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REHABILITATION IN PRACTICE

A picture of amputees and the prosthetic situation in Haiti

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Abstract

Purpose: The purpose of this study is to present the situation of Haitian amputees and to outline some of the major barriers in Haiti that prevent people from receiving prosthetic treatment.
Method: Interviews were conducted with amputees throughout Haiti using a 42-question questionnaire. Additionally, interviews were conducted with traditional healers, health care workers, and leaders of handicap associations. Each interview was manuscripted and the data were subsequently coded and analysed in the USA.
Results: There are three full-time prosthetic shops and two part-time prosthetic shops in Haiti, all of which are severely limited in the scope of services they are able to provide amputees due to insufficient supplies and inadequately trained personnel. Only 25% of the 164 amputees interviewed had ever had a prosthetic limb. Typically prosthetic treatment is inaccessible and unaffordable for amputees, which prevents many from seeking treatment. The most common cause of amputation in Haiti is infection, followed by motor vehicle accidents.
Conclusion: There must be additional cooperation between Haitian patients, doctors, traditional healers, prosthetists, and government officials in order to provide more adequate prosthetic care. Prosthetic treatment in Haiti can be successful with cooperation of different entities, proper rehabilitation therapy, adequately trained personnel, and development of culturally appropriate limbs.

Introduction and background

In Haiti, there is an alarming rate of disabled citizens with 800 000 of the nearly 8 000 000 people suffering from some type of disability[1], which numbers include a large amount of amputees. There has been no previous study done on amputees in Haiti, thus no statistics are available on amputees countrywide. A study done on amputees in other developing countries[2] approximated that there are 1–2 amputees per 1000 people in the population, which by application, would mean there would be between 8000–16 000 amputees in Haiti alone.

The purpose of this study is to outline the economic and social picture of Haitian amputees and to present the need for more prostheses in Haiti. Currently in Haiti there are only three full-time and two part-time prosthetic organizations, all of which are significantly limited in their efforts by an inadequate supply of medical and prosthetic equipment. Among these organizations, there currently exists little cooperation regarding prosthetic activities. Efforts need to be made to better understand the economic and social situation of amputees in Haiti in order to provide more complete and comprehensive rehabilitative services for the Haitian people.

The Republic of Haiti occupies the western third of the island of Hispaniola, which it shares with the Dominican Republic. Plagued with seemingly incurable political strife, Haiti is the poorest country in the Western Hemisphere.[3] More than one-third of the population live in Haiti's capital Port-au-Prince[1], 70% of the population live in abject poverty[4], and Haiti's medical facilities are scarce and substandard. There are continuous shortages of medical goods and services, especially true outside of Port-au-Prince and other main cities. Malnutrition is extremely widespread and contributes to a high infant mortality rate of 80.3 per 1000 births.[1] A large portion of the population has no access to health facilities and many diseases go untreated. Out of the total population 65% participate in agriculture and commerce, and among those who work, the annual income is less than $225US.[5]

Political unrest in Haiti today is a significant barrier

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for non-governmental organizations, which provide a considerable amount of the health care services in the country. Due to extreme political turmoil and the coup d'état during the early 1990s, the USA and European nations enacted an embargo on Haiti, halting medical supplies to the already struggling country. Even today, it is difficult for foreign funds and donations to clear customs so that they can be put to direct use for the sick and the injured.

Traditional medicine is widely practiced throughout Haiti, including treatment given by herbal healers and vodou practitioners, and many Haitians meet their health care needs through these methods. Barnes-Josiah *et al*.[6] observed that often Haitians delay seeking medical care from western institutions because many have little possibility of reaching an appropriate medical facility, and recognize that they might not receive adequate care when the facility is reached. For many, traditional medicine is the most accessible method of medical care. Regrettably, in the situation of amputees traditional medicine can offer the patient limited solutions. Most amputees in Haiti have little hope of obtaining a prosthetic limb or receiving any type of physical rehabilitation. The availability of these services is scarce and the cost of these services is typically unaffordable.

