An Investigation of the Surgical Referral Process Utilized by Non-Governmental Organizations in Guatemala

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Executive summary

Two principle questions are addressed by this study:

1) What factors do non-governmental organizations (NGOs) identify as facilitators and barriers to quality of surgical care in Guatemala?
2) How can surgical services provided by visiting medical teams be improved in terms of quality of patient experience?

Ten in-depth interviews were conducted with Guatemalan NGOs and data were coded and analysed for frequent themes. Results and analysis sections of the report include: barriers and facilitators to access to surgery, reputations of visiting surgical teams, and ideas for a shared referral system. Issues that arose include the costs associated with surgeries, lengthy and confusing processes for receiving surgeries, and lack of post-surgical follow-up care.

- Current surgical referral processes require up to 50 staff-hours to complete
- Language barriers, racism, ancillary costs, and patriarchal family structures pose critical difficulties for patients needing surgeries
- NGOs had mixed levels of willingness to work with the government health system
- All participating NGOs indicated a desire to collaborate in a shared referral system

The key recommendation arising from the study is the development of a working group or network of NGOs to build collaborations and work toward a shared referral process. Open-access technologies should be considered to facilitate information sharing.

[1] The NAPA-OT Field School is a project of the American Anthropological Association and the U.S. National Association for the Practice of Anthropology. It is a transdisciplinary program, drawing students and faculty from anthropology, occupational therapy, and public health, and is dedicated to the promotion of health and occupation as human rights. For more information, please visit our website (above) or email info@napaotguatemala.org.

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Introduction

Building on widespread acknowledgment that the surgical needs of low-income members of Guatemala's population are not met by the government health system, there is growing recognition that the multiplicity of surgical referral pathways used by non-governmental organizations (NGOs) could be streamlined to better utilize resource inputs. With the support of Wuku' Kawoq and Link for Health, this project was carried out by students from the NAPA-OT Field School during July and August, 2011. The project sought to better understand the current methods that NGOs use to connect patients with surgical services, whether offered by in-country providers or visiting foreign surgical teams. The goal of the project was to identify strengths and weaknesses of current surgical referral procedures and to highlight points-of-entry for collaboration amongst NGOs, potentially leading to a shared referral process. This report is intended as an initial step to prompt further investigation of these possibilities and discussion by NGOs.

Research statement

Two main questions informed this research project. First, *what factors do NGOs identify as facilitators and barriers to quality of surgical care in Guatemala?* Second, *how can surgical services provided by visiting medical teams be improved in terms of quality of patient experience?* In order to address these larger questions, our research also sought to answer the following component questions:

- How does the referral process for surgeries currently take place?
- What populations are currently served by visiting surgical teams? What populations are not?
- What is the context and history of short-term medical teams in Guatemala and how do they interact with NGOs?

Finally, the project aimed to summarize the information gathered and offer feedback and recommendations for an improved coordination of services among NGOs and surgical teams.

Methods

Sampling

Ten semi-structured interviews were held over a 4-week period in July and August of 2011 with representatives from various NGOs in Guatemala. Interviewees were selected through snowball sampling, using Link for Health resources as a starting point for identifying key informants. The sample represents a mix of NGOs who undertake health care provision and surgical referrals as a primary organizational activity and those who only rarely need to refer a client for surgery (Table 1). Each participant was asked about their existing networks and other key players who could also be potential participants in the study for future research.

Table 1: Summary characteristics of study sample (n=10)

	Yes	No	Not Applicable
Health services as a primary activity	7	3	-
Services provided in a Mayan language	6	4	-
Full or partial coverage provided for ancillary surgical costs (e.g. – transportation, lodging, etc.)	6	1	3
Services provided to patients' families (e.g. – funding to accompany to surgery, information on the surgery, etc.)	6	1	3

Procedure

The study team consisted of six members (see Annex 1), all with English as a first language and two fluent in Spanish. Interviews were conducted at the participants' NGOs or the researchers' office. All sessions were audio-taped to ensure accuracy in data transcription.

An interview instrument, consisting of 12 semi-structured interview questions, was developed and translated into English and Spanish (see Annexes 2 and 3). Interviews were conducted in Spanish or English depending on the preference of the interviewee. The interview instrument was piloted with the first interview and feedback was incorporated accordingly. Each interview lasted, on average, between 60 and 90 minutes.

Project team members took electronic notes during interviews and created transcripts of each interview session. For interviews in Spanish, transcripts were translated back to English for analysis. Data was coded and analyzed for common themes, which are reported in the results section of this report.

Ethical Considerations

This research was conducted in compliance with Saint Louis University's Institutional Review Board (IRB) Human Research Application. A full consent form outlining the benefits and risks of participation was read aloud to each person prior to their interview. Each participant was assured of their confidentiality. Each participant gave their verbal consent and a witness signed the consent form. No compensation or further services were offered to participants during this project.

Relevant Literature

It is important to situate this report in terms of other qualitative research that has been completed on NGOs in Guatemala. Green, et al. devised a wide qualitative study of perceptions of short-term medical volunteers in Guatemala (2009). Green, et al. were concerned about the perceptions of short term volunteers on the ground in Guatemala, and interviewed a small sample of key stakeholders, including patients, NGOs, and local community activists (2009).

Abom's (2004), "Social Capital, NGOs, and Development: A Guatemalan Case Study", informed our understanding of the impact pathways of NGO services in Guatemala. Abom's research drew on semi-structured interviews with 42 NGO representatives, community members, and community activists. His goal was to understand the qualities of the relationships between service-providing NGOs and those actors engaging in collective, community action geared toward the development of social capital. This social capital, in turn, would enable people to enact change in Guatemala (2004: 347). Abom identified top-down service delivery and implicit encouragement of dependency on NGO service provision as barriers to the accumulation of social capital by community action groups of Guatemalans trying to enact change within their own communities and the country (2004: 349). Abom explains, "It was expressed that service/welfare programmes contributed to competitiveness and individualism by creating jealousy and conflict among beneficiaries concerning the distribution of benefits" (2004: 350). Although NGOs were successful at building relationships of reciprocity in Abom's study, social capital and trust between NGOs and the beneficiaries of their services were compromised by community politics that sometimes became embedded in NGO service provision through the use of "community leaders" (Abom 2004:350).

