.
 - (b) Management
 - 1. Initiated introduction of the module to the person and family.
 - 2. Assumed primary responsibility in developing problem list and management plan.
 - 3. Provided expertise in rehabilitation nursing techniques and in interpretation of home care nursing orders.
 - Offered ongoing supervision of health assistants' activities.
 - (c) Referral
 - 1. Relayed knowledge regarding community resources (health, financial, recreational, education) available to person and family; referred to appropriate agency.
 - (d) Follow-up/Follow-through
 - 1. Assurred that referral process was adequately completed; provided feedback on success of that process.

- (3) Health Assistant
 - (a) Assessment
 - 1. Provided ongoing assessment of person during periodic home care visits; also assisted family situation, social and economic setting, and any other factors affecting a person's progress and care.
 - 2. Provided assessment of any family members that needed professional care.
 - (b) Management
 - Relayed information about home visits to the team in the Problem Oriented Medical Record format to use in matching person's needs and resources in home environment to the other team member's skills.
 - 2. Helped in preparation of health assistant problemoriented task list.
 - 3. Performed the bulk of direct service to person and family in the home.
 - 4. Educated person and family for self-management.
 - 5. Provided some transportation for person.
 - (c) Referral
 - 1. Assisted in referrals to other agencies (social, educational, health care agencies according to person's assessed need).
 - (d) Follow-up/Follow-through
 - 1. Through follow-up home visits, provided continued feedback on success of referral programs in meeting the specific needs of persons (p. 45-47).

As the health assistants were the primary providers of direct

services to the patients, it is important to present a further

description of their duties and training.

1. Services Performed by the Health Assistant

The activities of the health assistant represent the extension of selected skills of the physician, nurse, social worker, and rehabilitation therapists, such as occupational therapists, physical therapists, speech therapists, and audiologists. The objectives of health assistant activities pertaining to rehabilitation were to assist the patient to achieve and maintain an optimal

level of physical functioning and to prevent, as far as possible, secondary complications of the disease process. In general, the rehabilitation functions focused on activities of daily living: bathing, dressing, going to the toilet, walking, feeding, etc. The health assistant provided or taught others to provide therapeutic exercises to increase muscular strength and coordination so that the person was better able to carry out activities of daily living and prevent or delay physical deterioration. The health assistant also performed household management tasks intended to provide a safe and healthful home environment and increase the person's mobility--as for example, physical modification of the home to accommodate loss of physical functioning, and light housekeeping as necessary until other more permanent arrangements could be made.

Other health assistant activities were designed to promote social functioning and were also varied and individualized. A therapeutic relationship was established with the person and family that enabled improved communication of concerns, social problems, and conflicts that may have interfered with the person's care and rehabilitation. Discussion about the disease process was facilitated to increase the patient's understanding of and adaptation to disease, disability, and the care process. Support in the terminal stages of the disease was provided when necessary. In addition, the health assistant aided the patient in developing greater social awareness by direct interaction, helped the patient and family participate in community activities and find productive, enjoyable ways to use leisure time. The health assistant sought to alleviate economic problems by suitable referrals and made arrangements for housing if the patient's living situation was unsafe or inadequate for the person's or family's needs.

2. Training for Servide

The goal of the instructional program for health assistants was to provide a systematic learning experience by which specialized knowledge, attitudes, and skills were acquired. Thus, the health assistants were prepared to (a) provide assistance in selected patient care management functions in the home, (b) perform on-going assessment of patient functioning, and (c) help the chronically ill individual and his/her family to cope realistically with health-related and social problems.

The instructional program for health assistants was implemented in two phases over a nine-month, threequarter period. Phase I, the "pre-service" phase, required health assistants to enroll in selected introductory community college courses. These courses provided instruction in basic medical terminology, anatomy, physiology, nursing, and other topics considered to be consistent with overall objectives. Phase II, the "in-service" phase, provided a specialized field experience offered by the faculty of a Cadre Training Unit, a group organized as a training and continuing care module. This phase required the health assistant to increase knowledge and skills about care of the chronically ill and to demonstrate these in the home under supervision. Phase I and Phase II overlapped midway during the ninemonth period. Upon successful completion of the course of study, health assistants were granted a certificate.

A third phase of the educational program began when the health assistants and module professionals started a three-month period of service in the host agency, as a team. Team performance as well as individual performance were assessed. A program of continuing orientation in which the educational processes described above were reinforced and evaluated was then initiated and continued through the study period.

As a parallel activity, the professional development seminars for health care professionals were also implemented during the nine-month period, and required increasing time commitment up to eight hours a week. The physicians, nurses, and social workers selected for each module attended seminars related to professional problem-solving, team functioning, and the pattern and policies of module service (Papsidero et al., 1979, p. 49-50).

Papsidero et al. (1979) present some data describing the health assistant's home visits. During a thirteen month sampling period the patients received an average of 3.2 visits per month lasting an average of 46 minutes each (derived from Figure 5.1, Papsidero et al., p. 55). Health assistants completed activity forms describing their services in the home. Table 3 presents the percent of home visit time spent on various activities.

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Percent of Home Visit Time in Various Activities

Service Activity in the Home	%
Problem Assessment	41
Education of Patient	7
Education of Family	3
Direct Assistance	29
Transportation of Patient	6
Referral	1
Consultation	2
Other Care-Related Activity	10
Other Activity	1

(Adapted from Table 5.2, Papsidero et al., 1979, p. 56.)

Data Collection Procedures

The research was directed by a centrally-based team composed of the project director, a senior research analyst, two research associates, an economist, a cost analyst, a health educator, a nurse practitioner, a nurse educator, a social work educator, a physician, a statistician, four research assistants, three data coders, two computer programmers, two keypunch operators, two secretaries, and a field supervisor.

Two interviewers and a data controller were recruited in each of the five module areas. Interviewers were women between the ages of twenty-three and fifty-four. Most were married and collegeeducated. They were trained and supervised by persons with bachelor's degrees and with experience in health research interviewing. Interviewers had 40 hours of training consisting of seminar discussions about chronic illness and aging, sessions on the principles of research interviewing, and role playing sessions to practice interviewing.

The initial contact of the trained interviewer was always face-to-face, and in the case of the hospitalized patients, was made before discharge, whenever possible. Two-thirds of the initial interviews were obtained within 2 weeks before and after the subjects' entry into the study and about one half of the six and twelve month interviews were obtained within two weeks before or after the date scheduled for the evaluation (Papsidero et al., 1979, p. 35). Delays were most often due to temporary acute illness of the subject, poor roads, poor weather conditions, or the subject's temporary

residence outside the module area. Three attempts were to be made to complete interviews as scheduled.

All interviews after the initial one were conducted in the home. Telephone contacts were made only when requested by the participant. The exact wording and probes were specified in the interview protocols, and data items were precoded.

The interviewers were separated geographically and administratively from the service personnel, and their involvement in service was prohibited. Interviewers were not allowed access to information through which they could learn whether a participant was in the experimental or the control group. To provide continuity and maintain rapport, an attempt was made to have the same interviewer for all interviews for any one subject. Two-thirds of the participants had the same interviewer throughout the entire study (Papsidero et al., 1979, p. 34).

The field interviewers and data controllers from all sites attended meetings at Michigan State University on a regular basis. The evaluation coordinator instructed data coders to report to her any deviation in the forms received from the sites, which would then be reported.

All interview forms were edited by interview supervisors. Data were coded and checked for internal consistency by a central data controller and two coders. In addition, a 10% sample of all coded interviews were coded by both coders. The two coders agreed in 19,665 out of 19,780 codes, representing better than 99% agreement in this reliability study.

Data were entered onto punch cards and run through a cleaning and verifying program. Only about 0.05% of the 713,664 codes required correction of errors and inconsistencies. Data were

stored in both a permanent computer disc file and a back-up magnetic tape file to guard against loss (Papsidero et al., 1979, p. 35).

Table 4 represents the availability of data on patient outcomes at different follow-up time periods, i.e., the number of patients who were known to be alive or dead at each point following their entering into the study. Of the 934 patients in the original sample, 54 did not complete the initial interview and were thus missing the majority of the study measures. A further five patients could not be located at the six months interview and thus have no outcome data available. The total number of patients included in later analyses is therefore 875.

Table 4 indicates that outcome status (dead or alive) is known for a total of 875 patients at six months, for a total of 627 patients at twelve months, for a total of 290 patients at eighteen months, and for a total of 247 patients at twenty-four months.

The importance of these figures for the present study is centered around the question of possible bias in the knowledge of outcome status between the experimental and control comparison groups. It could be, for example, that those persons receiving services in the experimental group would be less likely to refuse the interviews than those in the control group. These persons might, for example, be more interested in their health and willing to discuss it, or of a more generally acquiescent frame of mind. In that case, it could be that there was more opportunity to learn about the deaths of patients in the experimental group than in the control group. In this situation, it could appear that there were a greater number of

	Outcome Data Availab	Outcome Data Availability by Study Time Period	
Interview Time Period	Number of patients contacted for interview (known to be alive) at time period	Number of patients known to be dead at time period	Number of patients with known outcome status (alive or dead) at time period
Initial	880	0	880
6 Months	774	101	875
12 Months	468	159	627
18 Months	113	177	290
24 Months	62	185	247

TABLE 4

deaths in the experimental group than in the control group, and that the services were harmful, when the number of deaths were actually equal--or even greater in the control group. It should be noted that this source of bias may be less problematic because, as noted earlier, the interviews were not the only source of data on patient deaths. The newspapers in all the module sites were examined throughout the study period for obituaries of all study subjects, even after they had refused or otherwise could not be contacted for interviews.

The extent of bias was examined by comparing the figures on outcome data availability for the experimental and control groups. For the purpose of this analysis, only the number of subjects who were contacted for interviews at each follow-up period were compared, to avoid confounding this analysis with the later comparisons of survival rates. A variable was created which gives, for each patient, the last interview at which the person was contacted: initial, six twelve, eighteen, or twenty-four months. When this variable was compared for the experimental and control groups, a chi-square of 10 resulted (df = 4, \underline{p} = .038). In contrast to what might have been expected, the control group subjects were more likely than the experimental subjects to have completed later interviews. This could indicate that there were more opportunities to learn of control group than experimental group deaths, thus possibly making the treatment look better than it really was.

Further investigation revealed that the higher percentage of later control group interviews was concentrated in the "final" control group. This is the group of 56 patients who were randomly

assigned to be interviewed only three times during the study: initial, six months, and a "final" interview at the end of the study. Apparently because of their special status, arrangements were made such that these final interviews were scheduled and completed for all of these patients before the end of the study. When the time of the last interview was compared for the experimental patients and all control group patients except the 56 "final" control group patients, the resulting chi-square was only 2.8 (df = 4, n.s.). It can be noted at this point that in order to assess the influence of this possible source of bias on the results, the major outcome analyses described below were rerun without the "final" control group patients, with no change in the results.

Measures

Four types of measures were needed for the present study. First, assessments of the patient's status at intake into the study were needed to be used as predictors, along with service use, in some of the outcome analyses and to describe the subgroups of experimental group service users and control group "user-like" subjects to be compared in some outcome analyses. For presentation purposes, the measures of intake status are divided into three groups: demographic, physical health status, and psychosocial health status.

Next, measures of the study process at the time of the initial interview were included as possibly important predictors of the patient's acceptance or non-acceptance of service. A measure of the treatment process, the number of home visits received by the patient, was included for use in some outcome analyses. Finally, two measures of survival, survivorship and length of survival, were included as outcome measures.

Some measures used in the Papsidero et al. study were not used here because they were not collected in the initial interview (e.g., income, mobility, walking) or were not considered relevant (e.g., identity of coder). Other measures were eliminated when examination of frequency distributions revealed that they duplicated other variables (e.g., outpatient or inpatient status at initial interview and place of interview) or that the frequency or variance was extremely low (e.g., relationship of the third other person present at the interview to the patient).

At this point also an examination was made of the pattern of missing data by patient. As reported earlier, the 59 patients missing both the initial and six months interviews were eliminated from the analysis. Missing data items on the initial interview for the remaining 875 patients were widely scattered across data items. The mean values of the items were substituted for any missing values as the most conservative procedure.

In the next stage of the analysis, some study process variables were eliminated when they showed extremely low correlations with service use in the initial analyses used to classify experimental group service users, to be described in the Results section. The list of measures to be discussed here is that used in the final discriminant function analysis used to predict service use. At a later stage in the analysis, to be described later in this section, the number of

intake status variables was reduced further for more efficient use as predictors in the outcome analysis.