Methods

The seven-member research team conducted 164 interviews of amputees throughout Haiti, in July 2001, traveling to each of the capitals of the nine departments, including Port-de-Paix, Cap-Haïtien, Fort-Liberté, Gonaïves, Hinche, Port-au-Prince, Jacmel, Les Cayes, and Jérémie. The research was conducted by Healing Hands for Haiti Foundation (HHH), an organization providing rehabilitation and prosthetic treatment in Haiti since 1997.

In cities where HHH had previously provided patients with prosthetics, the respondents for the interviews were found from records of those that had received prosthetics from HHH and also from amputees that were members of the local handicap associations. In those cities where HHH had no contacts, researchers contacted the local hospitals and found people by word of mouth and through radio announcements. Most interviews were conducted in a central location such as a church or other facility, but where circumstances permitted, interviews were conducted at the amputees' homes.

Each interview with the amputees followed a 42-question questionnaire (including additional demographics, see the Appendix) adapted from the questionnaire designed by Matsen[7] and members of the Prosthetics Outreach Foundation. If clarification was needed on any answer, additional follow-up questions were added as appropriate. The researchers conducted the interviews in Haitian Creole.

Additionally, less-structured interviews were conducted with traditional healers, health care workers, and leaders of handicap associations. Interviews with traditional healers (found by word of mouth) were to determine what healers could do for amputees. Interviews with health care workers (found through contacting hospital administrators) and leaders of handicap associations (found through referrals from HHH or by word of mouth) were to determine what types of problems clinics and organizations had in providing health care, especially prosthetic treatment. Because sample sizes of traditional healers, healthcare workers and leaders of handicap associations were small, the data from these interviews are not presented in statistical form, but rather as support for the information gathered from amputees.

Each interview was recorded directly onto a standard data sheet designed by the research team. The data were subsequently coded and analysed upon return to the USA by members of the HHH research team, including the authors of this paper.

Results

In Haiti, there are three permanent prosthetic shops and two part time prosthetic shops, which are all privately owned institutions. The three permanent shops included Saint Vincent's in Port-au-Prince, Hôpital La Providence in Gonaïves, and Canada-'Help the Aged' in Les Cayes. The two part time prosthetic shops (opened periodically when medical teams travel to Haiti from foreign countries) are Kay Kapab (run by HHH) in Port-au-Prince, and Centre de Coeur Eucharistique in Cap-Haïtien. While most of the organizations manufacture the prosthetics they give to patients in Haiti, some of the prosthetics are made in foreign countries. Each organization expressed frustration about having to limit its efforts due to the lack of available resources and personnel, and virtually no help from government officials.

For amputees living in cities where there was no prosthetic treatment, they had to travel long distances in order to receive care (see table 1). In those cities that were isolated from the other departments by geographical barriers (mountains, rivers, the ocean, etc.), prosthetic limbs were virtually not available to any of the amputees; this was reflected by the fact that in some

Table 1 Distances to two nearest prosthetic clinics from different cities

City of departure	*Travel distance (km)*	*Town with prosthetic clinic*
Jérémie	229[a,b]	Port-au-Prince
	67[a,b]	Les Cayes
Jacmel	92	Port-au-Prince
	161	Les Cayes
Hinche	97[a,b]	Port-au-Prince
	92[a,b]	Gonaives
Gonaïves	150[a,b]	Port-au-Prince
	89[a]	Cap-Haïtien
Port-de-Paix	70[a,b]	Gonaives
	159[a,b]	Cap-Haïtien
Fort Liberté	54[a]	Cap-Haïtien
	293[a,b]	Port-au-Prince

[a]Dirt roads
[b]Extremely difficult and time-consuming

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isolated cities no amputees had, or ever had limbs, and in other cities only very few did.

The existing prosthetic clinics were often overwhelmed by the amount of patients needing health care and prosthetic limbs.

Of the 164 people interviewed, 72% ($n = 118$) were male and 28% ($n = 46$) were female, with respondents ranging in age from 5 to 85 years old (parental supervision was used during interviews with amputees under age 18). Out of those interviewed, 53% were unemployed, 11% were students, 10% were farmers, and 10% were involved in commerce. Other occupations were tradesmen, technicians, taxi drivers, teachers, health professionals, etc. Notably, some of the respondents who stated that they had an occupation were unable to currently complete the duties associated with the occupation, so the percentage not working was higher than the number reporting unemployment. When asked about their occupation previous to the time they lost their limb ($n = 101$), only 7% said they were unemployed, 38% were farmers, 21% were tradesman, 9% were involved in commerce, and 8% were students, along with others who were taxi drivers, janitors, teachers, cooks, health professionals, etc.