Key Terms

A *jornada* is defined as a visiting medical team. When the term *jornada* is used in this report, it refers a visiting medical team that both a) consists of foreign doctors and surgeons from Europe or North America (and potentially translators, anaesthesiologists, nurses and other support staff) and b) is in Guatemala to perform surgeries.

The *surgical referral process* is the steps taken in guiding a patient from the assessment of a condition requiring surgery through the acquisition and completion of surgical care.

Results

Steps Taken in Referrals

Diagnosis and Booking

NGOs represented in our sample have various methods for keeping track of their patients and booking surgical slots. There is no shared, standardized process for booking a patient for surgery; however, some NGOs stated that they know when *jornadas* will be available and use various technologies to organize their patient referrals. For example, some participants reported using a master calendar to keep track of incoming *jornadas* and know when future surgical slots will be available for their patients. Other NGOs stated that they did not know when certain *jornadas* would be available and that this made pre-booking patients difficult.

Study participants who are directly involved with surgical referrals said that they refer people to government hospitals for emergency care, *centros de salud* ("health centers"), other NGOs and, on rare occasions, private specialists for non-emergency care.

Double-diagnosis was raised as a critical issue within the current diagnosis and booking process. When NGOs diagnose a patient and refer them to another facility to receive treatment, the patient is diagnosed again by the receiving health care facility. This redundancy can be problematic because it wastes the time and resources of both the referring and the receiving organization, in addition to complicating the process of seeking health care for the patient.

Most interviewees said that the purpose of diagnosing or evaluating patients is to ensure that they will be properly matched with an incoming *jornada* based on their medical needs. Two NGOs reported having success using a detailed referral form to gather details on the needs of their patients and to match these with available surgeries. Using this system, they prioritize the patients' needs according to three categories of surgical urgency: immediate, necessary and elective.

Booking Follow-up and Pre-surgical care

Participants who reported engaging in follow-up after the booking stated that they did so for various reasons. One cited reason cited by several was to ensure that patients maintain a level of health that will not disqualify them for the surgery when the time comes. For example one organization said that they support babies by giving them milk and other nutritional supplementation to reach or maintain a healthy weight prior to surgery. Another key pre-surgical activity is education of the patient and their family on the events that will occur and advice on the logistics of travel and what to bring. Also, confirmation that the patient understands the date and time of appointments was a critical step cited by some participants. For example, one participant mentioned use of different colored invitation cards to correspond to the day of the

week the patient is to attend a diagnostic appointment, which helps overcome confusion related to appointment times.

Pre-surgical care instructions were a concern due to lack of coordinated, accurate and culturally-accessible instructions. Interviewees frequently described the confusion and resultant damage to trust between NGOs and patients that arise from miscommunication in these areas. For example, one participant mentioned that their NGO refers patients not only to surgeries but also to preliminary tests and screenings. Therefore, they put utmost importance on making sure that their patients understand the nature of their referral, since they do not want the patient to have unmet expectations. Two participants discussed the importance of trust and reputation with patients. These organizations reported that they have worked hard to build a trusted referral network and to ensure that they are very careful about what they promise, as they want to deliver on their promises.

One of the reasons NGOs cited for investing a considerable amount of time and resources into referrals is to manage the expectations of patients, particularly in light of the occasional overbooking of *jornadas*. For example, one NGO explained their practice of telling waiting patients that they would be travelling for an "evaluation," rather than to definitely receive surgery, and that "the surgeon would have the last say". This allows for the possibility of visiting medical teams being over-scheduled, which can happen to ensure that they work at their maximum capacity during the limited period of time in Guatemala. Some patients who do not meet the requirements for surgery on the day (for example, their blood pressure is too high) are turned away, which allows for some of the extra patients to take these surgical slots but leaves others with unmet expectations.

Post-Surgical Care Instructions

As for post-surgical follow-up care instructions, lack of cultural sensitivity and appropriateness was cited by some participants. One participant offered the following scenario: a poor, rural Kaqchikel-speaking woman receives a hernia surgery and then is told by her American *jornada* doctor, in Spanish, that she should be on strict bed rest for the following two weeks until coming back to the hospital for a check-up. In this example, the patient's gender, class, area of residency, level of education and little personal experience with surgery prevent her from following any of these instructions. As the interviewee explained, the patient cannot take time away from her daily duties such as laundry or child care, nor can she lobby her husband for permission and money to make another faraway journey for another check-up. In this case, a Guatemalan health care provider, more familiar with this woman's socio-economic context, may be able to adapt the instructions by showing alternative ways to go about her daily duties without re-injuring herself.

Post-Surgical Follow-Up

Half of the participants stated that they routinely do post-surgical follow-up as a part of the referral process. For example, one NGO provides specific medicines and ointments as required by recovery procedures. The other half of the NGO's reported that post-surgical follow-up is not standard procedure. Although one in this group of participants mentioned that in the event of a complication as a result of the surgery, a health representative from their NGO will bring the patient to the hospital or help them obtain further medical attention at a local health center to ensure a safe recovery.

Barriers and Facilitators for Access to Surgery

Interview data with NGO representatives indicated that surgical patients face a number of logistical and social barriers to receiving care. Most frequently mentioned were logistical barriers, for both the patients needing surgeries and the for NGOs coordinating this service. NGOs also have several strategies to help facilitate patients' access to surgery and other health services.

Transportation

Transportation to surgical appointments, and the money needed for transportation, was the most commonly cited barrier. All of the NGOs interviewed reported that they seek to provide services for people with few economic resources. Those with the fewest economic resources tend to live in rural areas and often live great distances from the nearest health center. Therefore, the journey to urban centers where surgeries would take place is often long, unfamiliar, and unaffordable for the Guatemalans living in rural areas, thus making the cost and fear of transportation a major logistical barrier for receiving surgery.

Seven of the ten study participants emphasized the need to provide support and funding to cover transport costs for the patient and an accompanying family member, and three organizations actually provide a means of transportation for their patients. For example, one reported that they sometimes rent a large bus to take patients to their surgeries.

Accommodation & Food

A related logistical barrier to receiving care reported in our interviews was the need for accommodation and food due to the need to travel for surgery. Oftentimes, patients need to be away from home for an entire week for the surgery.