The measures used in this study are listed in Table 5 and presented in more detail in Appendix A. The major data collection instruments are presented in Appendix B. The references in Table 5 give the background and procedures for established measures. Recent reviews have demonstrated the widespread use of many of these measures (Katz, Hedrick, and Henderson, 1979; Hedrick, Katz, and Stroud, 1980/ 1981; Hedrick, Papsidero, and Maynard, 1981). Many measures had been used by members of the Papsidero et al. research team in an earlier experimental study of home care services (Katz et al., 1972) and were chosen in part because of "the demonstrated utility of the measures in that study, and the desire to compare findings between the two studies" (Papsidero et al., p. 30).

Appendix A presents the name of the measure with the variable label used in the analysis in parentheses. A description of the measure and a list of the variables included in an index or composite measure is included where appropriate. Next, the coding and range or frequency distribution and the dummy coding used for several variables is given. Finally, the source of the measure is presented. Some measures were obtained from the forms used to screen patients into the study. The majority of the measures were obtained from the form used to record the face to face interview with each patient. This is indicated by an "I" in the Data Source column. The numbers indicate the number of the question or questions on the form from which the data were obtained. The measures can now be

TABLE 5

Principal Measures

DEMOGRAPHIC

Age Sex Ethnic Group Marital Status Index of Economic Dependence (Staff of Benjamin Rose Hospital, 1961) Socio-Economic Status of the Aged (Bloom, 1972) Type of Residence Residence Stability Number of Cohabitants Identity of Cohabitants (11 variables) Number of Non-Working Adult Cohabitants Relationship of Principal Care Giver to Patient Residence of Principal Care Giver

PHYSICAL HEALTH STATUS

Diagnostic Risk Severity of Illness Morbidity Number of Physical Screening Criteria Satisfied for Entry Into Study Index of Independence in the Activities of Daily Living (Staff of Benjamin Rose Hospital, 1958, 1959; Katz et al., 1963, 1970, 1976) Screening Source Physician (77 variables)

PSYCHOSOCIAL HEALTH STATUS

Social Role Functioning (Spitzer, Gibbon, and Endicott, 1971) Contentment (Bloom and Blenkner, 1970) Mental Status Questionnaire (Kahn et al., 1958, 1960, 1961, 1962; Pollack et al., 1958) Raven Coloured Progressive Matrices (Raven, 1962)

STUDY PROCESS

Site Interviewer (10 variables) Location of Interview TABLE 5 (Continued)

TREATMENT PROCESS

Number of Home Visits Received

OUTCOME

Survivorship Length of Survival discussed in more detail in order as they appear in Table 5 and Appendix A.

Demographic Measures

Age and sex were both obtained from the screening form and are self-explanatory. Ethnic group is classified here as white, black, or other language. This last group is people who reported that they speak a language besides English with friends and/or relatives. Marital status was dichotomized with those widowed, divorced or separated, or never married coded as not married. The next measure is the Index of Economic Dependence, first developed by members of the research team in 1961 (Staff of Benjamin Rose Hospital, 1961) and used in the earlier study of home care (Katz et al., 1972). The index combines measures of employment status, home ownership, and public and private agency support into a five-point scale from most to least financial, independence.

The second index used, the Socio-Economic Status of the Aged scale, covers different areas, combining education, occupation, and a source of income scale. This scale was developed based on Bloom (1972). The index is also a five point scale, from highest to lowest status. Education and occupation are scored and weighted using the Hollingshead (1957) system. The source of income scale determines the source from which the person receives the most income and bases the score on the usual amount of income, prestige, power, and independence provided by that income source. The seven sources of income range from the highest status source of "annuities, insurance,

interest, dividends, rentals, etc." through salary; pensions;
"withdrawals from savings, cashing bonds, selling things you own,"
gifts, loans, or private social agencies; and public assistance; to
"no regular income" as the lowest status score.

The next measure, type of residence, was dichotomized so that people were coded as living in their own or spouse's homes, or in any other type of residence. Residence stability was measured on a six point scale with one end point being people who had lived in their present residence for ten years or more and the other being people who were moving to their residence at the time of the interview.

The next measures concern the people the patient lives with, or cohabitants. The first variable is the number of cohabitants, which ranged from none to seven. The next eleven variables describe the relationship of the cohabitants to the patient: wife, husband, daughters, sons, grandchildren, siblings, other relatives, friends, and others. Daughters and sons were further divided into younger (30 years of age or less) and older (greater than 30 years of age). This was designed to help distinguish between family situations in which the patient lived with dependent single younger children and those in which the patient was living with an older child and the child's family, a situation in which the patient was more likely to be dependent.

Variables that indicated whether each cohabitant worked fulltime or not were combined into a measure of the number of non-working adult cohabitants to serve as an index of the number of people in the

home who might be free to give personal care to the patient during the day. All except fourteen patients did name someone, known as the primary care giver (PCG), who gave them "the most help with personal care and household tasks." The relationship of the PCG to the patient was coded on a four point scale as spouse, child, other relative, other. The residence of the PCG, with or not with the patient, was also determined.

Physical Health Status

The patient's primary diagnosis was identified as the diagnosis which led to the most recent hospital admission, or for those patients whose entry into the study was not preceded by a hospitalization, that associated with the patient's major disability, e.g. paralysis or missing limbs. The diagnoses were first coded using the twelve major categories of the International Code of Diseases, adopted for Hospitals (H-ICDA) (Commission on Professional and Hospital Activities, 1968). These twelve categories were then combined into a dichotomous measure of diagnostic risk. Patients were coded as having either a high risk or low risk diagnosis, with high risk diagnoses being neoplasms (cancer), diseases of the nervous system and sense organs, and diseases of the circulatory system. Another dichotomous categorization of diagnoses was based on assessments of the severity of the diagnosis made by a project physician. High severity diagnoses were defined as degenerative diseases of the cardiovascular, renal, central nervous, and pulmonary systems; neoplasms; and diabetes.

Morbidity was measured by the number of bed disability days: the number of days during the past two weeks spent as an inpatient or in bed all or most of the day.

The next measure is the number of physical screening criteria for entry into the study the patient satisfied. There were six criteria used: need for help with bathing; need for help with dressing; need for help with walking; shortness of breath; cough or sputum; and joint pain, stiffness, or swelling. Some patients met only one of these while others met all six, indicating a progressively greater number of coexisting chronic illnesses.

The major measure of physical function at entry into the study is the Index of Independence in the Activities of Daily Living or ADL. Papsidero et al. describe this measure:

Measures of activities of daily living, walking and mobility had been developed and applied by the authors during more than seventeen years. One of these, the Index of Independence in Activities of Daily Living, is a sociobiologic measure that ranks people according to their level of dependence in six basic functions, namely; bathing, dressing, going to toilet, transferring, continence, and feeding (Katz and Akpom, 1976; Staff of Benjamin Rose Hospital, 1959). In a single summary grade, the Index reflects the adequacy of a person's organized neurological and locomotor behavior. A particularly useful characteristic of this measure is the behavioral relationship among the activities contained in the scale. Its basic nature has been supported by the observation that the order in which independent functions are regained parallels the functional development of children. The usefulness of the measure has been demonstrated in numerous epidemiologic studies, in surveys, and in experiments (p. 31-32).

The index is scored from zero to six, the number of the six functions that the person performs independently, i.e. without assistance or supervision from another person. The internal consistency of the measure, as measured by the standard score coefficient alpha (Cronbach, 1961) is .80.

The next measure is the screening source, or the place from which the patient was screened into the study. This was dichotomized into acute general hospital, for those people who were hospital inpatients at screening, and other sources, which included outpatient clinics and public health clinics. This variable has been used as a measure of the patients' stage of illness, with patients who were hospitalized at intake being seen as having a condition with a more recent onset or acute exacerbation.

The final measure in this section is the identity of the patient's primary personal physician. This measure was included in the study based on reports by project staff that indicated that a major factor in patients' failing to accept project services was opposition from their physicians who were concerned about losing their patients to the project physician. Patients listed 183 different physicians as their primary physicians. Physicians who were listed by only one, two, or three study patients were eliminated, leaving 77 physicians who were listed by 4 to 36 patients. Variables called Physician 1 to Physician 77 were then constructed, each of which was scored as 0 if the person did not have the particular physician, and 1 if the person did have this physician.

Psychosocial Health Status

Four measures of psychosocial health status are included in this study. The first is a measure of social role functioning based

on Spitzer, Gibbon, and Endicott (1971). This measure is defined as the highest level of role function the person assumed in the last two weeks. It is measured as the greatest amount of activity the person engaged in with his/her spouse, relatives, or friends. People who reported doing nothing with anyone were scored lowest, followed by people who reported doing only "a few things," followed by people who reported doing "many things" with at least one category of person.

The next measure is a five-item scale of contentment, based on Bloom and Blenkner (1970). The score is determied by the number of "contented" responses given to five questions concerning happiness, satisfaction with household arrangements, satisfaction with way of life, worry over health, and whether "things keep getting worse for me as I get older." The standard score coefficient alpha of the scale is .54.

The mental status questionnaire (MSQ) assesses whether the patient is oriented to time, place, and person. This measure has a long history of development and use in studies of long-term care populations and clinical settings (Kahn et al., 1958, 1960, 1961, 1962; Pollack et al., 1958). It is scored as the number of correct answers to ten questions asking the person the month, day, year; his/her age, month and year of birth; current location; and the current and former Presidents of the United States. This scale has a standard score coefficient alpha of .78.

The Raven Coloured Progressive Matrices (Raven, 1962) was used in this and previous studies by members of the research team as

a measure of observation and clear thinking. Papsidero et al. report that the test:

has been standardized for evaluation of elderly people and has been found to correlate well with the Wechsler Adult Intelligence Scale (Raven, 1962). The Raven test consists of sets of multiple choice problems arranged in order of increasing complexity. Each contains a graphic pattern from which a segment has been removed and six possible inserts from which the subject selects the matching insert. Since manual dexterity and the ability to speak are not necessary, it is very useful in testing aged and disabled people. It also covers a range of intellectual complexity that is appropriately discriminating of the capacities of old and disabled people (p. 32).

The scores range from 0 to 18. This variable had the largest amount of missing data in the study, as 250 people refused or were unable to take the test, often because of poor vision.

Study Process

The first of the three study process measures used is the geographical site. As reported earlier, chronic disease service modules and data collection units were set up separately in five sites around Michigan: Grand Rapids, Cass County, Gratiot County, Saginaw, and Manistee. These five sites undoubtedly differ in rural vs. urban character, availability of health care services, socioeconomic status of the residents, ethnic group mix, etc. Also, in spite of the great attention paid in the study to standardizing patient care and data collection procedures across sites, the inevitable differences between sites in these procedures could also affect patient outcomes. Site was thus included in the analyses as four dichotomous dummy variables. The next measure is the identity of the interviewer who conducted the initial interview with the patient. This was felt to have a potential effect on the patient's decision to accept or not accept home care services. Only those interviewers who interviewed more than twelve patients were included, resulting in ten interviewers who interviewed from 13 to 279 patients each. The resulting ten variables, Interviewer 1 to Interviewer 10, were scored as 0 if the person did not have this particular interviewer and 1 if the person did.

The final study process measure is the location in which the initial interview took place, dichotomized as hospital or other. This measure was also felt to be a potential influence on the patient's likelihood of accepting services.

Treatment Process

The intensity of home care service received by the experimental group subjects who received home care visits is the number of such visits they received over the study period. This measure is felt to be a reasonable basic indicator of service intensity which is useful in clarifying the patient outcome analyses performed.

Outcome

Information about patients' deaths was obtained at the time of the scheduled interviews, from the study service providers, and from an established procedure of checking the obituaries in the newspapers of all the locations of the modules. Obituaries were checked for all patients, including those who refused services, those who refused interviews, and those who refused both. These obituaries were continued to be checked for a period of 15 months after the end of the follow-up interviews. Death certificates were obtained for all subjects who died to verify information about the date and circumstances of death.

The information on death was then used to construct two measures of survival: survivorship and length of survival. Survivorship is dichotomized as survival or non-survival at the end of the study period for each patient. Length of survival is the number of days from entry into the study until death, for those patients who did die during the study period.