It was found that the most common cause of amputation was infection (33% of respondents, $n = 162$), followed by motor-vehicle accidents (26%). Other causes given included birth defects, falls, work-related accidents, and complications due to gun wounds, diabetes, and vodou or magic (see table 2).

Most of the amputations (77%) involved the leg and 33% involved the arm. Of these amputations ($n = 159$), 53% were done above the joint (typically the knee or elbow), 42% done below the joint, and 5% were done right at the joint.

Out of the amputees interviewed, 25% had either had a prosthetic limb (or limbs) in the past, or currently had a prosthetic limb; 75% had never had a prosthetic limb. Respondents were asked about the barriers in seeking prosthetic treatment, specifically, why they had waited to obtain a prosthetic limb, or why they had never had a prosthetic limb (see table 3). Of those responding to the question ($n = 78$), primarily those who had received limbs, 26% said they did not wait, but received their limbs as soon as the wounds were healed, 27% waited because of a lack of money, 14% waited because they did not know where they could receive a prosthetic limb, and 22% waited because of a combination of those reasons. Other reasons given for not receiving a prosthetic limb were because of geographical barriers, incompatibility of prosthetic with limb because of poor amputation, and personal preference of not wanting a prosthetic (more common in those missing limbs from congenital defects).

Of those 25% ($n = 57$) who had a limb, 35% were still using it; others had returned their limb to the shop (21%), left it at home and never used it (16%), left it at home and used it periodically (7%), or they had discarded, broken, or lost it. The majority of people who had a prosthetic limb said that they were overall satisfied (33%, $n = 66$) or very satisfied (42%) with their prosthetic treatment. Up to 45% ($n = 66$) had received

Table 2 Cause of amputation

Cause	*Number responding (n = 162)*	*Frequency (%)*
Infection	54	33.3
Car accident	42	25.9
Birth defect	14	8.6
Falls	10	6.2
Other	10	6.2
Work-related	9	5.6
Hit by object	8	4.9
Gun wound	8	4.9
Diabetes	4	2.5
Vodou/magic	3	1.9

Table 3 Barriers to receiving prosthetic treatment

Reason	*Number responding (n = 78)*	*Frequency (%)*
Lack of money	21	26.9
Did not wait	20	25.7
Did not know location	11	14.1
Both did not know location and lack of money	17	21.8
Other	9	

the limb at no cost and the remainder received their limb at a variety of costs, ranging from inexpensive to expensive (meaning exceeding the average yearly income for Haitians).

Discussion

The amputees had lost their limbs from a variety of causes (see table 2), ranging from personal factors (disease, accidents) to social and political factors (poor roads, poor sanitation programmes, political unrest, etc.). Most Haitians do not have access to medical care, either because of distance from the hospital or the inability to pay, and so simple injuries often lead to complications requiring amputation. Several people interviewed explained that their infections began as minor problems (such as stepping on a thorn, small sores, etc.) but because of a lack of proper medical care escalated into serious infections requiring amputation. Many of the people interviewed said they had waited months after infection had begun before they went to seek treatment at a hospital. One man explained that he had a severely infected sore on his leg and because he lived far away from any hospital and did not have any money to pay hospital fees, he had used his own knife to cut away at the infection. His methods were unsuccessful, and when he finally went to the hospital, his infection had grown so serious that amputation was the only solution.

In many situations people turned to traditional healers because they were closer, more affordable, and trusted. Staats[2] suggested that for patients with infections in developing countries, going to a local traditional healer and using indigenous treatments can be a better alternative than not seeking any type of treatment at all. Traditional healers often dress the wounds and take measures that can help impede the progression of the infection. This can make a significant difference for an individual who is kept from travelling to a hospital or clinic because of geographic barriers or a lack of resources.

