# An Epidemiologic Study of Amputees in the East Harlem Community

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M ASS screening for one or a number of diseases is classic public health methodology. The effectiveness of screening programs depends on several factors; notably, their success in reaching high-risk groups, the extent to which the diseases identified are subject to therapeutic attack, and the availability and accessibility of followup care. To

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the extent that mass screening or any like programs fulfill these criteria, they perform a valuable health service within a community; that is, they have the potential of leading to reductions in morbidity, mortality, or disability.

The problem often is, however, that existing programs for one reason or another are weak, especially in reaching the desired population and in the area of followup care. The question arises as to whether there is any way of using the valuable experience of traditional public health methodology to reach the community with an approach that would be more responsive to its health needs and more effective in meeting these needs.

To that end we proposed and executed a pilot study that was based on the resolve of the department of community medicine, Mount Sinai School of Medicine, "to identify and solve health problems in the community." We decided to select a disease that was easily identifiable by the general population and for which there was a relatively simple and highly visible solution. The approach was to be one of search and service, with a view to developing a network of indigenous epidemiologic intelligence within a given community; namely, East Harlem.

Amputation of an extremity was selected as the most recognizable disease entity for which followup services are accessible, available, and effective. In this study an amputee is defined as a person lacking part or all of one or more extremities.

#### **Objective and Method**

The project had the following objectives:

1. To identify all amputees in the East Harlem community and to review their medical and socioeconomic characteristics

2. To assess the current need

of the East Harlem amputees for rehabilitation services, and to evaluate the quantity, quality, and accessibility of these services within the community

3. To make appropriate referrals to treatment agencies. (No referrals were necessary.)

4. To determine, as far as possible, the viability of a searchand-service approach in raising the health level of a community.

These objectives were approached through an investigation of the formal medical care system for the management of amputees in the East Harlem community and the development of new channels for gathering data on amputees in the community.

## Hospital-Based Data Search

Lacking a central registry for amputees, we began our search for data at the three major hospitals in East Harlem. One was a public hospital and the other two were voluntary nonprofit organizations. Our staff pursued multiple sources of information on patients in gathering the data, including interviews with chiefs of the rehabilitation services. physiatrists, occupational and physical therapists, ward clerks, secretaries, and social workers. They also exhaustively searched hospital medical records.

In all the institutional records from which we located our study population there was a marked absence of integrated data and no easily accessible condensation of information. In one institution, for instance, we found it necessary to examine five sources of data for each amputee. Our staff was astonished by the number of simple discrepancies in objective information, such as age, address, and marital status, in the same record. Our field notes indicate that it once took 27 minutes

to resolve the age of a patient. While hospital personnel were scrupulous about dating major entries concerning patients, this practice was not followed in everyday transactions with the patients.

Further, we were looking for many variables that we thought -though important to record for any patient regardless of his major presenting problemwould be particularly significant for the amputee. Examination of the tables clearly demonstrates that this information was not as readily available as we had anticipated. For example, emphasis on the patient's need to understand his illness and to comply with instructions seemed particularly important for an amputee. We would have expected information on educational background and linguistic ability to be readily accessible. Similarly, an indication of marital status, often lacking, seemed important since problems of the amputee are compounded if he lives alone. Information about economic status and transportation to the hospital was not reported consistently at any of the hospitals. The patient's response to his prosthesis might be indicated in a number of places or might be missing. And the staff quickly discovered that service personnel having day-to-day contact with the amputees carried in their heads many vital observations that never were recorded.

The absence of specific information that is desirable in the history of a patient's amputation was even more striking. In many instances our staff could not find the date of the amputation. In addition, the records often failed to indicate whether the hospital providing rehabilitative services also performed the amputationan omission that made it difficult to assess continuity of care. The staff also encountered many problems in attempting to determine the patient's prosthesis status. We were unable to trace this variable to completion in a surprisingly large number of cases. It became increasingly clear that "rehabilitation records" in all three major hospitals were inadequate as sources for obtaining a composite of the amputee's health status or for developing any reasonable perspective about the sequence of medical events in the life of the amputee. If the patient had more than one amputation, the difficulties naturally were compounded.

### **Clinic Services Available**

Within East Harlem were three certified clinics where patients could receive followup care after an amputation, as well as auxiliary clinics for patients requiring additional medical services. While adequate facilities were available, the quality of service differed to some extent with the institution. For example, two amputee clinics concentrated specifically on the state of the amputated stump and progress of rehabilitation. The third clinic also inquired about associated illnesses, the patient's current socioeconomic problems, and, to some extent, the patient's psychological state.

The clinics also differed in degree of intimacy, friendliness, and sensitivity to the patients. Some patients expressed a real distaste for these sessions, and concern for maintaining the patient's dignity before others varied with the clinic.