Many NGOs reported the need to cover these additional costs, with one organisation providing their own housing for patients. Five out of the six NGOs interviewed whose primary focus is health care provision stated that not only do they help patients pay for the surgery but also for the associated costs such as transportation, food, accommodation, and pre- and post-surgical care. The one health-focused NGO that does not help with these things works very closely with another organization that provides accompanying family members of surgical patients with free housing and two meals a day in exchange for their help with cleaning.

Overburdened Facilities

An additional barrier to receiving care is the disproportionately high amount of patient need relative to available services, care facilities and personnel. For example, the NGO might refer a patient to another organization for a surgery, but there is no guarantee that this facility will have the resources to attend to the patient. This was cited by NGOs as reason for patients sometimes receiving inadequate medical attention. Many organisations reported the need to manage expectations in this case.

Lack of Health Education and Experience with Biomedical Services

Another barrier for patients is the lack of knowledge and education about available biomedical treatments among NGOs' target populations. A lack of patient knowledge and experience with biomedical health services results in fear among potential surgical patients, and it some cases leads to stigmatization and avoidance of surgery.

All of the NGOs spoke of the need for more health education. For example, cleft palate is a common surgery coordinated by some of the NGOs interviewed; however, in some communities, it is not known that this is a fairly common problem and that is relatively easy to fix with surgery. One participant explained,

> In the past, it was difficult to find babies with cleft palate because the parents hid them. They feel shame. When you go and talk to them, they don't want to come and have surgery. They don't believe in the surgery.

Another NGO described to us a case in which a mother refused to have a feeding tube inserted for her malnourished child. The procedure was unfamiliar to her and she found this distressing. Part of the role of community health promoters used by some of the NGOs is to increase people's familiarity with surgical procedures, in this way dispelling fears or doubts.

Indeed, many of the NGOs interviewed serve predominantly indigenous rural communities. One important factor for these NGOs to keep in mind is the lack of knowledge of biomedicine in many of these areas. In some cases, certain biomedical procedures are unheard of or, at the very least, unfamiliar to people. It is this unfamiliarity with or distrust of biomedical procedures that would cause a mother to feel uncomfortable about feeding tubes. Indeed, several NGOs spoke of difficulties they had in convincing patients that surgery was in their best interest.

Language & Ethnicity & Gender

Another important factor for access was the provision of health services in the first language of the patient, particularly in light of Guatemala's linguistic diversity with 23 officially-recognized languages. Although it was infrequently addressed as such, a patient's first language and ethnicity constitute a compound barrier to seeking health care, which is often provided only in Spanish. A third of NGOs in our sample reported that racism is highly prevalent throughout Guatemala and impacts the provision of health care.

The issue of the language barrier applies to indigenous and *ladino* patients alike when incoming *jornada* teams do not speak Spanish. Interestingly, there were mixed opinions among our sample about whose responsibility it is to provide interpreting services at a *jornada*. A common assumption was that indigenous patients could fare well enough in Spanish to get by or that they could always bring a family member who could effectively translate for them. One NGO mentioned that they ask the incoming *jornada* teams to bring their own Spanish-English translators but that this often does not happen. In these cases, the NGO have all their own ways of managing language barriers for Spanish, English and Mayan languages. Only one NGO in our sample emphasizes the provision of health care in first-languages. The quality and accuracy of translation, as well as exploring whose responsibility it is to provide health information in patients' first language, are all potential areas for further focus and improvement.

In addition, seeking and receiving medical attention is also strongly impacted by patients' gender and their normative understandings of gendered health roles. In every interview, examples of "machismo" culture as a barrier to health care were discussed. Eight out of ten

participants offered the example of married indigenous women being forbidden by their husbands from travelling to receive surgery.

Need for Accompaniment

Two of our ten participants strongly emphasised the need for patient accompaniment by staff members as a way to overcome barriers such as racism, corruption, language, and unfamiliarity with the receiving facility and/or location. With respect to racism, one NGO spoke of "gatekeepers".

> *The doctors are very good and very nice...But the problem is with the guards, secretaries and nurses. Once you get through the gatekeepers, the doctors are fine and ready for the patients. It's the secretary, for example, who doesn't let people in. That's why accompaniment is important* (Interview ID#1).

This was a powerful example for the need for staff members to travel with and advocate for patients within the health system. Family member accompaniment was also described as important for emotional, and sometimes, language support.

Surgical Fees

There were mixed opinions about how to charge for surgeries for people from impoverished backgrounds. One organization in particular stressed the need for NGOs to pay for "symbolic quotas". A symbolic quota refers to charging patients an affordable fee for a surgery, rather than giving the surgery for free or charging at cost. The assumption is that if patients do not pay an amount, then they may not value the service. Thus, charging patients a symbolic quota means the patient is participating in the health service transaction. One NGO questioned the need for a symbolic quota, as it does not take into consideration the patients' transportation, food and accommodation expenses, or lost wages. Also, it appears that NGOs actually often pay the symbolic quota to one another on behalf of clients who are unable to pay, rendering the "buy-in" element for the patient moot. Other NGOs interviewed, however, said that they do insist on charging a small fee, depending on the capacity of the person to contribute. Thus, this is one area in which NGOs differ in respect to service delivery models, although all are committed to ensuring that costs are not a barrier to service delivery.

Perceptions of Government Services

The public government health system is run by the Ministry of Public Health and Social Welfare (MSPAS) (Green et al. 2009: 3). These public health services consist of hospitals, health centres, health posts and ambulatory teams. The MSPAS also has a role in providing leadership on health policies, regulation and management (PAHO 2007).

During the interviews, there were mixed opinions about government health care services. All ten NGOs stated that the government health care system lacks the necessary funding, equipment, staff and medicine to meet the needs of their patients. "It's always been very well known that the government system isn't very good," one interviewee explained. Another participant stated, "[Here's] an example of the paucity of resources: if you break your arm and go to the public hospital, you will be seen [for] free, but there is no casting material. You have to buy materials to get fully treated. Lack of supplies put the onus on the patient to buy them prior

to being admitted." One participant stated, "The [national] hospitals' capacities are so low that sometimes people receive an appointment for a much later date, and then when they go back, they get another appointment to get tests run... So they have to wait a lot time to manage to get a surgery." Another participant referred to the government health care system as a "system of postponing", at the end of which adequate health services are not provided.