Haiti has poorly maintained roads that are overcrowded with buses, trucks, cars, and street-vendors, and frequent traffic accidents, often involving pedestrians and street-vendors resulted in injuries requiring amputation. Because of the limited or non-existent medical services, people reported waiting days after an auto accident before they went to the hospital to receive treatment, and explained that when they arrived, the only option the doctors presented was amputation. One woman at the main hospital in Port-au-Prince had been in a *tap-tap* accident (a *tap-tap* is a small truck used as public transportation) and had dislocated her femur, but had waited 6 days before going to the hospital. When she arrived at the hospital, the femur had become infected and the doctors told her they would need to amputate her leg.

Accidents related to poor working conditions were the cause of several amputations. One example, found in various cities, was accidents with a *moulen*, or sugarcane processor, by which several amputees said that they had lost their arms through becoming caught in the machine while they were feeding in the cane. In Petit-Goave, a small city about $1\frac{1}{2}$ hours outside Port-au-Prince, four out of the 12 amputees who were interviewed said they had lost their arms through accidents with *moulens*, and said they knew of others who had suffered similar accidents.

Causes of amputation varied according to geographic location and different social circumstances. For example, among amputees from Cité Soleil, Haiti's poorest slum, several people had lost their limbs from gunshots fired during the *coup d'état*. In contrast, amputees from areas in the mountains or cities were more likely to report infection, falls, and work-related accidents as cause of amputation. Vodou curses were mentioned as the cause for amputation in a few cases, but these cases seemed to be the exceptions.

Having a social network of family and friends was essential for an amputee's survival in Haiti, and amputees without family or friends usually faced more financial problems. Many of the amputees were completely reliant on their family's support for life's basic necessities. Typically, the amputee would help perform small tasks inside the home, like cleaning or preparing food, but they were an economic burden because they could not help provide income.

Being handicapped intensified the difficulty of being able to find a job in Haiti's struggling economy, and many amputees could not find employment. Amputees that were fortunate enough to work had varying positions as cooks, tailors, or roadside merchants, all jobs that did not require much motility. Participating in agriculture, a mainstay of Haitian economy, was very difficult for amputees. Some amputees resorted to begging.

Many amputees found it difficult to find transportation. Drivers of *tap-taps* and buses would not pick up amputees because of time lost waiting for them to board. Most of the amputees without prostheses used crutches (sometimes a single crutch) for motility, but often these were in disrepair. Because of the rough conditions of broken-up roads and mountainous terrain, wheelchairs were generally inefficient and rarely used.

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Many of the amputees said they would like to attend church and other activities, but were restricted by their inability to travel.

In some of the major cities in Haiti there were handicap associations organized by disabled people to help provide support to each other. They desired to facilitate the entrance (or re-entrance) of their disabled members into the workforce, to help them become productive members of society. Leaders of these associations attempted to aid amputees in locating affordable prosthetic care and expressed great frustration in not being able to find the avenues to help their members find treatment.

Most amputees had never had the opportunity to receive a prosthetic limb (see table 3). After amputation, patients were not educated about the process of receiving prostheses and where to go to receive rehabilitative care. For those who did know about prosthetic shops, monetary limitations often prevented payment of even relatively modest fees. Additionally, for amputees travelling long distances for prosthetic treatment (see table 1), costs incurred by travel, food, and lodging made treatment unaffordable, even when the prosthetic was free. Natural geographic boundaries created significant barriers in certain locations, as illustrated in Jérémie, a city isolated from the rest of Haiti by mountains and the ocean, where none of the amputees interviewed had received prosthetic limbs.

Unavailability of prosthetic treatment is partly due to the lack of trained professionals in the field of prostheses, partly due to a lack of supplies, and partly due to a lack of governmental support. Many amputees complained that the doctors who treated them did not amputate the limb in the proper location or did not prevent secondary infection through proper follow-up care. Patients were not taught what to do in preparation for receiving a prosthetic limb, and many who came to the clinics had to be turned away because their limb was not properly healed, was inflexible, or had lost major muscle tone. Follow-up care, for both medical and prosthetic services was made difficult by rough travel conditions, long distances to hospitals, lack of patient education, and overall problems associated with poverty. Those prosthetics shops that were located in the provinces cut down the patients' travel time and facilitated follow-up visits; however, these shops typically addressed only the needs of amputees in their own provinces, and rarely those of surrounding provinces.