Data Reduction

As indicated at the beginning of the measures section, the complete list of demographic, physical and psychosocial health status, and study process measures just described are those that were used in the discriminant function analyses to obtain the greatest amount of predictive power in classifying subjects as service users or nonusers. The variables were not severely reduced in number or clustered, a priori, in order to obtain the maximum predictive power available in the data set. Since the purpose of the analysis was not to explain service use, such an empirical approach could be supported. This is not the case with the outcome analyses, however. The purpose of including measures of patient status at intake in the outcome analyses is to help obtain more precise estimates of the relationship of service use to survival by including a smaller number of measures as

predictors in the analyses. An efficient use of these measures in Table 5 in the outcome analysis required a reduction of their number.

Rational considerations were used to select the predictors for the outcome analyses. The major intent was to include demographic measures, physical health status measures, and psychosocial health status measures. The study process measures such as the identity of the interviewer and the location of the interview, as well as measures such as the identity of the patient's physician, while included in the discriminant function as predictors of service use, were not seen as important predictors of survival and were therefore eliminated.

Beginning with the demographic measures, the thirteen measures used as predictors in the outcome analyses can be described. Age and sex were used as presented in Appendix A. The measure of ethnic group presented in Appendix A as two dummy variables categorizing patients as black, white, or other language was simplified into one dichotomous variable by combining white and other language. The Socio-Economic Status of the Aged measure was used as presented in Appendix A. The multiple measures in Appendix A describing the patient's living arrangements were represented by one measure derived from Katz et al. (1972) describing the type of person(s), if any, with whom the patient lived:

1. with spouse

2. without spouse, with child

3. without spouse or child, with other relatives

4. without relatives, with others

5. alone.

All six of the measures of the patient's physical health status, excepting the identity of the physician, were used as these variables were thought to be especially important potential predictors of survival. As measures of psychosocial health status, the social role functioning score and the mental status questionnaire were used. The low reliability of the contentment scale and large amount of missing data on the Raven scale weighed against their use. To summarize, the thirteen measures used as covariates in the later outcome analyses are age, sex, ethnic group, socio-economic status, living arrangements, diagnostic risk, severity of illness, morbidity, number of physical screening criteria met, index of independence in the activities of daily living, screening source, social role functioning, and mental status questionnaire score.

CHAPTER III

RESULTS

A clear explication of the relationships between subject characteristics, home care services, and survival required that a multi-stage analytic approach be used in this study. The outcome analyses were repeated in both experimental and quasi-experimental designs using different operationalizations of survival, different operationalizations of the use of home care services, and different techniques for incorporating the subject characteristic variables into the analysis. The pattern of results from these analyses, that is, the extent to which the results converge, was examined to obtain the most precise and generalizable estimates of the predictive power of the factors of interest. This multi-stage analytic approach has been advocated by Boruch (1978), Boruch and Rindskopf (1977), and Boruch and Gomez (1977), and applied in the Weissert et al. (1979) study reviewed earlier. This data set allows at least 12 separate but related tests of the basic research question. The basic features of these analyses are presented schematically in Table 6. The numbers in the cells of the table refer to the number of the analysis, described below.

TABLE 6

Data Analysis Plan

	Without Cov	ariates	With Cova	riates
	Survivorship	Length of Survival	Survivorship	Length of Survival
Experimental Distinction	I	2	3	4
Quasi-Experimental Distinction	5	6	7	8
Service Intensity (Experimental group only)	9		10	

1. Experimental Distinction with Survivorship

Analyses 1 through 4 were comparisons of outcomes for all patients assigned to the experimental and control groups. In the first analysis, the crosstabulation of this experimental distinction by survivorship, the patients' status as alive or dead by the end of the study period, indicated that the percent of experimental group subjects surviving was 78% (321 of 411) compared to 77% for the control group (357 of 464) (χ^2 = .11, n.s.). There appeared to be no relationship between the experimental distinction groups and survival.

2. Experimental Distinction with Length of Survival

The next analysis used the second operationalization of the outcome variable, the length of survival. This was measured as the number of days survived from entry to the study by those 197 patients who died during the study period. The length of survival ranged from 3 to 967 days for these patients. The relationship between the experimental distinction and length of survival was marginally significant (point biserial correlation coefficient = .12, p = .051). The coefficient indicates that the direction of this finding was that being an experimental group subject was associated with living a shorter number of days. This finding, in isolation, is not necessarily evidence for a negative effect of treatment. However, if it is supported in later analyses, it may be an important finding.

3. Experimental Distinction with Survivorship with Covariates

The next analyses were designed to obtain a more precise estimate of the relationship of the experimental distinction and the outcomes by attempting to control for any differences between the groups in the status of the subjects at entry into the study. Thirteen measures of the subjects' demographic, physical health status, and psychosocial health status were chosen, as described in the Measures section, through examination of preliminary analyses of their relationship to the outcome of survivorship and their theoretical importance. These measures were age, sex, living arrangements, ethnic group, socioeconomic status, screening source, number of physical screening criteria satisfied for entry into the study, severity of illness, diagnostic risk, morbidity, social role functioning, activities of daily living, and mental status questionnaire scores.

In this analysis, a regression of survivorship on the experimental group variable was performed, with the 13 intake status variables entered first into the analysis, in stepwise fashion, followed by the experimental distinction variable. The summary table for this analysis, presented in Table 7, shows that the experimental distinction variable did not add significantly to the equation (\underline{F} to enter = .5, n.s.). The simple \underline{r} between the treatment variable and survivorship was only .013 and the partial \underline{r} remained fairly constant throughout the steps of the analysis, suggesting that the relationship between the treatment groups and survivorship was independent

	TAB Summary of Regression	TABLE 7 Regression Predi	ILE 7 Predicting Survivorship	rship		
Variable Entered	F to Enter	Significance	Multiple R	R ²	Overall F	Significance
Activities of Daily Living	52.03	.000	.24	•00	52.03	.000
Severity of Illness	44.03	.000	.32	.10	49.33	.000
Sex	25.27	.000	.36	.13	42.23	.000
Age	13.24	.000	.38	.14	35.44	.000
Diagnostic Risk	7.84	.005	.39	.15	30.15	.000
Living Arrangements	7.06	.008	.40	.16	26.48	.000
Ethnic Group	4.89	.027	.40	.17	23.50	.000
Mental Status Questionnaire	5.46	.020	.41	.17	21.35	.000
No. of Screening Criteria Met	4.38	.037	.41	.17	19.54	.000
Screening Source	4.08	.044	.42	.18	18.06	.000
Social Role Functioning	2.70	.100	.42	.18	16.69	.000
Socio-Economic Status	2.08	.150	.42	.18	15.50	.000
Morbidity	2.02	.155	.43	.18	14.48	.000
Experimental Group	.50	.478	.43	.18	13.47	.000

of the other variables. This lack of moderator effects lends further support to the finding in analysis 1 of no relationship between the experimental distinction groups and survivorship.

4. Experimental Distinction with Length of Survival with Covariates

Next, the relationship between the experimental distinction and length of survival was further analyzed in a similar regression analysis with length of survival as the criterion and the 13 intake status variables entered into the analysis before the experimental distinction variable. The simple <u>r</u> between the treatment variable and length of survival, .12, which was reported as significant in analysis 2, was reduced to a partial <u>r</u> of .05 during the steps of the analysis and the variable did not add significantly to the equation (<u>F</u> to enter = .5, n.s.). It would thus seem that the relationship between the experimental groups and length of survival is largely accounted for by the linear combination of the intake status variables. Therefore, this finding does not support any contention of negative effects from the module treatment.

5. Quasi-experimental Classification with Survivorship

A quasi-experimental approach to the data set is indicated by the fact that a large number of the subjects assigned to the experimental group did not use the home care services. Boruch (1981) recently discussed several approaches to this common situation as a part of the analyses of the Seattle and Denver Income Maintenance

Experiments. In the approach used here, survival outcomes were compared for two groups of patients selected from the total experimental and control groups. These two groups are the service users: experimental group patients who used the home care services, and the userlike control group patients: control group patients similar to the service users at intake to the study. A discriminant function analysis was used to discriminate between service users and non-users in the experimental group, using the demographic, physical and psychosocial health status, and study process variables in Table 4. The intent of this analysis was not to explain service participation, but to find the classification function that best discriminated the users and non-users. Since the intent was not on describing the contribution of individual variables, multicollinearity was not a major concern.

In a preliminary discriminant function analysis all 124 measures presented in Appendix A were included. The following measures were found to have very small canonical discriminant function coefficients and were eliminated from the analysis at that point: age, type of residence, residence stability, 36 of the Physician 1 to Physician 77 variables, and Interviewer 7. The final function, made up of 85 variables, was highly significant with a chi-square of 154.90, $\underline{p} < .0001$, and contained 34% of the variance accounted for in service use.

The function correctly classified 77% of the experimental group patients as service users or non-users. As 60% of the experimental subjects were non-service users, a random selection of control

group subjects includes, in a sense, 40% errors. Use of the discriminant function removes 42% of this error, i.e., (77-60)/40. Therefore, the use of the discriminant function to choose user-like control group subjects does represent a gain in accuracy.

When the discriminant function was applied to the control group, 149 of the 464 control group patients, or 32%, were categorized as service user-like patients. This group was compared to the experimental group service users in the following analyses.

The crosstabulation of this quasi-experimental classification by survivorship resulted in findings quite similar to those resulting from the comparison of the survivorship of the original experimental and control subjects in analysis 1. Here, 77% of the experimental subjects (128 of 166) and 75% of the control subjects (111 of 149) survived at end of study (χ^2 = .17, n.s.). There appeared to be no relationship between membership in the service user or user-like control groups and survivorship.

6. Quasi-Experimental Classification with Length of Survival

In this analysis, the relationship between the quasi-experimental classification and the length of survival, for the 76 patients from these subgroups that died during the study, was assessed. This relationship was not significant (point biserial correlation coefficient = .16, n.s.). That is, there was no relationship between the treatment variable and length of survival. This finding further supports the earlier conclusion that the marginally significant

correlation between the experimental distinction and length of survival found in analysis 2 was due to other factors besides the treatment.

7. Quasi-Experimental Classification with Survivorship with Covariates

In this regression analysis, the 13 intake status variables described earlier were entered into the analysis first, followed by the quasi-experimental classification variable, with survivorship as the criterion. The classification variable did not add significantly to the equation (\underline{F} to enter = .83, n.s.). The simple \underline{r} of .03 remained fairly constant as a partial \underline{r} throughout the steps of the analysis, indicating that the relationship between the classification groups and survivorship was independent of the other variables. The lack of moderator effects in this analysis lends further support to the finding in analysis 5 of no relationship between the classification groups and survivorship.

8. Quasi-Experimental Classification with Length of Survival with Covariates

This next regression analysis examined the relationship between the quasi-experimental classification and length of survival, with the 13 intake status variables entered first into the analysis. The classification variable did not add significantly to the equation (<u>F</u> to enter = 1.28, n.s.). The partial <u>r</u> changed from .16 to .05 on one step of the analysis, and by much smaller degrees on the others. This finding does not offer much support for the existence of any moderator effects influencing any relationship between the classification variable and length of survival.

9. Service Intensity with Survivorship

Analyses 9 and 10 employed a new operationalization of the treatment variable. A basic measure of the treatment process, the intensity of the home care services received by the subjects, was operationalized as the number of home care visits received by the patients in the first twelve months following their entry into the study. As subjects for whom these figures were missing or who had received only one such visit had been placed in the non-service user group, the number of visits received by the subjects ranged from 2 to 191.

In Analyses 9 and 10 the number of visits was entered into the regression analyses as the treatment variable to analyze the relationship of this variable to survivorship. A parallel analysis with the length of survival as the outcome was felt not to be meaningful because patients living longer would naturally have more visits than those living shorter amounts of time simply because they were around to have such visits. Analyses with length of survival were therefore not completed.

It was felt that the time during which the home care visits took place could be an important influence on their effectiveness. In particular, it was felt that the number of visits received by the patients in their first month in the study, at a time presumably closer to the health event that made them eligible for the study, would be more important than visits occurring later in the study. In preliminary analyses, therefore, the service intensity variable was operationalized as two measures: the number of visits in the first month and the total number of visits in months 2 through 12. When these variables were entered into the regression analysis in that order, the number of visits in the first month did not enter significantly into the equation, while the number of visits in months 2 to 12 did. These variables were therefore combined and the total number of visits was used as the service intensity variable in the main analyses reported here.

In analysis 9 there was a significant relationship between the total number of visits and survivorship (point biserial) correlation coefficient = -.19, \underline{p} = .006). The direction of this coefficient indicates that the more visits a person received the greater the likelihood that the person would be alive at the end of the study.