A final issue is the lack of continuity of services. Rural communities are particularly disadvantaged in this regard since they live in places where people may only have access to a doctor once a month. It is true that the government has made an effort to make some health care services accessible in rural areas by creating rural health posts and ambulatory health teams; however, like the national hospitals, these health posts and ambulatory teams have very few resources. One participant described: "[If you rely on an ambulatory team] you just have to hope that if you do get sick, it's when the doctor is around." With respect to accident victims and other situations requiring immediate emergency care, these waiting times can mean life and death or can result in a lifelong disability. One participant gave the example of a man living in a rural area who waited too long to get an infection seen by a doctor. Ultimately, he had to get his leg amputated, a consequence which was entirely preventable had he received medical attention earlier. These types of complications were cited as common for those living in rural communities. Government health services were deemed "not adequate in terms of [geographical] coverage," and one NGO observed, "[Currently,] the whole system is set up in a way that the indigenous villages are totally forgotten." This was repeated by other interviewees who pointed out that people from rural communities do not have the financial resources to pay for transportation to access government hospitals. Still, a couple of participants mentioned that community health services are beginning to improve: "Ambulatory teams [are] trying to improve access. We see this as a good step as people may access health care this way."

Further, the maintenance of medical records is not seen as important and necessary. One NGO explained that they've had problems with patients getting exams done elsewhere and the record, if they received one, being lost or destroyed. The participant described, "Lab technicians don't explain that it's important to save records and present them to their next doctor. So follow-up is an issue because there aren't usually written documents or these don't get passed on." It may be that maintaining treatment records is assumed to be a patient responsibility, but the incidence of this issue indicates that this knowledge is not universally shared by patients and that this policy currently lacks standardization.

One concern about the government health care system had to do with the interface between this and the private health care sector. Two of ten participants stated that there is a problem with corrupt medical doctors working in both the public and the private health care systems. They said that these doctors persuade patients they see in the public sector to seek surgeries or other forms of medical attention in the private sector for which they also work. One NGO explained,

> A woman sees a doctor [in the public health care system] and they tell her they'll do some surgery [for her cancer] in 30 days. Then the doctor pulls her aside and says he could do the surgery [at his private practice] the next day for 8000Q. So, this woman rushes into surgery, it's botched, and now she owes $1000.

Such 'slippage' between the public and private health care systems highlights the public sector's incapacity to handle certain surgeries in a timely manner and explains why patients must seek alternative solutions. In this case, the NGO described its role as an advocate for the woman to

help her find a surgery that would not have put her in great debt. Yet, one can see how a doctor like this, teetering between both systems, has the ability to create a false sense of urgency and coerce patients into seeking care in the private health care system. Moreover, treating in the private system presents the opportunity for profit making with vulnerable patients.

A final critique of the government health care system was its lack of effective record-keeping. Two participants pointed out that having no paper trail has a negative impact on continuity of care and quality of services. “Everything is treated as an isolated incident,” one interviewee described. “And there is a lack of cross-referencing medication,” they added.

Not everything said about the government health care system was negative. Some positive comments were said regarding the national system’s ability to manage particular types of surgeries. One participant stated, “Complicated surgeries work really well [in Guatemala], but it's the simple ones for which there is no support.” Although one NGO described national emergency health services as “inadequate,” another NGO whose primary purpose is health care delivery commented that they don’t do emergency care because “the emergency health care system works fine in Guatemala.”

Perceptions of Private Medical System

Although perceptions of the private sector were not discussed in all of the interviews, others had strong opinions. In general, patients and health service-providing NGOs perceive the private medical system as qualitatively better in terms of care yet prohibitively expensive. For the kinds of populations that NGOs seek to help, receiving health care in the private medical system is mostly inaccessible without the help from an outside source such as an NGO. Understanding this, several interviewees mentioned that they only refer patients to private practices as a last option.

As much as participants disliked the private system’s exorbitant costs for the average Guatemalan, they also recognized that the alternative – the public system – is not an attractive option either. Indeed, the public system was perceived to be inefficient almost to the point of non-functionality. As discussed above, concern about medical professionals unethically benefiting by working between both public and private systems was discussed.

Methods for Gaining Community Trust

> “You can’t just go to a rural area without prior knowledge of the community. You really need to know how to present yourself step-by-step and make the community accept you and understand why you’re coming before you start working, or else you’ll waste a lot of time and energy and encounter many obstacles.” – NGO Director

The challenge of obtaining a community’s acceptance before initiating programs and services was echoed by nearly all of the NGOs interviewed. One of the factors cited as complicating this process was communities’ distrust, fueled by fear and a general lack of information. As one NGO put it, “The main challenge is to convince people that this [surgery] is for their own good.” Several participants mentioned that people are afraid to go to the hospital because they think they will die there. Moreover, when they do see a doctor, they do not know that it is acceptable for them to ask questions.

In some cases, surgeries are not pursued because people simply do not know of their availability. One NGO explained that, in their experience, most people live so far away that they do not even know that a surgery can help. Some NGOs use local health promoters who announce upcoming *jornadas*. They spread news of the *jornadas* through word-of-mouth, posters and, in some cases, via radio programs. These health promoters also serve as the organization's first point of contact with the communities. They are described as being leaders of their communities, and it is their responsibility to find those who need surgeries, coordinate in their villages and gain the trust of the people.

Sometimes, a lack of trust also stems from people not understanding the surgical referral process. A couple of the NGOs involved in surgical referrals explained that before surgery, they hold informational meetings in which they describe the exact surgical referral process to the patient, what steps he or she needs to complete and any associated costs for which they will be responsible. Many NGOs also spoke of the importance of accompaniment, sending a representative of the NGO with the patient to their referral appointment. Accompaniment is important for several reasons that have already been discussed. According to several of our participants, this is an essential component of the surgical referral process which could easily be overlooked if an NGO or surgical team were not familiar with the social context or barriers to service.

Another issue cited as being based on the culture is the fact that 'well' visits are not a common practice, especially in rural Guatemala. As one NGO put it, "When the kids aren't sick and parents are given appointments, sometimes the parents will bring another child, one who's actually sick, instead of the one for whom the appointment was made. There's this idea that if there's nothing wrong, then there's no need to go to the doctor." Another NGO explained that they've made special efforts to improve continuity of care so that it this will "lead to some normalization of doctor visiting".