Many of the amputees who had received prosthetic limbs said that they were not taught what adjusting to a new limb entailed (i.e. initial discomfort, frustration of trying to learn to use the limb), or if they were, they were not given the proper therapy to help them manage the difficult adjustment. They often expected receiving the limb would be an immediate remedy for recovering to a full functioning capacity. The lack of therapy was discouraging and many amputees discontinued use of the limb within the first few months of wear. These limbs were then left in house corners, shoved under the bed, or returned to the shop, and were never used again.

Many organizations brought used limbs from the USA and other countries, and attempted to recycle the limb for a Haitian amputee. Some amputees were expected to wear prosthetics with parts that were too large, too long, or too small. Those amputees who had significant weight fluctuations (e.g. growing children) since receiving their limbs usually had no adjustments made to their limbs for proper fit and had to discontinue use. Some patients tried home-remedies, such as stuffing multiple pieces of material into the socket, using safety pins, and other ineffective devices in order to prevent their limb from slipping around and to attempt to rectify the problems.

The cosmetic appearance of the limb was often a primary concern for amputees. A few of the patients interviewed had prosthetic limbs with skin colours designed to match the skin of Caucasian patients; these patients expressed embarrassment at wearing their limbs in public places, and said they would only wear the limb when it was a necessity for function. Some amputees were given limbs that functioned well, but did not cosmetically resemble a human leg (e.g. appeared like a titanium bar), and these patients expressed serious discontent and embarrassment when wearing their limbs in public.

Local environmental conditions should have an influence on the design and materials used by prosthetic agencies.[8, 9] Haiti's broken roads and tropical climate wore significantly on limbs, and in some conditions, made it impossible to use the limb effectively. Patients complained of their limbs being too heavy for use in rough walking conditions, and the foam feet on many of the prosthetics were deteriorating and could not fit properly into shoes. Most people interviewed had some type of broken component on their limb, and did not have the money needed for the repair. Additionally, all of Haiti's five prosthetic shops were understaffed and experienced a continual shortage of supplies, so often the repairs that were performed were insufficient. Some limbs were, as Meanley[8] discussed, '... so complex that they require[d] considerable maintenance and [were] totally unsuited to patients who live[d] any distance from a prosthetics facility'.

There were many cases of successful prosthetic treatment, where the amputees complained of minimal

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problems and wore their prosthetic continually, but the majority of the amputees complained of not being able to use their prosthetic effectively because of multiple problems.

Conclusion

As with other developing countries, the situation of amputees in Haiti with regard to the hope for successful prosthetic treatment and rehabilitation is greatly hindered by a number of economic problems, including limited amounts of resources involving supplies and personnel. The existing prosthetic agencies within Haiti need to combine resources and personnel in order to ensure that Haitians throughout the country, and not just those in larger cities, have access to prosthetic treatment and recuperation from their disabilities.

A directed effort focusing on the education of patients and doctors as to the proper treatment of infections (the most common cause of amputation) and other mishaps that lead to amputation could help people avoid the loss of their limb. Such things as proper care of the wound at the time of infection, sterile bandaging and early treatment could help prevent the transformation of minor infections into those serious enough to warrant amputation. Physicians should be instructed to amputate limbs in a manner conducive to the facilitation of a prosthetic limb, should the patient ever have the opportunity to receive one.

Additional effort must be made to take into consideration the needs of individual patients and the capabilities of different clinics, in order to develop prosthetics that are appropriate for Haiti's unique environmental and economic circumstances. Patients undergoing amputations at hospitals should be educated about the different avenues available to them after their surgery. Prosthetic agencies must make efforts to provide their patients with well-rounded treatment, including rehabilitation and instruction on proper prosthetic use, so that the care can be continuous and long lasting.[2, 6, 8, 9–11] Regular follow-up care should be offered to ensure that problems will be fixed and patients will be able to learn to use their limbs correctly. Otherwise, if patients have no way to repair their limbs when components break, then the benefits to the patient are short-lived and inadequate.