10. Service Intensity with Survivorship with Covariates

In this analysis the relationship between the number of visits received and survivorship was analyzed while attempting to control for any differences between subjects in the 13 intake status variables. When these variables were entered first into a regression analysis, the zero order correlation between the number of visits and survivorship was reduced from -.19 to a partial r of -.13 and the variable did not enter significantly into the equation (\underline{F} to enter = 2.46, p = .119). Thus, it appears that the relationship

between the number of visits and survivorship is largely accounted for by the relationship of the intake variables and survivorship.

Interactions

The final set of analyses explored the question of interaction between the subject intake characteristics and home care services in their relationship with survivorship. The results of the regression analyses reported earlier did not offer much support for the existence of such interaction, but it was felt that an exploratory analysis would be warranted by the findings of such relationships in several of the twelve studies reviewed in the Introduction. The intake characteristics chosen for analysis here, all of which had been included in the 13 intake status variables used in earlier analyses, were those that had been found to have such interactions in the reviewed studies. These characteristics were age, ethnic group, living arrangements, and the level of independence in the activities of daily living.

In this study, regression analyses were done in which the 13 intake status variables were entered into the analysis first, followed by the treatment variable, which was followed by the product of the treatment variable and one of the four intake variables selected (Cohen, 1980). This analysis was therefore conducted four times with the experimental distinction variable as the treatment variable, once each for age x treatment, ethnic group x treatment, living arrangements x treatment, and activities of daily living x treatment. In no case did this interaction term enter significantly

into the equation. For age x treatment, the <u>F</u> to enter was .001, n.s.; for ethnic group x treatment, the <u>F</u> to enter was .04, n.s.; for living arrangement x treatment, the <u>F</u> to enter was .79, n.s.; and for activities of daily living, the <u>F</u> to enter was 1.17, n.s.

These four analyses were repeated with the quasi-experimental classification as the treatment variable, with similar results. In this case, for age x treatment, the <u>F</u> to enter was .10, n.s.; for ethnic group x treatment, the <u>F</u> to enter was 1.13, n.s.; for living arrangements x treatment, the <u>F</u> to enter was .24, n.s.; and for activities of daily living x treatment, the <u>F</u> to enter was .005, n.s.

It would thus appear that any relationship between group membership and survivorship in this study is not mediated by any of the variables found to fulfill such a function in other studies.

CHAPTER IV

DISCUSSION

The present study is seen as one contribution to the crucial task of investigating the patient outcomes that are associated with home health care services, one of the currently proposed alternatives to the present long-term health care system for the chronically-ill elderly. This study was designed to examine the relationship between one type of home care, that offered by a health assistant as a part of a multi-disciplinary team of health care providers, and one patient outcome, survival. There has been a great deal of recent interest in home care because of its potential for better meeting the needs of the chronically-ill elderly and doing so at a lower cost than the currently institutionally-based long-term care system (Blum and Minkler, 1980; Brickner et al., 1976; Colt et al., 1977; Comptroller General of the United States, 1977; Somers and Moore, 1976; Van Dyke and Brown, 1972). Many observers have agreed, however, that rigorously designed evaluations of home care and related community-based care programs have demonstrated few significant effects on patient outcomes and have not resulted in any conclusive consistent accounting of the outcomes that may be expected from these programs (Doherty et al., 1978; Dunlop, 1980; Iglehart, 1978; Kane and Kane, 1978, 1980; Urban Institute, 1978).

One exception to the general lack of significant findings has been the ultimate outcome of patient survival. Community-based programs have never cited higher rates of patient survival as a realistic service goal for this chronically-ill elderly population. In fact, few programs have even felt improved physical function to be an achievable goal, and have focused on a slower rate of deterioration in physical function, avoidance or postponement of institutionalization, and improved patient and/or family morale. In the Introduction. 14 experimental or quasi-experimental studies of community-based care services that had included measures of patient survival were reviewed. Six of the studies found that the experimental group had a significantly lower mortality rate than the control group (Bryant et al., Selmonoff et al., Skellie et al., and all three studies of Weissert et al.). One study found that the experimental group had a significantly higher mortality rate than the control group (Blenkner et al.). Seven studies found no differences between the groups (Applebaum et al., Bakst and Marra, Hughes et al., Katz et al., Nielsen et al., Posman et al., Weiss). The fact that, contrary to expectations, half of the studies reviewed found significant differences in mortality rates served as a major impetus behind the present study.

In the present study, a multi-stage multivariate analysis strategy, as advocated by Boruch and colleagues (1977, 1978), was developed and applied to data on patient survival from a major experimental study of home care (Papsidero et al., 1978). The

results from this intensive analysis of the relationship of service use and survival can now be summarized.

The analysis strategy developed for this study included both experimental and quasi-experimental approaches and different operationalizations of the use of home care services and survival. In the experimental analyses, the comparison of the total experimental and control groups revealed no differences in the number of patients who were alive at the end of the study period. That any relationship between group membership and survival was not suppressed by differences between the groups in their status at intake to the study was supported by the failure of the treatment variable to enter the equation significantly after the entry of 13 measures of the patients' intake status.

There was a marginally significant relationship between experimental group membership and length of survival, the number of days survived by those patients who did die during the study. However, the failure of the treatment variable to enter into the equation significantly after the entry of the intake status variables indicated that any relationship between treatment and length of survival was a spurious one accounted for by differences in patients' intake status.

A series of quasi-experimental analyses comparing the experimental group patients who actually used the home care services with a group of user-like control group members was designed to permit a more precise estimate of the relationship between service use and survival in face of the fact that 60% of the experimental group

subjects received no--or only one--home care visit. The findings from these analyses were very similar to those from the experimental analyses described above, and offered no support for a relationship between service use and survivorship or length of survival.

Another series of analyses also failed to support such relationships. The Blenkner et al., Skellie et al., and Weissert et al. studies reviewed in the Introduction found that four intake status variables: age, race, living arrangements, and independence in the activities of daily living, mediated the relationship between service use and survival. For example, patients living with others were more likely to survive in the service group than in the control group, while such differences were not found for patients living alone. In the present study, the interactions of measures of each of these four variables and the treatment group did not enter significantly into the regression equations following the intake status and treatment measures alone. These analyses thus offered no support for the contention that any relationship between group membership and survival was mediated by any of the variables found to fulfill such a function in the studies reviewed.

Finally, an assessment was made of the relationship between survivorship and a basic process measure, the total number of home care visits received by those subjects receiving visits. Such a relationship was found (point biserial correlation coefficient = -.19 p = .006) and indicated that those subjects receiving a greater number of visits were more likely to survive than those receiving fewer visits. However, this relationship appeared to be largely

accounted for by the relationship of the intake status measures to survivorship, as the service variable did not enter significantly into the equation following the entry of the status variables.

The results of this study indicate no support of any kind for any relationship between the type of home care studied and survival. These results put this study firmly in the group of seven studies reviewed in the Introduction in which no relationship between service and survival was found. There are several possible explanations of why this study would be in this group rather than in the other group of seven studies in which such relationships were found.

The first set of explanations concerns the possibility that the type of home care service studied here does positively affect survival rates but that this particular study failed to show those effects. One possible explanation is that factors in the implementation of the research study, other than the treatment itself, were responsible for the outcome. Such factors include the patient samples, designs, measures, data collection procedures, follow-up time periods, and so forth. For example, it could be that the services assessed could affect survival rates, but the patient sample did not include those who could show the greatest survival benefits. Some support for this type of explanation can be achieved from a comparison of the available data describing the Papsidero et al. sample with that describing the samples from the studies with positive findings reviewed in the Introduction. To take one example, patients in the Papsidero et al. sample, when compared to patients in the Weissert et al. homemaker study, seem to have been younger,

more likely to be male, less likely to live alone, and less dependent in the activities of daily living. As the subgroup analyses performed in the Weissert et al. study indicated that age, living arrangements, and activities of daily living all influenced the results found in that study, such differences in samples could account for some part of the differences in results.

As another example, it could be that if measures other than those used here were selected as operationalizations of the variables of interest. different results would be obtained. Different operationalizations of intake, process, and outcome variables could all be important. For example, the patients' living arrangements might be revealed as a significant influence on their response to treatment if the measure included more detail on the persons lived with and the extent of present and potential support provided by those persons. A more detailed understanding of the process of care and its relationship to the outcome might result from the use of information on the content of the home visits received in addition to their number. Finally, it could also be that different operationalizations of the outcome variable of survival could result in different findings. Although two different measures of this variable were used in this study, this complex variable can also be measured in other ways such as differences between actual survival curves and the survival curves expected for persons of similar age and sex in the general population.

As a second possible explanation, this study could have failed to demonstrate existing effects of the home care services on survival

because of problems in the implementation of the treatment itself. Sechrest et al. (1979) present support and guidelines for a greater concentration on assessing the strength and integrity of the treatment in evaluation research. Boruch and Gomez (1977) have discussed the same concerns, describing the great decrease in statistical power resulting from a decline in treatment integrity. In their reanalysis of the data from their study of home care reviewed in the Introduction, Hughes, Cordray, and Spiker (1978) reiterate the importance of the inclusion in outcome analyses of data on the actual implementation of the treatment, in their case, the number of home visits received by the subjects.

In the present study, an examination of data on the number of home care visits actually received by the subjects indicated that only 40% of those assigned to the experimental group received more than one home care visit. This level of treatment integrity certainly severely reduces the possibility of any existing treatment effect being demonstrated.

The efforts in this study to compare the service-users with a more comparable group of user-like control group patients was successful in that the discriminant function correctly classified 77% of the experimental group as service users or non-users and did results in a large enough group of user-like control group patients for comparison purposes. Of course, it is probable that the use of this technique succeeded in forming a group that, while certainly more comparable than the total control group, had been equated with the service users on only a portion of the many factors responsible

for or related to their self-selection. The self-selection problem remains a possible rationale for differences in outcome between this and other studies.

As a further issue in treatment integrity, it can be noted that the number of visits received by those patients that did receive visits ranged from 2 to 191. In this study, the treatment was not designed as a standard package such that each patient was supposed to receive a certain number of visits no matter what his or her condition. In common with other health care services, the number of visits was determined during the treatment process as part of the ongoing care plan individually prescribed for each person by the team members. The treatment procedures as specified in Papsidero et al. including in depth training of the team members, detailed treatment guides, supervision by central office service providers, and the use of the three-month baseline period in each site to test treatment procedures before data collection began would indicate some support for a contention that, for those receiving any visits at least, appropriate levels of service were prescribed.

The number of visits was, of course, also influenced by the length of time the patient remained in the study as determined by factors such as the time at which he or she entered the study and his/her institutionalization or death. Here again, the self-selection factor was operating as the patients could accept or reject home care visits at any time during the study. The wide range in the number of visits received could, in summary, be seen as reducing the possibility of locating any existing treatment effect. The use of the number of

vistis received as the operationalization of the treatment variable in one set of analyses was seen as one possible approach to better understanding any treatment effect, though in this case it did not result in any different results from those in the other analyses.

The major alternative explanation for the results of the present study is that the study resulted in a valid assessment of this type of home care service and that there is no association between this treatment and survival. It must be remembered that community-based services were never designed or expected to have effects on this ultimate health outcome and that the unforseen nature of the significant findings in the studies reviewed in the Introduction was in part the impetus for this study. While the type of service studied here seemed to be most similar to the studies of home health aide care, the type that seemed most likely to be associated with positive effects on survival in the literature, this explanation would hold that the differences in outcomes could be due to differences in the services not accounted for in the rudimentary classification system used in the Introduction. The type of service studied here was newly developed especially for the Papsidero et al. study and no doubt differed in design and implementation in myriad subtle and not so subtle ways from the home health aide services in the reviewed studies in personnel selection, training, assigned roles, rules of operation, etc. Even a seemingly minor difference in any of these factors could conceivably be enough to account for differences in patient outcomes.

Directions for Future Research

As reported in the Introduction, a recent policy paper by the Health Care Financing Administration (1981) concluded from three of the studies reviewed here that "community-based services appear to have a positive impact on survival rates" (p. 46). The overall results of the 14 studies reviewed in the Introduction, as well as the results of the present study, would seem to indicate the need for major qualifications of that statement. If such over-simplified interpretations of the literature lead to policies advocating any and all types of community-based services for any and all elderly patients, there may be unexpected and unfortunate results. The critical need at present is for research to help clarify which types of community-based services have what effects for what types of elderly persons in which settings. The results of such research can then be formulated into statements of the type of care which is likely to prove most beneficial for each type of patient. Only when the criteria governing people's access to federally-funded communitybased care are grounded on such statements of expected benefits will the long-term care system improve in effectiveness and humanity.