Reputations of Visiting Surgical Teams

Quality

Our participants reported that, in general, *jornadas* have very positive reputations because they are able to help people who are in medical need. The current government health care system in Guatemala cannot adequately provide the surgical services that *jornadas* are able to fill. The *jornada* teams are in the country for a fixed amount of time to perform a set number of surgical procedures. Comprised mostly foreign doctors and staff, the *jornada* teams perform the surgeries at little or no cost to the patient, and the referring NGO often subsidizes any other costs of the surgery. Four participants reported that they work with the same *jornadas* year after year. One NGO explained that *jornadas* that return often and perform good work are seen by communities as "*buena medicina*," good medicine. These enjoy a good reputation both with the local communities in which they work and the hosting NGO. These positive relationships might be a fertile starting place for NGOs to build a functioning, trustworthy internal network for their own referrals and surgical services.

Drawbacks

While *jornadas* are able to provide a service for the community, they are not without complications. For our participants, the greatest drawback of *jornadas* is the lack of comprehensive post-surgical care. Since *jornadas* are in Guatemala for a set period of time,

they are not usually present post-surgery to assist the patient with any complications that might arise. Misunderstandings of post-surgical care instructions were also mentioned by several NGOs. *Jornadas* giving post-surgical care instructions in a language that the patient cannot understand is further complicated by the notion, on the part of the patient, that he or she cannot ask any questions of the health care professional. The problem of culturally-insensitive post-surgical care instructions has already been discussed, but it is worth mentioning again as it severely compromises the quality of post-surgical care given by *jornada* teams. A similar problem is when doctors are not aware of their patient's financial circumstances and prescribe medications to help with recovery that the patient cannot afford.

The limited time availability of *jornadas* is also problematic because people may need urgent surgery when there are no *jornadas* currently in the country for the specific type of surgery needed. In these cases, patients just have to wait. Then, when *jornadas* are in-country, matching of resources with need can be problematic. A few participants expressed concern about *jornadas* asking for more patients than they can actually see. As discussed earlier, this is done to ensure that all of the surgical slots are filled and that, should one become available, there is someone to fill it. Another participant explained that *jornadas* tend to perform surgeries that produce demonstrable results. Thus, they might choose to only focus on a particular type of surgery because it is easier to do not because it reflects the need of the population. This may also be seen to be advantageous for the surgeon as it can increase the productivity of the *jornada*. Performing numerous less-complicated surgeries can give the impression of more patients being helped; however, it might not truly fulfil the needs of the community. Indeed, a couple of the NGOs stated that there are certain conditions--such as spina bifida--for which there are not any *jornadas*.

A final drawback of *jornadas* that was brought up in the interviews was the additional costs for medication, equipment and travel. Most of the NGOs reported that *jornadas* often bring down their own equipment and medication; however, there was no consensus on whether or not this is cost-effective. One participant said that the costs of bringing *jornadas* to Guatemala (e.g. – the costs of travel, hotels, and of importing medicines) amount to thousands of dollars, which would be a small fortune for an NGO budget. "With that amount of money, we could pay for several hundred complicated surgeries to get done here in Guatemala," this participant explained. Overall, it is clear that *jornadas* are not the ideal system of surgery delivery but that these visiting medical teams are currently many Guatemalans' best chance of getting the surgery they need.

Vision for Health System

Education and Preventative health care

Our participants have many ideas for how the health care system should operate in Guatemala. The majority of the participants agree that health education should be one of the top priorities, specifically, preventative health education. According to our interviewees, the majority of the health care problems in Guatemala are chronic conditions, and preventative education focusing on health care and diet are seen as a long-term solution. Decreasing the amount of chronically-ill people will alleviate the heavy burden on the crippled and overburdened national health care system.

Accessible and Permanent structures

Participants also believe in making health care more accessible to all populations of Guatemala. Nearly all of the participants view distance as a barrier to receiving health care, and most of the participants believe that health care should be available at the local level. As mentioned before, rural health posts and ambulatory teams are trying to help bridge this gap, but permanent, local health care facilities would be ideal. *Jornadas* are temporary and are perceived to provide very little or no post-surgical care. Permanent structures, however, have the potential to provide more continuous health care, including pre-and post-surgical care and quality training for health care providers. The presence of a permanent health structure in rural areas of Guatemala could also help normalize preventative check-ups, thereby helping to switch the focus of health care in Guatemala from curative medicine to preventative medicine.

Communication and Cooperation

Participants also expressed the view that health care is something that can be drastically improved. Nearly all of our participants agree that communication is a key element in improving health care in Guatemala. Improved communication between NGOs, the community and the public health care system was seen as crucial to creating a more seamless health care system to which all populations have access. Such a system could also reduce the number hours of staff labor used for tasks such as diagnosing a patient.

In addition to communication, cooperation between NGOs was also cited by our participants as a necessary component of an ideal health care system. Cooperation between existing NGOs in Guatemala and NGOs in foreign countries looking to offer their services in the local community as well as cooperation between existing NGOs in Guatemala has the capacity to greatly enhance the health of the community. Participants stated that there should be better collaboration between NGOs outside of Guatemala and local NGOs so that the former can tap into the network resources which are already rooted in the community. Collaborating with an already existing group would mean that new incoming groups would not have to waste resources on establishing a trusted community network. It would also help prevent the duplication of services and enable service-providers to focus on other areas of need in a community.

In term of working towards sustainability of NGO's, one participant suggested that Guatemalan and visiting health professionals and NGO leaders should work together to build capacity in local institutions.

Potential for a Shared Surgical Referral System

Need for collaboration

Eight of the ten organizations discussed their vision for the need to collaborate with other NGOs to improve quality of service delivery. Many talked about their desire to be more collaborative with other networks, but some stated that most NGOs do not have the resources that it takes to incorporate network-building into their daily work. Another mentioned that this could be financially beneficial given that working together could be potentially more resourceful in the long run. One stated, "[NGOs'] main purpose is the patients. If we want to provide health, we should start working closer as a team."