Cummings[12] stressed that, in developing countries, limbs should be:

> ... low cost, locally available, capable of manual fabrication, considerate of local climate and working conditions, durable, simple to repair, simple to process using local production capability, reproducible by local personnel, technically functional (not gratuitously high-tech), biomechanically appropriate, as lightweight as possible, adequately cosmetic, and psychosocially acceptable.

He additionally stated that efforts should be made to 'replace a technology which is characterized by high cost and over-sophistication by one which is acceptable in terms of cost-benefit and effectiveness, technical appropriateness and environmental adaptability'. Prosthetists should provide limbs that are repairable through simple equipment and available resources, and also should be trained to fix all types of prosthetic limbs existing in the country, including imported 'high-tech' appliances.

In summary, there must be more cooperation between patients, doctors, traditional healers, prosthetists, and government officials in order to provide more universal prosthetic treatment for the people of Haiti. There must be increased public awareness about the situation of amputees in all areas throughout the country in order to adequately address amputees' needs. As evidenced by the testimony of several of the amputees interviewed during this study, prosthetic treatment in Haiti can be successful with cooperation of different entities, proper rehabilitation therapy, adequately trained personnel, and development of culturally appropriate limbs.

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Appendix

QUESTIONNAIRE FOR AMPUTEES

Demographics: Name, date, location of Interview, city, religion, birth date, gender, occupation, marital status.

Were you married before the amputation? Do you have children? How many?

How many gourdes (Haitian money, 25 gourdes = 1 USD) do you spend a day? Per week?

Date of amputation, level of amputation, right or left limb, cause of amputation

1. Who do you depend on for medical care?
2. How do you travel to receive medical care?
3. What type of transportation do you use on a daily basis?
4. Have you had an artificial limb before?
5. If so, where did you obtain it and when?*
6. Where is the prosthesis now?*
7. Were you measured or fitted for your current prosthesis?*
8. How many times did you come back before you got the prosthesis?*
9. At what date did you receive your current prosthesis?*
10. Were you taught how to use the prosthesis?*
11. Have you returned to the prosthetic shop where you received the prosthesis?*
12. How satisfied are you with the appearance of your prosthesis (scale of 1 – 5, with 1 being low).*
13. How much did you pay for your prosthesis?*
14. Is the prosthesis comfortable?*
15. If not, what hurts?*
16. Have any components or the complete prosthetic been replaced?*
17. Do you know how to get it fixed?*
18. Do you know where to get it fixed?*
19. Why did you wait to get an artificial limb?
20. On an average day, how many hours do you wear the prosthesis?*
21. Do you wear it to go to public places (i.e. shopping, family parties, church, or other social gatherings)?*
22. Do you wear it at home?*
23. Do you have trouble with your residual limb? (e.g. phantom pain, pressure sores)
24. How have immediate family members responded to you as an amputee?
25. How have close friends responded to you as an amputee?
26. How have people in social or religious groups responded to you as an amputee?
27. Have you experienced any of the following since your amputation:
    a. loss of job
    b. divorce
    c. being ostracized
    d. not accepted with vodou society
28. What things can you do despite the amputation?
29. What things can't you do because of the amputation of the limb?
30. If currently employed, what are your job requirements?
31. Can you go up and down stairs step over step?*
32. Can you walk uphill and downhill on paved roads?*
33. Can you walk uphill and downhill on rocky roads?*
34. Can you walk while carrying a load? If yes, approximately how much of a load?*
35. Approximately how long can you walk without pain?*
36. Do you have enough prosthetic socks to use a clean one daily?*
37. How many operations have you had on your amputated leg?
38. How do you feel about the results of your surgery?
39. Are you satisfied with the results of your prosthetic treatment?*
40. Do you use any assistance devices to walk such as canes or crutches? Which?
    a. Which did you like?
    b. Which don't you like?
41. Are you more comfortable with or without your prosthesis?*
42. What responsibilities do you have at home?

Additional Comments:

**Only asked of amputees with a current or past prosthesis*

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