The first direction suggested for future research is the analysis of the relationship of community-based services and survival in other existing data sets. The application of the multi-stage analysis strategy developed in the present study is suggested, with multiple operationalizations of the use of services and survival, with the use of measures of the patients' intake status as covariates, and especially with the use of discriminant function in the formation

of groups of more comparable subjects as one approach to the common problem of service self-selection. This research can contribute to the field through further study of the effects of using various operationalizations of intake, process, and outcome variables, and of the comparability of groups established through the use of the discriminant function technique.

An intensive analysis of survival data from multiple existing data sets--data which in many cases have been subject to only cursory analysis--could help to achieve a great deal of information about the relationship between service and survival with a fraction of the time and cost needed to mount a new study of the same topic.

The data archive in the Department of Community Health Science, Michigan State University, contains or will very shortly contain data sets and documentation designed for just such analyses from five studies of community-based care alternatives (Cummings, Kerner, Arones, and Steinbeck, 1980; Katz et al., Shealy, 1979; Skellie et al., and Weissert et al.).

Finally, it should be noted that this study was not intended to be an all-encompassing assessment of all possible outcomes of service, but an intensive examination of one important outcome, patient survival. A second direction for future research would be to apply the analysis strategies used here to other patient outcomes in the Papsidero et al. and other existing data sets. Other major goals of a health care service for this chronically-ill elderly population focus on quality of life. The aim is to maintain the person at the highest level possible in physical, psychological, and social

function for as long as possible. In fact, although for simplicity's sake in the present study survival was referred to as an exclusively beneficial outcome, a service that kept patients alive for a longer period of time, but at a completely dependent functional level, may not be considered successful. Similarly, a service that did not increase the number of days survived, but did increase the subjects' level of function during those days, may be considered successful. Any policy analysis evaluating the effectiveness of community-based care should be based on an exhaustive synthesis of research on all possible outcomes of care. Only in this way can the most accurate picture of the complex synergistic effects of any service designed to change people's lives be obtained. APPENDICES

APPENDIX A

DESCRIPTION OF VARIABLES

MEASURES DEMOGRAPHIC Age (AGE) Sex (SEX) Ethnic Group (BLACK,OLANG)	Description of Meas <u>ODING AND RANGE OR F</u> ange 45-98 o data - 0 = F - 522 = M - 361 No data - 0 = Black -	DATA SOURCE Screening form I Ba, Bb
Marital Status (MARRIED)	2 = White - 610 0 0 0 3 = Other language - 169 0 1 No data - 8 1 = Married - 470 2 = Not married - 409 No data - 4	1.7
Index of Economic Dependency (ECON) Home ownership Employment status Public agency support Private agency support	 Employed, owns home and not on agency support (public or private) - 71 2 = Owns home, not employed, not on agency support (public or private) Or employed, does not own home, not on agency support (public or private) - 383 3 = Does not own home, not on agency (public or private) - 383 	[1,5,5](3),59
	Or not employed, owns home, on agency (public or private or both) support - 228 4 = Not employed, does not own home, on agency (public or private or both) support 5 = Other combinations (non-scale) - 12 No data - 72	

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Appendix A

. MEASURES	CODING AND	CODING AND RANGE OR FREQUENCY	DATA SOURCE
Number of Cohabitants (NCOHAB)	0 - 187 1 - 406 2 - 124 3 - 53	4 - 42 5 - 29 6 - 14 7 - 18 no data - 10	6 I
Lives with Wife (WIFE)	0 - 629 1 - 254		I 10, 11
Lives with Husband (HUS)	0 - 678 1 - 205		II 10, 11
Number of Younger (30 or younger) Daughters Lives with (YDAU)	0 - 803 1 - 59 2 - 16	3 - 5 4 - 1 5 - 1	I 10 , II
Number of Older Daughters Lives with (ODAU)	0 - 805 1 - 77 2 - 1		I 10, 11
Number of Younger Sons Lives with (YSON)	0 - 784 1 - 70 2 - 17	3 - 5 4 - 6 6 - 1	II ,0I I
Number of Older Sons Lives with (OSON)	0 - 834 1 - 47 2 - 2		II ,0I I
Number of Grandchildren Lives with (GKIDS)	0 - 803 1 - 37 2 - 17	3 - 14 4 - 9 5 - 3	I 10 , 11
Number of Siblings Lives with (SIB)	0 - 843 1 - 34 2 - 6		11 ,01 1
Number of Other Relatives Lives with (OREL)	0 - 857 1 - 22	2 - 3 3 - 1	I 10, 11
Number of Friends Lives with (FRIEN)	0 - 857 1 - 15 2 - 6	3 - 3 5 - 1 6 - 1	11 0, 11
Number of Others Lives with (LOTH)	0 - 761 1 - 97 2 - 12 3 - 6	4 - 2 5 - 2 6 - 3	II 10, 11

MEASURES	CODING AND RANGE OR FREQUENCY	DATA SOURCE
Socio-Economic Status of the Aged (SES) Education Occupation Occupation Source of Income Scale: Rating of highest source of income along following scale ranked from highest to lowest in income prestige, power, and independence: Interest; salary; pension; with- drawals; gifts; loans; social security; public assistance; no regular income	<pre>1 = Highest score - 4 2 2 - 38 3 - 308 4 - 328 5 = Lowest score - 153 No data - 52 This score is based on education (times a weight of 7) plus a source of income score (times a weight of 11). The score (times been scored using the rule</pre>	I 7, 61-66, 67-72, 73-78, 79-84, 85-88, 51
(See Department of Community Health Science, no date)	that a married woman's score is based on her husband's occupation and education; a divorced woman's score is based on her own occupation and education, if she is employed outside of the home; a widowed woman's score is based on her own occu- pation and education, if she is occupied outside of the home and has been widowed for 10 years or more. Otherwise, a divorced or widowed woman's score is based upon her past husband's employment and her own education.	
Type of Residence (OWN HOME)	1 = Own or spouse's home - 722 2 = Other No data - 7	
Residence Stability (STABLE)	1 = Moving there now - 0 $2 = Less than a month - 34$ $3 = Less than a year - 72$ $4 = At least 1 years - 164$ $5 = At least 5 years - 164$ $5 = At least 5 years - 129$ $6 = 10 years or more - 476$ No data - 8	

MEASURES	CODING AND RANGE OR FREQUENCY	DATA SOURCE
Number of Non-Working Adult (25 years old or older) Cohabitants (CWORK)	0 - 388 3 - 3 1 - 432 4 - 1 2 - 58 6 - 1	1 11, 14
Relationship of Principal Care Giver to Patient (PCG)	<pre>1 = Spouse - 394 2 = Child - 214 3 = Other Relative - 148 4 = Other - 113 No data - 14</pre>	15
Residence of Principal Care Giver (PCG with)	l = with patient - 508 2 = not with patient - 359 No data - 16	I page l
PHYSICAL HEALTH STATUS Diagnostic Risk (DIAGRISK) Severity of Illness (CATDIAG)	 1 = High risk diagnosis - 418 2 = Low risk diagnosis - 401 No data - 64 High risk diagnoses are neoplasms, diseases of the nervous system and sense organs, and diseases of the circulatory systems. 1 = Low - 359 2 = High - 509 No data - 15 High severity diagnoses are degenerative diseases of 	Medical records and patient's physician Medical records and patient's physician, and project physician
	nervous, and pulmonary systems, neoplasms, and diabetes.	

MEASURES	CODING AND RANGE OR FREQUENCY	DATA SOURCE
Morbidity (MORBID)	$\begin{array}{cccccccccccccccccccccccccccccccccccc$	I 21, 22
Number of Physical Screening Criteria Satisfied for Entry into Study from six possible criteria: (SCREEN) 1. need for help with bathing 2. need for help with dressing 3. need for help with walking 4. shortness of breath 5. cough or sputum 6. joint pain, stiffness, or swelling	1 - 241 2 - 210 3 - 185 4 - 113 5 - 96 6 - 38 No data - 0	lst stage screening form 3, 4, 5
Index of Independence in Activities of Daily Living (ADL) The number of following activities patient performs independently: Bathing, Dressing, Feeding, Toileting, Continence, Transfer	0 - 29 1 - 74 2 - 165 3 - 73 4 - 97 5 - 156 6 - 279 6 - 279 No data - 10	I 44, 45, 46, 47, 48, 49

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MEASURES	CODING AND RANGE OR FREQUENCY	DATA SOURCE
Screening Source (SOURCE) Source from which patient was screened into study] = Acute general hospital - 719 2 = Other - 164 No data - 0	
Physician (DOC 1 - DOC 77) 77 variables indicating whether the patient did or did not have a particular physician as his/her private primary physician. For phy- sicians who were named for at least 4 patients in study.	. 0 = Did not have this physician 1 = Had this physician	
PSYCHOSOCIAL HEALTH STATUS		
Social Role Functioning (SOCIAL) Highest level of role function- ing in last 2 weeks - ability to do things with spouse, other relatives, friends.	1 = Lowest - 27 2 = - 589 3 = Highest - 260 No data - 7	I 24, 25, 27
Contentment Scale (HAPPY) Number of "contented" responses out of possible score of 5.	$\begin{array}{cccccccccccccccccccccccccccccccccccc$	I 20, 31, 50, 52, 53
Mental Status Questionnaire (MSQ) Orientation to time, place, and person. Number of correct answers out of ten questions.	Lowest 0 - 2 1 - 3 2 - 1 3 - 12 4 - 10 5 - 10 5 - 10 6 - 13 6 - 13 8 - 81 8 - 81 9 - 236 Highest 10 - 469 No data - 10	I 89-98

. 99

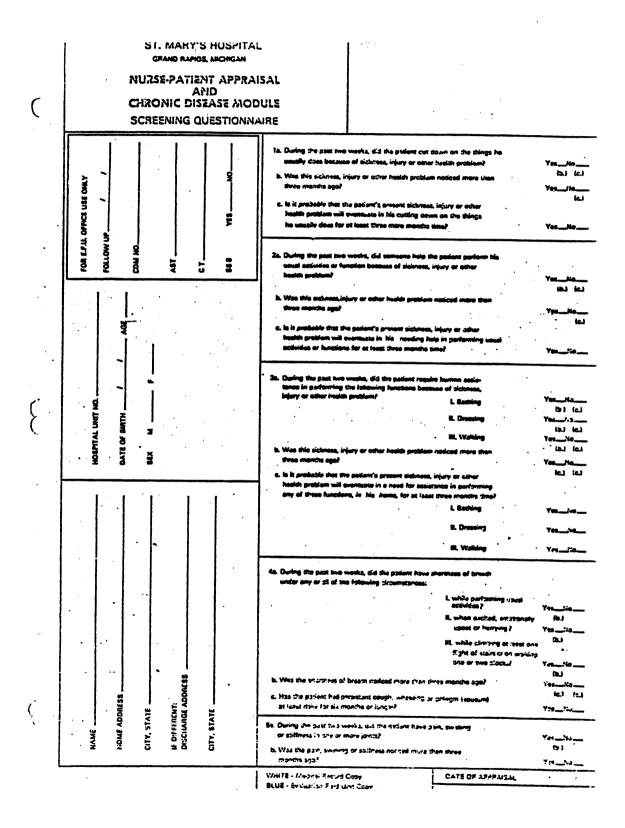
MEASURES	CODING AND RANGE OR FREQUENCY	DATA SOURCE
Raven Coloured (RAVEN) Professional Matrices Scale	0 - 1 10 - 42 1 - 1 11 - 53 2 - 5 12 - 65 3 - 8 13 - 69 4 - 68 5 - 22 15 - 73 6 - 22 16 - 56 7 - 33 17 - 26 8 - 35 18 - 13 9 - 57 No data - 250	I p. 20
STUDY PROCESS		
Site	$ \begin{array}{c ccccccccccccccccccccccccccccccccccc$	I, Cover Sheet
Interviewer (INT 1-10) 10 variables indicating whether the patient did or did not have a particular interviewer. For interviewers who interviewed 5 or more patients.	0 - Did not have this interviewer 1 - Did have this interviewer	I, Cover Sheet
Location of Interview (I PLACE)	1 - Hospital - 216 2 - Other - 667	I. p. l
TREATMENT PROCESS Number of home visits received (by those who received visits)	(VISITS) Range 1 -	Health Assistant Activity Sheets