Barriers to collaboration

Several barriers to getting NGOs to work together were mentioned. Interestingly, four of the respondents also mentioned the existence of competition, jealousy, and 'conditional' collaboration (i.e. – agreeing to collaborate on the condition to "get credit" for the work). These issues reflect Abom's (2004) findings in previous research with NGO networks in Guatemala. One participant explained, "Sometimes NGOs are jealous…of other NGOs, so they exclude other people who could do good. This is very sad. This has more to do with egos than real needs in the population". Another interviewee said that there needs to be "less jealousy and less [concern about] who gets the credit."

Five of the participants then went on to discuss the issues of time and logistics. For example, one stated,

> If you work in an NGO you always have more to do than you can accomplish. It's hard to invest time and energy in networking if you don't need something immediately. This is a structural problem I don't know how to solve.

Others talked about the need for organizations to start with research and to recognize the networks that already exist, although many of these are based on personal, rather than institutional, relationships. It was also discussed that another important prerequisite for building relationships is trust between networks.

Creating a Shared Referral System

One of the questions asked of interviewees was, "If there were a shared referral system used by other NGOs to help match health resources with patient needs, would your organization want to participate?" All said they would, with some indicating specific conditions that the network would have to meet in order for them to participate. For example, one NGO said that they would like to participate in the future but that currently they were "at capacity" in terms of receiving referrals for surgeries. This NGO went on to highlight that the current partnerships they have with other NGOs has resulted in them being overwhelmed with surgical referrals. This comment highlights the need for a wider referral network so that all surgical needs can be satisfied.

A second question asking for suggestions as to how such a system should work elicited the following ideas. Here, we will begin by discussing the most frequently cited suggestions.

Collaboration with Trusted Network Partners

All of the NGOs stated that the shared referral system should be comprised of a trusted network of organizations with good communication and ample interaction among them. As one NGO put it, "The idea is to move away from the system of just doing *jornadas,* towards a system in which you work with a network of organizations you trust. Then the referral system becomes smooth. You won't need intermediaries."

Although many of the interviewed NGOs do work with other organizations, all agreed that there needs to be more collaboration. One NGO explained that, although in some cases they know exactly who to refer patients to, in other cases of surgical needs in rural areas, they have "no clue" about what they can do to improve the situation except to give people money and send them to the capital. Only a couple of the NGOs reported having long-standing ties with each other and with specific *jornada* teams that come year after year. In these cases, extensive

backgrounds checks are done on the doctors, most of whom are recommended by doctors they've worked with in the past.

Several of the NGOs mentioned wanting to know more about what other NGOs are doing. According to one participant, the shared referral system would need to be open so that people know what others are doing and so they know to whom they can refer, in this way making the referral process more transparent and comprehensible. Another participant explained, "If all the associations knew each other better, they could spend less money and have more of an impact." "We need to work more as one team instead of different NGOs," another observed.

Network Funding

Another barrier to networking and collaboration that was mentioned was a lack of funding and special training for building NGO networks. One participant explained, "Everyone wants to fund programs but not networks." Another interviewee pointed out the need for special training for NGO directors so that they have "the capacity to run a bigger organization." This same person reported having witnessed the rise and fall of many NGOs that start out well and get more funding and power only to have their programs collapse: "I think it's only because it's hard for people to be focused when they don't earn much money, work long hours, [and] aren't necessarily appreciated by everyone." Thus, one suggested solution was to have someone or some entity in charge of organizing NGO collaboration. A few organizations have tried to build an NGO network; however, none of the NGOs we interviewed noted these networks as having much success yet. Lack of money, time and resources were again cited as barriers.

Pre-booking Surgeries

A third recurring suggestion for the shared referral network involves having an effective means by which to pre-book and coordinate surgeries. All of the NGOs we interviewed who are involved in the surgical referral process work, at least to some degree, with *jornadas*. Yet, the ability to pre-book surgeries varied greatly among the organizations we interviewed. Only two NGOs reported that they are able to pre-book surgeries without problem. They stated that they know the exact calendar of when *jornadas* teams are going to arrive, how long they'll be in Guatemala for, what kinds of surgeries they are equipped to do and how many patients they can expect to see. With respect to the surgical referral process then, these NGOs already have a fairly effective system set up: they can go out into communities, find out what surgeries are needed, schedule them and then deal with the logistics of getting the patient to the surgery. This was not, however, the experience of other NGOs. Several expressed frustration at not knowing when *jornadas* would be arriving nor the specific requirements and capacities of the medical teams. Moreover, they are further frustrated by not being able to discuss cases with surgeons beforehand. One NGO explained that when they tried to contact a *jornada* team to discuss a future patient, the doctor responded that they would see the patient when their team arrived in Guatemala. In this NGOs' opinion, the visiting doctors should "do it like they would in the States and pre-book patients before arrival."

Several interviewees suggested the adoption of an open calendar system, perhaps computerized, that would enable organizations to see what kind of surgeries will be available and when so that they can book surgeries more effectively. Such a booking system would also give smaller NGOs access to surgery slots. One NGO explained that it is sometimes difficult for a smaller organization like them to access surgeries because surgery providers tend to give bigger organizations priority. Another positive effect this open calendar system would have is it would help avoid disappointing patients who were referred to a surgery but then never got one

due to overbooking and lack of time and supplies on the part of the visiting surgical team. Several NGOs mentioned that this has happened to them many times and that such broken promises are detrimental to their reputations in the communities in which they work. Thus, the ability to pre-book would enable a more effective matching of resources with need as well as a more productive use of time and energy for the referring organization.

Provision of Needed Surgeries

Another suggestion advocated for the shared referral system to "respond appropriately to the individual needs of the people." This requires several courses of action. First, the surgeries offered would have to be surgeries that are needed. One organization told of a *jornada* that offered knee and hip replacements. "These kinds of surgeries are not for the really poor people," the interviewee explained. Another NGO spoke of the need to find teams with different specialties, so that they can refer patients with all types of surgical needs. A second way to ensure that the shared referral system departed from the needs of the people would be to make sure that everyone, including the *jornada* teams, understood the social context surrounding the patients. One NGO explained, "American doctors are well-respected, but not all of them are respectful of the culture." Only a couple of the NGOs mentioned that they provide their incoming *jornada* teams with information about Guatemalan culture, history and the logistics of travelling to and within the country.