### **Profile of Amputee Population**

In our initial search, we found 127 amputees living in East Harlem with fairly even geographic distribution throughout the East Harlem Health District. Of the 127 persons, we found 125 through the amputee clinics of three hospitals. The other two amputees were contacted on the street by members of the research team. These two persons pointed up the basis for a search-andservice concept. Neither one wore a prosthesis nor was receiving medical care related to his amputation.

Age and sex. The age-sex breakdown revealed a pattern not dissimilar to that seen by other investigators. A survey by Glattly (1) of amputations of any extremity due to any cause revealed that about 40 percent of the patients were 61 years of age or older at the time of the amputation. Vitale (2), reporting on figures of the British Ministry, stated that 59 percent of primary amputees were over 60 years of age at amputation, the pathology in most cases being diabetic or arteriosclerotic gangrene. Hansson (3), looking only at the lower extremity amputations, found in his largest series that 82 percent of the amputees had amputations at ages over 60.

Of the 127 amputees identified by our search, 63 were males. The age breakdown for the East Harlem population of amputees is presented in table 1. Eliminating the cases in which age of patient could not be determined by reviewing the records, we found that 45 percent of the major amputations occurred among persons over 60 years old at the time of surgery and that

 Table 1.
 Relationship of primary cause and age at amputation among 100 amputees with 121 amputations

Age group of patient (years)	Diabetic gangrene	Trauma	Other causes <sup>1</sup>	Total amputations
0–9		5	13	18
10-19		4	1	5
20–29	1	5	2	8
30-39		3	ī	4
40-49	2	5	4	11
50_59	11	ĩ	ġ	21
60_69	24	ó	Ś	29
70_79	18	ŏ	š	23
80–89	1	ĭ		2
- Total	57	24	40	121

<sup>1</sup> Other causes include congenital, tumor, infarction, arteriosclerosis without diabetes, and disease entities not included under diabetic gangrene or trauma.

 
 Table 2. Relationship between sex and primary diagnosis among 127 amputees

Cause	Male	Female	Total	Percent
Congenital Tumor Trauma Diabetes Other diseases <sup>1</sup> Unknown	6 2 21 29 17 5	4 4 5 24 8 2	10 6 26 53 25 7	8 5 20 42 19 6
– Total	80	47	127	100

<sup>1</sup> Other diseases include infection, arteriosclerosis without diabetes, and diseas entities not included under diabetic gangrene or trauma.

most of the elderly were diabetics. The largest number of amputations occurred among the age groups 60 to 69 and 70 to 79.

Sex and primary diagnosis. The relationship between sex and primary diagnosis for 127 patients is shown in table 2.

Our data indicate only five clearly recorded cases of arteriosclerosis without diabetes. The overwhelming preponderance of diabetes in the arteriosclerotic population is greater than any reported in the literature and is not readily explained.

Diagnosis and number of amputations. Distribution of patients according to diagnosis, with number of amputations per patient, is shown in table 3. Second amputations occurred often in patients with diabetes but seldom in those with trauma or tumors.

Site of amputations. We were also interested in the number of amputations above and below the knee, as it is much easier to rehabilitate a patient with an amputation below the knee than with one above the knee. We also studied the amputees according to diagnosis, hospital, and site of amputation (table 4). For this analysis we combined unilateral and bilateral amputees according to level of amputation. The "other" category refers to operations that could not be placed simply according to the sites listed.

In all diagnostic categories, patients known to hospital A had more amputations above the knee, while those known to hospitals B and C had more amputations below the knee. Patients at a specified hospital did not necessarily have their operations at that hospital, but for the 58 patients for whom the hospital of amputation was known, the same differences were found. Hospital A mainly did amputations above the knee, and the other two, mainly amputations below the knee. No change in this pattern has occurred in recent years.

Prosthesis and source of information. Comparisons of the three hospitals and the amputee's prosthesis status are shown in table 5. Ten of 11 patients in our study for whom prosthesis was not suggested because of concurrent illness and mental status were in hospital A.

In addition to the data we presented in tables 1 through 5, we determined from the records that 54 of the patients had associated diseases. We hypothesized that some of the remaining 73 patients had associated illnesses that were not recorded.

#### **Community-Based Search**

Having categorized the known amputee population, the staff directed its efforts to the search for amputees not found within the formal health system. For this phase of our project, we contacted community agencies and received assistance from church organizations, block associations, public health nurses, and welfare similar services. and These channels did not reveal a significant number of additional amputees. Some agencies where amputees were known did not provide enough information to pinpoint where the person lived.

A more profitable approach was the development of a questionnaire. Each of 1,500 randomly selected families was given a questionnaire with a returnaddress envelope. They were asked to list all names of known amputees living in their building or immediate neighborhood. Nine questionnaires were returned to us, four from amputees and five from nonamputees. The staff subsequently visited the homes of these nine persons.