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MEASURES	CODING AND RANGE OR FREQUENCY	DATA SOURCE
OUTCOME .		
Survivorship (SURVIVE)	Death certificate present - 0	Study records,
If person is alive or not at end of study.	Death certificate not present -]	obituaries, death certificates
Length of Survival (LOS)	Number of days from entry into study until death	Study records, obituaries, death
	Date of death minus date of entry into study.	certificates

APPENDIX B

DATA COLLECTION INSTRUMENTS



SAINT MARY'S HOSPITAL GRAND RAPIDS, MICHIGAN

Second-Stage Screening Questionnaire

M.S.U. Evaluation Field Unit

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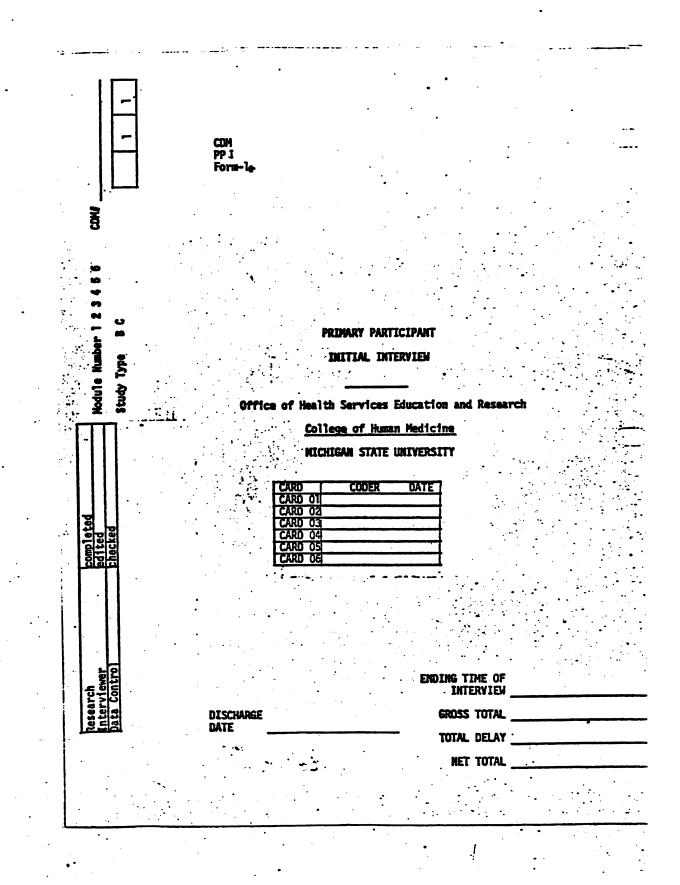
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21			~	ANSY	ER EITHER QUESTION 1 OR ALL PARTS OF QUESTION 2	AND QUESTION 3.
FOR EVALUATION FIELD UNIT OFFICE USE ONLY FOLLONUP / /	HOSP. UNIT NO.		FURTHER Yes		Regardless of present residence, does this path nursing services <u>in an institutional setting</u> (su home, extended care facility, rehabilitation how hospital)? If "Yes" is checked at right, <u>list nursing serv</u>	uch as a nursing spital, mental Yes 🗂
FOR EVALUATION FIELD		0.7.	OF FIRST- E SCREENING / / I	2ä. 2b.	in a residential setting (such as patient's own or friend's home, hotel, or state licensed per Who is the person who helps the patient most in setting? (Use your best judgement and any infi- have from the patient or family to answer this 1 a relative (specify relationship) 2 a friend or neighbor of the patient	n home, relative mit home)? Yes n the residential ormation you question.)
(first name)		(Phone) A.8.T.	DATE OF STAGE S	2c.	3 an employee of the patient or patient 4 a nurse or other health service worke 5 some other type of person (specify) What is the name, address and phone number of ed in 2b.7 (Be as specific as you can, with t available to you. Leave address and phone spa the address is the same as the address and phone Mr. Mrs.Miss (last name) (first name) (Street 5 number, if different from patient's)	r the person check- he information ces blank, <u>if</u> <u>ne at left</u> .) me)
(last name)	(Street & number)	(City)		2d	(<u>City & phone</u> , if different from patient's) If "yes" is checked for 2a., <u>list the services</u> patient, regardless of who provides the servic dential setting.	es in the resi-
				.3.	<pre>How would you describe the address at left? 1 This is an institutional setting 2 This is a residential setting</pre>	DATE COMPLETED <u>///</u> BY:

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Best Present Information: Discharge Address Controller DUE TO BE . STREET . DISCHARGED . ZIP PHONE CITY Data Room # ___ Best Present Information: Primary Care Giver Sex Age • Be Filled In By . CDM # NAME (PCG) RELATIONSHIP STREET ZIP • PHONE CITY Contact the following person to arrange initial appointment **_** • NAME PHONE ROLE الاردار المعاجب المعاجمة · · · · · · · · · · · Starting -· · Others Present During Interview Time of • Interview Name Role Lengh of Time M. 1/2 1/4 1 Sh. ĀΠ • • • • ÷ . . : . 5 . • •. • • . • . ٠ • • . • . Delay During Interview • • • • . • • . . : . Reason for Delay · From: · To: Ninutes | Total Mins. . . •. ' • ۰. • ۳. ÷ • ÷ ... Record of Interview Attempts . •. ٠ . . APPOINTMENT ARRANGEMENTS OUTCOHE REASON Date | Time | Place | Arranged with (name Role Complete Refusal Delay GIVEN. HŖ . . · : HR . .. HR . • • Control ler ۰. HR • . · . · MAHE · • AGE SEX CDM3 CON-PRI-Form le المسار ساد والمعادي فالمشار وسأد ••••• . .

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	1.	ARE YOU LOOKING FORWARD TO GOING HOME? 1. Yes: 2. No
·	2.	<pre>HOW LONG HAVE YOU LIVED IN YOUR PRESENT HOME? Time= 1. I'm moving there when I leave the hospital 2. Less than a month</pre>
	D/1	 Less than a year At least 1 year, less than 5 years At least 5 years, less than 10 years I0 years or more
		9. No codable answer given
	3.	WHAT KIND OF PLACE ARE YOU GOING TO WHEN YOU LEAVE THE HOSPITAL? IS IT YOUR OWN HOME, SOMEONE ELSE'S HOME, OR SOME OTHER KIND OF PLACE?
	D/2	
		 A permit home A hotel or boarding house First specific ECF in area (end interview, see below)
		 Second specific ECF in area (end interview, see below) Some other rehabilitation hospital (end interview, see below) A nursing home (end interview, see below)
	•	9. Any setting (as a class) to which the interviewer cannot obtain
((Only for those who answered with a 5, 6, 7, 8, or 9). I WANT TO THANK YOU FOR YOUR HELP WITH THIS STUDY. THAT'S ALL THE INFORMATION WE'LL BE NEEDING. GOODBYE.
	4.	WHAT WILL YOUR ADDRESS BE WHEN YOU LEAVE THE HOSPITAL? (Allow sufficient time for an unprompted response, before you mention the address supplied on page 1. Verify the address which has been given to you).
	D/3	()
•	5.	WHO IS THE PERSON WHO WILL GIVE YOU THE MOST DIRECT HELP WITH PERSONAL CARE AND HOUSEHOLD TASKS WHEN YOU HAVE LEFT THE HOSPITAL? (Probe: THINGS LIKE BATHING, DRESSING, LAUNDRY, COOKING, SHOPPING, CLEANING
	PCG/1	AND SUCH?) WHAT IS THIS PERSON'S RELATION TO YOU? 1. Spouse 2. Other relative (specify) 3. Friend 4. Neighbor 5. Employee
	-	6. Other (specify)
,	6. . `	(Ask only if the above named person does not live with participant) WHAT IS THIS PERSON'S NAME, ADDRESS AND TELEPHONE NUMBER? (If ques- tioned add, PART OF THE RESEARCH INVOLVES INTERVIEWING THIS PERSON YOU'VE MENTIONED ALSO.) AgeSex
N.,	PCG/2	
	•	(verify PCG address given on page 1)

(At this point ask items 1-8 on the sensory functioning forms. if the participant gives indication that a shorter interview is needed, skip all sensory function questions and proceed with item 7 below.) 7. ARE YOU MARRIED, DIVORCED, WIDOWED, SEPARATED (intentionally), OR HAVE YOU NEVER MARRIED? (note: Married takes precedence over also being divorced or widowed) 1. Married (spouse may be separated for other reasons, such as SEH/1 hospitalization, military service, etc.) Divorced or separated (intentionally) 2. Widowed 3. Never married 4. 8a. IS THERE ANY LANGUAGE OTHER THAN ENGLISH WHICH YOU SPEAK (CAN SPEAK) EASILY) WITH FRIENDS AND/OR RELATIVES? 1. No - speaks English only D/4a 2. Yes (specify language(s)) 8b. (Interviewer - observe, do not ask unless undecided) DO YOU THINK OF YOURSELF AS A BLACK (NEGRO) PERSON OR A WHITE PERSON? 1. Black (Negro) person D/4b • .-2. White person HOW MANY OTHER PEOPLE WILL LIVE WITH YOU WHEN YOU -> 9. LEAVE THE HOSPITAL? WHO WILL LIVE WITH YOU WHEN YOU LEAVE THE HOSPITAL? _ (Table relationship 10. & sex below) 11. HOW OLD ARE THEY? (Table age below) 12. WHO IS THE HEAD OF THE HOUSEHOLD OR FAMILY? (circle number below) 3,13. BEFORE YOU WERE HOSPITALIZED, WHO IN YOUR HOUSEHOLD WORKED FOR MONEY? (Place X in "employed" space below) --- 13a. ARE YOU EMPLOYED FOR MONEY OR PROFIT FROM YOUR WORK (even one hour a month)? (Record answer in row 7 below) . 14. WHICH OF THESE PERSONS WORKS FULL TIME? (Place X in "full time" space below) D/5,6,7,8,9,10 AGE Relationship Employed Full Time MIF To Participant 1. . . . 2. 3. , 4. 5. 6. 7. Self 8. Question skipped by RI

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9.

No codable answer given

However,

15. WHO OWNS THE PLACE WHERE YOU WILL LIVE? 11. No one who lives there - residence is rented from others by self or spouse No one who lives there - residence is rented from others by SEA/2 12. someone else who lives with participant 28. Self or spouse Same as line number 1 page 4 (unless relative 1 31. is spouse) 32. Same as line number 2 page 4 33. Same as line number 3 page 4 34. Same as line number 4 page 4 35. Same as line number 5 page 4 36. Same as line number 6 page 4 99. No codable answer given • • DO YOU (OR YOUR SPOUSE) OWN ANY RESIDENCES OR PROPERTY OTHER THAN THE 16. PLACE YOU WILL LIVE IN? 1. At least 1 other residence I (we) have lived in previously SEA/3 2. At least 1 residence I (we) have never lived in 3. Other types of property No other property is owned by the participant (or spouse) No property is owned by the participant (or spouse) 4. · 5. No codable answer given 9. 20. HAS YOUR HEALTH BEEN A WORRY FOR YOU DURING THE PAST TWO WEEKS? 1. No - unqualified CH/1 2. Any answer which indicates some worry 9. No codable answer HOW MANY DAYS HAVE YOU BEEN IN THIS PLACE (hospital)? 21. M/1 (Number of days) (Ask only inpatients who have been in the hospital less than 14 days) 22. HOW MANY DAYS DID YOU STAY IN BED ALL OR MOST OF THE DAY, JUST PRIOR TO M/2 BEING ADMITTED TO THIS PLACE (hospital)? (Number of days) ÷...