Good Follow-Up Care

A fourth suggestion for the shared referral system is for it to provide good follow-up care and medicines. One participant explained that some organizations are very committed to making the post-surgical process better but that "the nature of being a missionary team makes it very hard to have good post-surgical care." By this, they meant that the *jornada* teams' limited time in Guatemala complicates the delivery of good follow-up. Indeed, nearly every NGO we interviewed expressed a desire to see a surgical care system that is more "permanent." One response, typical of many of the NGOs we interviewed, was that *jornadas* "are very good but the real problem is that they come and then they leave, without giving good instructions [for follow-up care]." They further added that patients often don't have the money to buy medication needed for post-surgical care. Another interviewee put it succinctly: "Things are started but are not finished." A few participants had stories about patients suffering post-surgery complications and their surgeon already having left the hospital, town, or country even. The need for doctors to leave follow-up care instructions was echoed by many interviewees. One NGO referenced another organization that has a permanent staff that works with incoming surgeons. They saw this as one way to improve the situation of doctors constantly coming and going.

A Streamlined Diagnosis Process

A sixth idea bought up by several interviewees was the need for this hypothetical shared referral system to have a streamlined diagnosis process. One organization reported that it requires 50 hours of staff work to make one surgical referral from initial diagnosis to follow-up care. In some of the interviewees' experiences, if one doctor diagnoses a patient and then refers him or her, then the next doctor will often start over again, repeating the diagnostic stage instead of moving on to the treatment stage. One NGO explained that the main thing they'd like to change is the "really silly requirement that the only thing the referring organization can do is be the referrer [and] that the patient still has to pass through this totally redundant system." A couple of the NGOs described their surgical referral process as successful in this aspect. Both work with an invitation system: first health promoters and doctors are brought in to determine whether or not

a surgery is needed; then, if one is needed, the patient is given an invitation to come back either for a second consultation and official referral or for the surgery itself. Either way, the pre-evaluations done in the first step are seen as valid by the second party to receive the patient and so on, thus eliminating the redundancy experienced by some of the other NGOs. A streamlined diagnosis process would also require the maintenance of medical records and the ability for doctors to access these. This could perhaps be related to different cultural meanings assigned to documents, but it could also be linked to the boarder Guatemalan economy and some doctors' efforts to avoid leaving a paper trail.

Building Local Capacity

A final suggestion for a shared referral system that came up in the interviews is that the system should build local capacity. One interviewee explained that instead of making patients travel very far distances, each region should have the ability to attend to its own patients. Otherwise, if everyone is referred to the same place, the system becomes overloaded. Indeed, this was reported to be happening in many of the national hospitals and other places to which patients are often referred. Many stories of overflowing hospitals and of patients' surgeries being postponed over and over again came up in our interviews. Building local capacity would especially help patients living in rural areas.

One NGO that works primarily in rural areas explained, "The whole system is set up in a way that the [rural] indigenous villages are totally forgotten." Their solution was for each community to have at least one clinic and to be sure not locate these in only the main cities of each department. With respect to building local capacity, again the issue of how cost-effective *jornadas* are is relevant. In this case, building local capacity could include constructing local surgical facilities which would perhaps begin to redress the urban/rural imbalance of trained medical personnel. The availability of surgical facilities in more towns would greatly facilitate the surgical referral process.

Analysis

Given that Guatemala is linguistically and culturally diverse, this is an inclusive model that has the potential to empower the people who are to be the ultimate beneficiaries of these services. But the question remains: whose responsibility is it to provide and advocate for language support to ensure that important health information is transmitted across cultural and language backgrounds? Is it the patient, family, surgeon, NGO intermediary or the community? Language is a barrier to the community organization process, and having health care services only available in Spanish compounds and obscures the ability and willingness of non-Spanish speaking patients to actively participate in their own health-seeking. Many interviewees made some mention of language barriers impeding service delivery. While some insist that most of their target population speaks Spanish proficiently, one must question how service delivery in a language other than one's first language affects quality.

In terms of logistical barriers to access, the barrier to patient access constituted by transportation indicates that health services are not provided where they are desperately needed: in the rural areas. Health facilities tend to be clustered in urban areas, particularly Guatemala City. Because of the long distances and mountainous roads that connect rural villages to urban centers, accessing care is limited by distance and a lack of physical resources in patients' own areas. This makes patients less likely to seek care for what they perceive as

non-threatening conditions, and equally unlikely to pursue primary care in those faraway centers. Until full-time and permanent facilities are available in rural areas, rural populations are likely to continue to be underserved by biomedical health centres. Ambulatory teams, health posts, health centers and NGOs have all been part of the effort ameliorate this structural problem.

Half of the ten interviewees described one of the barriers that their patients face to accessing care as their patients' lack of commitment to their own health. Symbolic quotas to pay for care are used by seven of ten interviewees and serve as a material means to ensure their patients' "active participation" in securing and seeking care. With respect to these symbolic charges, one participant stated, "People need to understand that this [development project] is for their own health." The idea is that these quotas are a measure of personal and community commitment to health, yet there is no evidence that this is the most effective way to evaluate people's commitment to health. Quotas make most sense in a model where they significantly contribute to NGOs' financial sustainability by off-setting the costs of providing medical services.

One thing needed for citizen participation and community organization around health care is government interaction (Flores et al. 2009). The Guatemalan state's history of repressive political violence against rural and indigenous populations impedes the feelings of power and security necessary for community organization and personal engagement with NGOs to make health care and health care-seeking a normal part of village life.

NGOs referrers see the private system as corrupt because medical professionals work in both arenas: doctors work for the national health system for intellectual fulfilment, and then to cover their actual expenses, they also work in private health care facilities. The potential for corruption has already been discussed; however, it is clear that one of the keys to solving this issue is raising political pressure to properly fund the national health care system. This cannot be achieved by NGOs alone but rather is a task that will have to arise from the wider Guatemalan population.