Major pathological needs, both medical and social, had prompted the families of the five nonamputees to reach for help by way of our questionnaire. All five were Puerto Rican, and four of the five families had serious problems communicating in English.

Four amputees responded specifically to our offer of evaluation for rehabilitation services. They were all being seen or had been seen in the formal health care system, and their records were among those reviewed in our hospital-based search. There seemed to be questions and concerns that these patients believed

 
 Table 3. Relationship between primary cause and number of amputations among 127 amputees

Primary cause	1 amputation	2 or more amputations	Unknown number	Total
Congenital Tumor Trauma. Diabetes Other disease Unknown	5 5 20 27 13 4	2 1 2 21 7 1	3 0 4 5 5 2	10 6 26 53 25 7
Total	74	34	19	127

 
 Table 4.
 Relationship between source of data and site of amputation for 127 amputees

Cause and site of	Hospital source			Street	Total
amputation	Α	В	С	- contact	amputees
Diabetic gangrene:	25	16	11	1	53
Above knee	15	3	1	0	19
Below knee	8	13	5	0	26
Above elbow	0	0	0	0	0
Below elbow	0	0	0	0	0
Other or not					
applicable	2	0	5	1	8
Trauma	12	7	7	0	26
Above knee	6	i	i	ŏ	-Ř
Below knee	š	i	5	ŏ	ğ
Above elbow	ō	3	ŏ	ŏ	Ĵ.
Below elbow	Ĩ	Ĩ	ŏ	ŏ	2
Other or not	-	-	•	-	-
applicable	2	1	1	0	4
Other causes	24	14	9	1	48
Above knee	ĩi	3	ź	Ô	16
Below knee	5	ő	3	ĭ	15
Above elbow	ī	ĭ	ŏ	ō	2
Below elbow	3	i	ŏ	ŏ	4
Other or not	-	-	-	•	-
applicable	4	3	4	0	11
All causes	61	37	27	2	127
Above knee	32	7	4	õ	43
Below knee	16	20	13	ĭ	50
Above elbow	ĩ	4	Ő	Ô	5
Below elbow	4	ż	ŏ	ŏ	Ğ
Other or not	•	-	•	•	•
applicable	8	4	10	1	23

were not being handled satisfactorily under their existing source of care. Home visits revealed that three of the four amputees were managing quite well insofar as rehabilitative services were concerned, although each indicated that it would have been extremely helpful if a public health nurse had visited them at home early in their adjustment period.

The fourth amputee was a patient who badly needed services and was caught by problems of the medical care system that were beyond her control. She was a 40-year-old Negro with bilateral above-the-knee prostheses, who had been followed for many years by the staff of one of the three hospitals from which our original data were obtained. The patient was pleased with the care she had received at this hospital and had answered our questionnaire because she wanted someone to help her go back there. As a recipient of public assistance, she was one of a group whose medical care had been switched from the hospital of her choice to a group insurance practice closer to her home but which did not offer rehabilitative services. While the hospital's social service department was negotiating to return the patient to her original clinic, her stump became discolored, and one of her prostheses badly needed readjustment. This woman was anxious to work, but she was immobilized while the red tape was being unwound.

#### **Conclusions-Recommendations**

The amputees that we found in this study did not represent the total number of amputees living in East Harlem. The primary source of our data came from approved amputee centers

Table 5.	Relationship between source of data and status
	of prosthesis among 127 amputees

Prosthesis status —	Hospital source			Street	<b>T</b> - 4 - 1
	Α	В	С	- contact	Totai
Suggested and issued Suggested and not	37	28	24		89
issued	2	2	0		4
Not suggested	10	1	0		11
Not applicable	12	6	3	2	23
 Total	61	37	27	2	127

within this district; however, many other amputee centers were located throughout the metropolitan area of New York that East Harlem residents could attend.

We were not able to obtain data from the Veterans Administration hospitals about East Harlem residents who might have had amputations and aftercare in such institutions. In addition, our community-based search indicated that, in the perspective of the total community, amputeeism was not considered a priority problem. Thus it was difficult to generate enthusiasm among community agencies in tracking down cases that might exist and yet be unknown to any of the three hospital sources.

We concluded that the existing facilities, though varying somewhat in quality, were accessible, adequate in number to meet the demand, and potentially able to provide valuable ongoing services to East Harlem amputees. The problems seemed to lie in two major areas: recordkeeping, which directly affects many aspects of delivering service, and followup or ongoing aftercare.