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- 24. WOULD YOU SAY THAT DURING THE PAST TWO WEEKS YOU WERE ABLE TO DO MANY THINGS, A FEW THINGS, OR NOTHING, WITH YOUR HUSBAND (WIFE)? (Table answer below)
- 25. WOULD YOU SAY THAT DURING THE PAST TWO WEEKS YOU WERE ABLE TO DO MANY THINGS, A FEW THINGS, OR NOTHING, WITH YOUR OTHER RELATIVES? (Table answer below)
- 27. WOULD YOU SAY THAT DURING THE PAST TWO WEEKS YOU WERE ABLE TO DO MANY THINGS, A FEW THINGS, OR NOTHING, WITH YOUR FRIENDS?
- 28a. WOULD YOU SAY THAT DURING THE PAST TWO WEEKS YOU WERE ABLE TO NORK <u>FULL TIME, PART TIME, OR NOT AT ALL</u> AT YOUR JOB? (EMPLOYMENT FOR PAY, OR HOUSEWORK, if that is person's occupation). (Table answer below)

SR/1,2,3,4	•	•	(Mention of any	CO T	ntact	, i.e.,	phone	call	or	visit s	hould
			be recorded as	5 "a	few	things")					•

	<u>many</u> things (full time)	<u>a few</u> things (part time)	nothing (not at all)	DOESN'T APPLY I have no such relation	No Codable Answer
Spouse					
Other Relatives					
Friends	•				·.
Work (for pay)			• •	•	
Housework					•

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- 31. IN GENERAL, HOW SATISFIED ARE YOU WITH YOUR PLANS REGARDING YOUR ARRANGE-MENTS FOR HOUSECLEANING, COOKING, LAUNDRY AND SHOPPING, WHEN YOU GO HOME? <u>ARE YOU SATISFIED, PARTLY SATISFIED, OR DISSATISFIED</u>? (Be sure to read the <u>choices</u> to the respondent)
- CM/2

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- 1. Satisfied (include "I have to be satisfied")
- 2. Partly satisfied
- 3. Dissatisfied
- 9. No codable answer given

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38. WHO COULD YOU TURN TO FOR HELP IN AN EMERGENCY? DO YOU HAVE SOMEBODY'S NAME AND TELEPHONE NUMBER BY YOUR TELEPHONE (OR IN YOUR PURSE OR WALLET?) WHO IS THAT PERSON? (Probe: IS THERE ANYONE ELSE? - IS THERE ANYONE IN MICHIGAN?) (If more than one, record for "the one you'd call first")

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G/3 (Name)		(Relation)	
	•	• .	• `.
(Street & Number)	(City) -	(Phone)

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44. ARE YOU MANAGING MOST OF YOUR PERSONAL CARE BY YOURSELF? LET'S THINK OF SOME SPECIFIC THINGS. FOR INSTANCE, DOES ANYONE HELP YOU TO GET IN AND OUT OF THE ADL/1 BATHTUB OR SHOWER? (In the past two weeks) (Probe: HOW DO YOU BATHE? IN A SHOWER? TUB? OR SPONGE BATH? DOES ANYONE

HELP YOU BATHE? IF yes - DO YOU GET HELP WITH ONLY A SINGLE PART, OR MORE THAN THAT? DOES ANYONE GO WITH YOU TO YOUR BATH? DOES ANYONE BRING YOU YOUR BATH WATER?)

1. Independent

- a. bathes self completely, in shower, tub, or sponge bath.b. gets assistance, support or supervision in bathing a single part (such as back or disabled extremity), or

2. Dependent

- gets assistance, support or supervision in bathing more than one 2. part of the body, or
- gets assistance, support or supervision getting in and out of the tub, or to the bath
- has bath water brought to them C.
- d. does not bathe self
- 7. Refusal
- No codable answer 9.
- 45.

HOW DO YOU MANAGE YOUR DRESSING? (in past two weeks?) (Probe: DOES ANYONE HELP YOU GET YOUR CLOTHING OUT OF CLOSETS AND DRAWERS? ADL/2 DOES ANYONE HELP YOU GET DRESSED? DO YOU GET DRESSED EVERY DAY?)

1. Independent

a. gets. clothes from closets and drawers and

- b. puts on braces every day (if necessary), and
- c. puts on clothes, outer garments, stockings and shoes or slippers,
- and manages all clothing fasteners (except tying shoes, or zipping back zippers which is not necessary for an "independent" code)

2. Dependent

- a. receives assistance or supervision in getting clothing out of closets and drawers or receives assistance or supervision in getting dressed or
- b.
- does not change attire (i.e. remains partly undressed e.g. shoes C.
- off, in bathrobe over pajamas)
- 7. Refusal
- No codable answer 9.

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46. HOW ABOUT TOILETING? (in past two weeks?) (Probe: HOW DO YOU GET TO THE BATHROOM? DOES ANYONE HELP YOU WITH YOUR TOILETING - HELP YOU WITH GETTING ON THE SEAT, WITH ARRANGING YOUR CLOTHING, WITH CLEANING YOURSELF (PRIVATE PARTS). DO YOU EMPTY YOUR OWN BEDPAN (COMMODE)?

1. ADL/3

Independent

a. gets to toilet room, and

b. gets on and off toilet, and

c. arranges clothes; cleans organs of excretion, or

d. may manage own bedpan or commode at night only and empties it

e. note: it is acceptable for P to use mechanical supports such

as cane, crutches, walkers, wheelchairs, etc.

2. Dependent

a. uses bedpan or commode during daytime, or uses either at night, without emptying it, or

receives assistance or supervision in getting to toilet room, or ь.

receives assistance or supervision in getting on and off toilet c. seat, <u>or</u>

d. receives assistance or supervision in arranging clothes, or cleaning organs of excretion

7. Refusal

No codable answer 9.

47. CAN YOU GET IN AND OUT OF BED BY YOURSELF (AND/OR IN AND OUT OF CHAIRS)? (in past two weeks)

(Probe: HOW DO YOU GET OUT OF BED? HOW DO YOU GET OUT OF CHAIRS?)

ADL/4 1. Independent

ΪĆ

a. moves in and out of bed and chairs independently

b. note: may or may not be using mechanical supports such as canes,

- crutches, walkers, wheelchairs, etc.
- 2. Dependent

a. assistance in moving in and out of bed and/or chair or

- b. does not move from bed or chair
- 7. Refusal
- .9. No codable answer

48. DO YOU RECEIVE ANY HELP IN EATING? (in past two weeks)

ADL/5 1. Independent

a. gets food from plate (or its equivalent) into mouth b. note: not necessary that usual implements be used by P

c. note: acceptable to code as 1, independent if the participant 1

receives assistance in preparation of food, such as precutting of meat and buttering of bread.

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2. Dependent

a. assistance given by other in act of feeding or b. does not eat at all - reliant on intravenous feeding

7. Refusal

9. No codable answer ·....

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- 49. DO CERTAIN FOODS SEEM TO GIVE YOU PROBLEMS WITH ELIMINATION? (in past two weeks) DO YOU HAVE ACCIDENTS WITH DIARRHEA? DO YOU LOSE CONTROL OF YOUR BOWELS OR BLADDER: DO YOU HAVE ACCIDENTS?
- 1. Independent ADL/6
 - urination and defecation entirely self-controlled, either a. by internal control or external management such as enemas, suppositories colostomy, bedpan, urinal, etc.
 - 2. Dependent
 - partial or total incontinence in urination or defecation 2. or both <u>or</u>
 - Ь. partial or total assistance or supervision of control by enemas, catheters, or use of urinals and/or bedpans, or colostomy
 - 7. Refusal
 - 9. No codable answer
 - 50. WOULD YOU SAY THAT YOU HAVE BEEN HAPPY OR UNHAPPY DURING THESE PAST TWO WEEKS?
 - 1. Happy
 - Both happy and unhappy 2.
 - 3. Unhappy

CM/3

- No codable answer given 9.
- 51. LET ME READ YOU A LIST OF SOURCES OF INCOME. FROM WHICH OF THESE DID YOU (OR YOUR SPOUSE) RECEIVE YOUR INCOME IN THE LAST SIX MONTHS? (Circle as many codes as apply)
- 1. DURING THE LAST SIX MONTHS DID YOU (OR YOUR SPOUSE) RECEIVE ANY INCOME FROM SALARY, WAGES OR CONTINUESION? (even if only 1 hours SEA/4 (01) work per month) (also payment for any product of the participant's industry which results in a profit)
 - DURING THE LAST SIX MONTHS DID YOU (OR YOUR SPOUSE) RECEIVE ANY (05) 2. INCOME FROM SOCIAL SECURITY PAYMENTS? (Loes not include SSI payments) DURING THE LAST SIX MONTHS DID YOU (OR YOUR SPOUSE) RECEIVE ANY
 - (09) 3. INCOME FROM PUBLIC ASSISTANCE: (Aid to the Aged, Aid for the Blind, Aid for the Disabled, Welfare payments of any kind, including SS: (04) DURING THE LAST SIX MONTHS DID YOU (OR YOUR SPOUSE) RECEIVE ANY
 - INCOME FROM PENSIONS OR RETIREMENT FUNDS? (derived from own or spouse's past employment or savings, such as; veterans' compensations, company pensions, retirement plans)
 - DURING THE LAST SIX MONTHS DID YOU (OR YOUR SPOUSE) RECEIVE ANY INCOME FROM PAID UP ANNUITIES, INSURANCE, INTEREST, DIVIDENDS, RENTALS, ETC? (continuing income from a previous investment) (02)5.
 - DURING THE LAST SIX MONTHS DID YOU (OR YOUR SPOUSE) RECEIVE ANY INCOME FROM WITHDRAWALS FROM SAVINGS, CASHING BONDS, SELLING .(06) 6. THINGS YOU OWN? (one time income from a previous investment) 7. DURING THE LAST SIX MONTHS DID YOU (OR YOUR SPOUSE) RECEIVE ANY (07) INCOME FROM GIFTS FROM CHILDREN, RELATIVES, FRIENDS OR PRIVATE SOCIAL AGENCIES?
 - O. DURING THE LAST SIX MONTHS DID YOU (OR YOUR SPOUSE) RECEIVE ANY (08) INCOME FROM LOANS FROM ANY SOURCE?

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- (90)
- 9. No codable answer 10. No income (70)
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· 52.	IN GENERAL HOW SATISFIED ARE YOU WITH YOUR WAY OF LIFE TODAY? ARE YOU SATISFIED, PARTLY SATISFIED, OR DISSATISFIED? (Be sure to read the
	choices to participant)
CM/4	1. Satisfied 2. Partly satisfied
	3. Dissatisfied 9. No codable answer
53.	WOULD YOU AGREE OR DISAGREE WITH THOSE PEOPLE WHO SAY. "THINGS JUST KEEP
	GETTING WORSE FOR ME AS I GET OLDER"?
CM/5	1. Agree 2. Disagree
	9. No codable answer given
59.	WERE YOU EMPLOYED FOR MONEY OR PROFIT FROM YOUR WORK JUST BEFORE YOU ENTERED THE HOSPITAL? (even 1 hour a month) 1. Yes
SEA/	4 2. No

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- 61. WHAT KIND OF PAID WORK DID YOU DO AT THE HEIGHT OF YOUR WORKING CAREER? (This will probably be the last type of work for both retired and still employed persons) (this is not necessarily the work done for the longest time period. For instance, a woman may have been a housewife for the longest time, but taught school for 5 years. She was a teacher, or a housewife, depending on which job she feels was the height of her career.)
- SEH/2

(Probe: DID YOUR JOB HAVE A NAME? WHAT WAS THE NAME OF YOUR POSITION?)