Record keeping in all the hospitals was generally unsatisfactory. The primary source of data on amputees was kept in the physical medicine departments of the hospitals. In many instances

the data were neither accurate nor reliable and frequently lacked medical, social, and personal information. In addition, even where more complete information existed it was kept in multiscattered, uncoordinated, ple, and fragmented records throughout the hospital and the community. Under this system of recordkeeping it was virtually impossible for those caring for the amputee to have an accurate profile of the patient's total health status.

One method of resolving this problem would be a central registry that would identify all amputees in the metropolitan area and give their current status and prognosis for total rehabilitation. Another valuable aid would be data-processed information, which could be gathered from widely scattered locations and made available faster in a standardized format. Much study needs to be done in the development of guidelines that could be used consistently by agencies now providing services to amputees.

In implementing our searchand-service concept, we found few patients who had not benefited from some form of prosthesis. Most amputees contacted were known to the rehabilitation services, and many were still under care. In addition, most patients expressed satisfaction with the care they had received or were receiving, despite our observation that there were many unsolved problems with the prostheses and few patients for whom maximum rehabilitation had been approximated.

From our contacts we concluded that the chronic social, environmental, and financial deprivation experienced by these patients had created a lifestyle of resignation about most serious problems. This lifestyle seemed to have a definite impact on the attitudes of these people toward rehabilitation, and many of them lacked the motivation to improve their rehabilitation status, even when it was eminently possible. The fact that they, as a group, responded positively and with satisfaction to even minimal rehabilitation service seems to advocate further search and service to deal with some of their problems and encourage a more vigorous approach to maximum rehabilitation. This concept could include the development of outreach techniques by the existing clinics offering service.

We believe that the weakest link in the chain of assistance to amputees was in followup and ongoing care. Infrequent visits to a clinic cannot cover the range of daily difficulties an amputee may face immediately after the amputation. Visits to an amputee clinic may be as much as 6 months apart, and the problems of home management in the interim often go unchecked and result in aggravating the patient's health status.

In the fairly heterogeneous population of amputees that we found, the elderly diabetic person was predominant; and in our contacts with these amputees, the problems of the diabetic, particularly, were underscored. The level of ignorance about diabetes and the necessity for proper foot care was astonishingly low, even among people who had gone through the ordeal of at least one amputation. Several did not know they had diabetes until they needed an amputation. In the perspective of his home, the diabetic amputee is followed by care from a physical medicine department, a clinic for diabetics, and often an eye clinic when indicated. Frequently, each service is maintained by a different institution, and the fragmentation of care results not only in a confused medical picture but in an equally confused patient.

Many amputees complained that their prosthesis was too heavy and that it was an added burden to them when maneuvering at home. In discussions, the prosthetists indicated that a prosthesis is of minimal weight and that its weight cannot be reduced without adversely affecting the balance of the wearer. This information apparently has not been understood by most patients, who have considered this weight problem as the most significant one in handling the prosthesis.

The research staff recommended that much greater emphasis was needed on education and orientation of the patient to problems that could be anticipated before he returned home. In addition, it seems that more collaboration between institutions and community services, especially the services of the public health nurses, might be a productive and valuable way to improve service to the patient. This effort would not only ease the early phase of his adjustment at home but would alert and sensitize those providing care to the many problems a patient faces when he is at home in his community.

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Researchers in the department of community medicine at Mount Sinai School of Medicine interviewed staff members and searched the records of three amputee clinics in East Harlem hospitals to seek out a selected population and gain information on the quality of followup care offered to it. Questionnaires also were sent to 1,500 community residents to learn about the existence of amputees in their area. Nine persons responded: four amputees and five nonamputees. Of the 127 amputees found living in East Harlem, 125 were found through the hospital records, including the four amputees who responded to the questionnaire, and two amputees were found through street contact.

Of 121 amputations among 100 amputees, 54, or 45 percent, were in persons over 60 years of age, 43 were the result of diabetic gangrene, one of trauma, and 10 of other causes.

Among the 127 amputees, 80 amputations were in males and 47 in females; 74 of the 127 had one amputation, and 34 had two or more. The number of amputations among 19 other amputees could not be determined from the records.

For the 125 amputees treated at the three East Harlem hospitals, prostheses were suggested and issued to 89, suggested and not issued to four, and not suggested to 11 others. Prosthesis status was not applicable in 21 other cases. Existing facilities, though varying somewhat in quality of care, were accessible, adequate in number to meet the demands of the amputees, and potentially able to provide ongoing service.

Problems encountered in the search for this population were inadequate recordkeeping, little knowledge on the part of the diabetic amputees of the care required for diabetes, and lack of coordinated followup care of amputees by all agencies.

A central registry of amputees was recommended, along with much greater education and orientation of the patient as to problems that might be encountered after he returned home. In addition, a more collaborative relationship between institutions and community services, especially public health nurses, was thought to be a productive and valuable way to improve service to the patient.