- 62. WAS THIS JOB WITH GOVERNMENT, PRIVATE BUSINESS, OR WERE YOU SELF-EMPLOYED? (government includes Federal, state, county, and local, as well as public schools, and state universities, or military services) (do not assume farmers are self-employed)
- SEH/3 1. Government
 - 2. Business (private schools and non-profit corporations)
 - 3. Self-employed
 - 9. No codable answer
- 63. DID YOU HAVE A TITLE? WERE YOU ANY KIND OF OFFICER, OFFICIAL, OR PARTNER? (especially important for managers, self-employed, military service, and other governmental employees) (check for skilled, semi-skilled, and unskilled or clerical, if person was ever a <u>foreman</u> or <u>supervisor</u>) (Probe: WERE YOU INVOLVED IN ADMINISTRATION? WERE YOU INVOLVED IN SUPERVISION? IS SO, HOW MANY PEOPLE DID YOU SUPERVISE (HAVE UNDER YOU?)
- SEH/4

(For persons employed in government skip 64, 65, and 66)

64. WHAT WAS THE NAME OF THE ORGANIZATION (COMPANY NAME)?

SEH/5

(Ask items 65 and 66 only for persons who were "self-employed" in 62 or who were officers or held titles in business in 63. Skip items 65 and 66 for all others)

65. WHERE WAS IT LOCATED (CITY AND STATE)?

SEH/6

66. HOW LONG AGO WAS THIS (HEIGHT OF WORKING CAREER)?

SEH/7 (years, approximately)

67. WHAT WAS THE LAST GRADE IN SCHOOL WHICH YOU COMPLETED? (circle grade)

SEH/8

None K'Garten 1 2 3 4 5 6 (Go to bottom of page 16)
 7 8 9 (Go to bottom of page 16)
 10 11 (Go to bottom of page 16)

4. 12 (Ask #68) 9. No codable answer

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68. DID YOU GRADUATE FROM HIGH SCHOOL? 1. yes no (skip 69,70,71, and 72)
 question skipped by RI
 No codable answer SEH/9 69. DID YOU ATTEND COLLEGE? 1. yes 2. no (skip 70,71, and 72) SEH/10 8. question skipped by RI 9. No codable answer 70. WHAT WAS THE LAST YEAR OF COLLEGE (college credit granting institution) YOU COMPLETED? 1. 1 2 3 (skip 71 and 72) SEH/11 2. 4 • : 3. 5 or more 8. question skipped by RI 9. No codable answer 71. DID YOU GRADUATE, WITH A BACHELOR'S DEGREE (OR EQUIVALENT) FROM COLLEGE? 1. yes SEH/12 2. no (skip 72) 8. Question skipped by RI No codable answer 9. . 72. DID YOU COMPLETE AN ADVANCED DEGREE (GRADUATE OR PROFESSIONAL DEGREE)? 1. No-not even a bechelor's degree 2. No=completed a bachelor's degree SEH/13 3. Yes-completed at least 1 graduate or professional degree 8. Question skipped by RI 9. No codable answer (For all men and all women who have never been married) go to page 20, skip pages 17, 18, 19 (pink pages)

(For all women who have or had husbands ask pages 17, 18, 19 (pink pages)

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73. WHAT KIND OF PAID WORK DID YOUR HUSBAND (EX-HUSBAND, LATE HUSBAND) DO AT THE HEIGHT OF HIS WORKING CAREER? (This will probably be the last type of work for both retired and still employed persons) (This is not necessarily the work done for the longest time period. For instance, a man may have been a carpenter for the longest time, but taught school for 5 years. He was a teacher, or a carpenter, depending on which job . . . his wife feels was the height of his working career.) FSEH/1 (Probe: DID HIS JOB HAVE A NAME? WHAT WAS THE NAME OF HIS POSITION?) 74. WAS THIS JOB WITH GOVERNMENT, PRIVATE BUSINESS, OR WAS HE SELF-EMPLOYED? (government includes Federal, state, county, and local, as well as public schools and state universities, or military services) (do not assume farmers are self-employed) FSEH/2 1.2. Government Business (private:schools & non-profit corporation) Self-employed · 3. Question skipped by RI 8. 9: No codable answer 75. DID HE HAVE A TITLE? WAS HE ANY KIND OF OFFICER, OFFICIAL OR PARTNER? (especially important for managers, self-employed, military service, and other governmental employees) (check for skilled, semi-skilled, and unskilled or clerical, if person was ever a foreman or supervisor) (Probe: WAS HE INVOLVED IN ADMINISTRATION? WAS HE INVOLVED IN SUPERVISION? IF SO, HOW MANY PEOPLE DID HE SUPERVISE (HAVE UNDER HIM)? FSEH/3 (For persons employed in government skip 76,77, and 78) 76. WHAT WAS THE NAME OF THE ORGANIZATION (COMPANY NAME)? FSEH/4 (Ask items 77 and 78 only for persons who were "self-employed" in 74 or who were officers or held titles in business in 75. Skip items 77 and 78 for all others) 77. WHERE WAS IT LOCATED (CITY OR STATE)? FSEH/5 78. HOW LONG AGO WAS THIS (HEIGHT OF WORKING CAREER)? FSEH/6 (years, approximately) 17

WHAT WAS THE LAST GRADE IN SCHOOL WHICH YOUR HUSBAND COMPLETED? (circle grade) 79. 1. None K'garten. 1 2 3 4 5 6 (Go to top of page 19) FSEH/7 2. 7 8 9 (Go to top of page 19) 3. 10 11 (Go to top of page 19) 4. 12 8. Question skipped by RI 9. No codable answer given 80. DID HE GRADUATE FROM HIGH SCHOOL? yes 1. FSEH/8 2. no (Go to top of page 19) Question skipped by RI 8. 9. No codable answer given 81. DID HE ATTEND COLLEGE? Yes 1. FSEH/9 2. No (Go to top of page 19) 8. Question skipped by RI 9. No codable answer given 82. WHAT WAS THE LAST YEAR OF COLLEGE (college credit granting institution) HE COMPLETED? FSEH/10 1. 1 2 3 (Go to top of page 19) 2. 4 3. 5 or more (ask 84) Question skipped by RI 8. 9. No codable answer given DID HE GRADUATE, WITH A BACHELOR'S DEGREE (OR EQUIVALENT) FROM COLLEGE? 83. 1. yes no (Go to top of page 19) 2. FSEH/11 8. Question skipped by RI 9. No codable answer given 84. DID HE COMPLETE AN ADVANCED DEGREE (GRADUATE OR PROFESSIONAL DEGREE)? 1. No - not even a bachelor's degree 2. No - completed a bachelor's degree FSEH/12 3. Yes - completed a least 1 graduate or professional degree Question skipped by RI 8. No codable answer given 9.

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(Ask the four remaining items only of women who are divorced or widowed now and who have defined themselves as having had a work life. See Page 15, #61) All others go to top of page 20.)

THE WORK YOU MENTIONED WHICH YOU DID YOURSELF - WAS IT DONE ONLY WHILE 85. YOU WERE STILL MARRIED, OR ONLY AFTER YOU WERE WIDOWED (DIVORCED OR SEPARATED)?

FSEH/13

- 1. Work done <u>only</u> while she was still married (Go to top of page 20) 2. Work done both while married and when no longer married

 - Work done <u>only</u> after end of marriage (skip to 87)
 Work done <u>only before</u> marriage (Go to top of page 20)
 Work done both before and after marriage, but not during marriage (skip to 87). Question skipped by RI
 - 8.
 - No codable answer given 9.
 - DID YOU KEEP RIGHT ON WORKING AFTER YOUR MARRIAGE, OR DID YOU START TO 86. WORK AGAIN SOMETIME AFTER YOUR MARRIAGE?

FSEH/14

1. Worked straight through between marriage and no-marriage (go to 88)

- 2. Started to work again after marriage
- 8. Question skipped by RI
- 9. No codable answer given

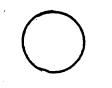
HOW MANY YEARS AFTER THE END OF YOUR MARRIAGE DID YOU START TO WORK (AGAIN)? 87.

- FSEH/15
- 1. Less than one year
- One year to less than five years 2.
- 3. Five years to less than ten years
- 4. Ten years or more
- Question skipped by RI 8.
- 9. No codable answer given

HOW MANY YEARS WERE YOU WORKING AFTER YOU WERE NO LONGER MARRIED? (altogether) 88.

FSEH/16

- 1. Less than one year
- One year to less than five years 2.
- 3. Five years to less than ten years .
- 4. Ten years or more
- Question skipped by RI 8.
- 9. No codable answer given



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(Ask items 89-98 before starting this page. Record answers for this page on table, page 21.)

NOW THIS IS A SOMEWHAT DIFFERENT THING I'M GOING TO HAVE YOU DO

(For participant who appears mentally alert, and physically able) I'M GOING TO ASK YOU TO GO THROUGH THE PAGES OF THIS BOOKLET AND MARK THE CORRECT CHOICES ON THIS SHEET. (DON'T PAY ANY ATTENTION TO THE PAPER CLIPS) (You may help participant by turning the pages.)

20

(For participant who appears mentally alera but physically unable or unwilling to write) I'M GOING TO ASK YOU TO GO THROUGH THE PAGES OF THIS BOOKLET AND TELL ME THE CORRECT CHOICE FOR EACH PAGE. (DON'T PAY ANY ATTENTION TO THE PAPER CLIPS) (You must have them tell you the number of the problem before each answer choice, or you must visually verify that they are at the right page of the book. They may turn two pages at once. If this happens early in the test, all their answers will be in error. If they come out with one more or less answer than there are answer spaces, try again.)

•

(For all other participants) I'M GOING TO ASK YOU TO LOOK AT EACH OF THE PICTURES I SHOW YOU, AND DECIDE WHICH OF THE PIECES COMPLETES THE PICTURE.

STANDARD DIRECTIONS FOR PICTURE AT

LOOK HERE (Point finger at edge of upper picture) THIS IS A PICTURE OF A PATTERN (DESIGN) WITH A PIECE CUT OUT OF IT. EACH OF THESE PIECES (Point to each of the six pieces in turn) IS THE RIGHT SHAPE TO FIT THE SPACE. (Use finger to go around the outline of figure 2., the plain green piece. Then put your finger inside of the missing space in the upper figure) ONLY ONE OF THESE PIECES IS THE RIGHT PATTERN (DESIGN) TO MAKE THE PICTURE COMPLETE. POINT TO THE ONE PIECE WHICH IS RIGHT (TELL ME WHICH ONE PIECE IS RIGHT). TAKE AS MUCH TIME TO DECIDE AS YOU NEED. BE CAREFUL, LOOK AT EACH PIECE. BEFORE YOU DECIDE. YOU MAY CHANGE YOUR MIND IF YOU FEEL YOU NEED TO.

After each choice is made, accept the choice with approval, such as an up and down nod of the head, or OKAY/ ALL RIGHT/ FINE/ GO ON/ GO RIGHT AHEAD/ GOOD/ UH HUH/ YES/ I'VE GOT THAT ANSHER, etc. Record the number of each answer in the recording space. If you think an answer is wrong, give no hint of this to the participant. Keep moving right along. <u>Do not give a</u> <u>positive response to a participant who fails to respond with a definite</u> <u>choice. Probe: YOU MUST CHOOSE ONLY ONE. REHEHBER, ONLY ONE IS RIGHT. WHICH ONE OF THE PIECES COMPLETES THE PICTURE? POINT TO THE ONE PIECE WHICH CAME OUT OF THIS PICTURE (PATTERN). TAKE AS MUCH TIME AS YOU NEED, BUT BE SURE TO CHOOSE JUST ONE OF THE PIECES.)</u>

STANDARD DIRECTIONS FOR PICTURE AD

IT'S ALL RIGHT TO TAKE AS MUCH TIME AS YOU NEED. BE SURE TO LOOK AT THE PICTURE OF THE PATTERN (DESIGN). MAKE CERTAIN YOU LOOK AT ALL SIX PIECES BEFORE YOU MAKE YOUR CHOICE.

STANDARD DIRECTIONS FOR PICTURE BI

REMEMBER TO LOOK AT THE PICTURE TO SEE WHAT PART OF THE DESIGN IS MISSING. THEN LOOK AT EACH PIECE TO SEE WHICH ONE CAME OUT OF THIS PICTURE. TAKE AS MUCH TIME AS YOU NEED.

THAT NEARLY COMPLETES THE INTERVIEW. THERE ARE JUST A FEW MORE QUESTIONS I MUST ASK YOU. MSQ/1 89. WHAT IS THE DATE TODAY? ____ (Ask only if not given in answer to "89" above) WHAT MSQ/2 90. MONTH IS IT NOW? MSQ/3 91. WHAT YEAR IS IT NOW? : MSQ/4 92. HOW OLD ARE YOU? MSO/5 93. WHAT MONTH WERE YOU BORN? MSO/6 94. WHAT YEAR WERE YOU BORN? WHAT IS THE NAME OF THIS PLACE? (Probe: WHAT DO YOU CALL MSQ/7 95. THIS PLACE?) (Write out name of hospital.) WHERE IS IT LOCATED? (Write out city, street or address MSQ/8 96. given.) WHO IS PRESIDENT OF THE UNITED STATES? MSQ/9 97. MSO/10 98. WHO WAS PRESIDENT BEFORE HIM? • •

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•	م معرف م معرف م	B5 -			. · Ab5		5
 	•	B7	•		Ab7		7
	•	<u>B9</u>			ÅЪ9		19
•••••	•	811			A911		

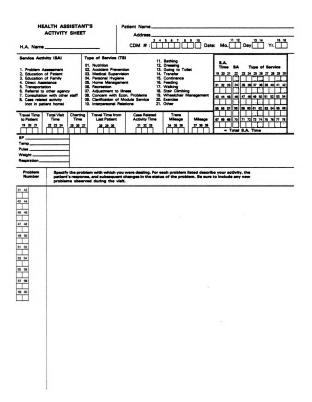
THANK YOU VERY MUCH FOR YOUR TIME. I'LL BE BACK TO SEE YOU AND TALK TO YOU AGAIN. GOOD-BYE FOR NOW.

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(If possible, check over interview for completeness before leaving.)

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