Unfamiliarity with and distrust of biomedicine is another barrier to access and has been explored by other researchers as well, among them, T.S. Harvey. In his article "Maya Mobile Medicine: The 'Other' Public Health" (2011), Harvey advocates the incorporation of marginalized forms of public health that contest biomedical authority and calls for "an expansion of our understandings to include localized forms of health care, access, and wellness" (65). This is not to say that NGOs should not offer biomedicine, but rather to emphasize the importance of understanding the community in which one is working and the various systems of health care to which they can resort. As one NGO pointed out, there are many different systems of health care in Guatemala, none of which are mutually exclusive. There are health posts, health centers, national hospitals, traditional healers, NGOs and Mayan mobile medicine, to name a few. Many people will use two or more simultaneously: for example, a person might seek health care at a national hospital but also visit a *curandera* (traditional healer). It is important for any NGO seeking to provide yet another health service to recognize the existence of these other systems, and to take these into account as they try to implement their health care services in a community.

Government Health System

The Guatemalan Government Health system has historically been characterised as fragmented and segmented (PAHO 2007). Corruption has also often been a factor influencing activity, with money being funnelled into health services that fail to be inclusive of the health needs of the entire Guatemalan population. For example, despite international initiatives in the past 40

years to improve indigenous and rural populations' access to public health services, this has proved unsustainable due to corruption in a government system that has been historically set up for disempowerment and exclusion of rural and indigenous communities (Green et al. 2009: 3). In addition, in terms of the private health services, although high in quality, these are accessible to only the wealthiest people in Guatemala, not for the majority of the population (Green et al. 2009:3). In fact, this system is accessed by less than 25% of the population (PAHO 2007). This gap in services also opens up the potential for vulnerable patients who lack the financial resources to be exploited within the private system when desperate for access to a certain basic standard of health services.

This has led to the proliferation of NGOs stepping in to provide and coordinate affordable or free health services in Guatemala. These are filling the gap not serviced by private or government systems. NGOs in Guatemala number currently more than 10,000 (PAHO 2007). One of our participants envisioned,

> One area that's realistically good to invest in now is integrating the NGOs with the government systems. Perhaps there needs to be more research around the possibilities of not only collaboration between NGOs, but collaboration between government, private [organizations] and NGOs.

Statements like these indicate the perceived need not only for better coordination within NGO services but also at a wider level with private and government health services. This includes the potential of coordination with traditional medical services (PAHO 2007) which are community-based but whose efficacy was not brought up by participants in this study. This may also potentially include the need for a medical record paper trail to improve continuity of care between sectors. Other areas that also merit consideration include facilitating training delivery for staff in the different health sectors and setting quality standards across NGO, government and private systems.

Priority areas defined by the MSPAS in primary care, women, paediatric and emergency care (PAHO 2007) is echoed in the comments by NGOs in terms of which services are working and which are failing to meet the needs of the population. For example, the participants identified other urgent gaps in services such as treatment of longer term chronic conditions like diabetes, cancer and malnutrition. In addition, many of the participants explained that the services failed to meet emergency needs of the patients in a timely fashion resulting in preventable serious medical consequences. This is especially the case for those living a significant distance from emergency medical services. In addition, some surgeries appeared to be working to meet the needs of patients and others were not. NGOs would benefit from further research into defining exactly what referral systems and medical services are working at a satisfactory standard and which areas need improvement. At the same time, NGOs can continue to support those government services that are working well and are well-resourced. This will support the vision and movement towards what PAHO describes as the "harmonization of service provision" (2007: 33).

Despite some of the Government systems working very well, all participants emphasized the drastic lack of equipment, quality staffing and basic medicine and resources. According to PAHO, "the Drug Registration and Control Department aim is to guarantee the availability of quality drugs . . . and The Drug Access Program (PROAM), created in 1997, is to ensure equal access for all Guatemalans to quality affordable drugs placed in state and municipal pharmacies, hospitals, clinics, and rural infirmaries for the general welfare of all." (2007: 42). However, many of the NGOs complain of the need to fill in the gap by providing funding or

provision of essential drugs due to their non-availability. In addition, NGOs stated that for government services, mostly the onus is on the patient themselves to provide equipment needed for medical procedures. Most patients cannot afford such equipment. NGOs frequently cited that government medical services lack the availability of important equipment and technology. This is also echoed in the PAHO report with MSPAS annual budget being historically "very low for equipment maintenance and replacement, improvement of infrastructure, and consequently implementation of new technology" (2007: 42). In addition there "is no inventory-based information system of the entire network of hospitals, which would make it possible to assess the needs for preventive maintenance and repair, in order to plan and schedule these repairs in advance" (PAHO 2007: 42).

Finally, the last major issue was in regards to access to government-provided health services for people who are living in geographically rural areas, especially indigenous Mayan populations. As described in the report by PAHO (2007), despite an increase in health services coverage to 71% in 2004 by the Health Ministry, NGOs complain that health services are still not reaching rural and remote communities at WHO standards (accessible transport within 60 minutes of a health service). The PAHO report (2007) describes the inequality of access, in terms of coverage by specific programs throughout Guatemala. According to Green et al. "as of 2001, 18.8% of Guatemalans were estimated not to have access to any part of the healthcare system...and although access to professional medical care is limited to all ethnic groups in Guatemala, it is especially limited to indigenous people" (2009: 3). This issue was frequently repeated by NGOs, and facilitating access often became the core area of work to overcome barriers due to geographical location or ethnic/language background. In addition, it may be worth questioning the amount of emphasis placed on, and amount of funding allocated to, biomedical interventions since traditional Mayan medicine may offer a more viable, sustainable and accessible treatment of chronic conditions

Collaborating to Create a Shared Referral System

Investigation of the positive effects of collaboration among NGOs is far from new. In their article "Do Networks Really Work?" Provan and Milward (2001) revisit Alter and Hage's (1993) work on inter-organizational relations and explain that a prevailing view has been that interdependent groups who decide to work together are more effective at providing community-based services than if they were to work alone (415). Provan and Milward explain,

> The logic behind this belief is powerful, and it builds on concepts from game theory that cooperation will produce outcomes that are more favorable to both parties than when the parties compete (Axelrod 1984). The belief has been especially strong in health and human services, where norms of competition have not been nearly as strong as they have in the for-profit business sector. (415)

Indeed, this seems to be the consensus among most of the NGOs interviewed, as the majority expressed a desire to see more collaboration and team work among them. "We could achieve better things if we worked together as one and used similar referral systems," one participant explained. Yet, Provan and Milward also go on to discuss the problems that can arise when multiple organizations, with multiple sets of stakeholders, try to collaborate: "The joint production of services…may also raise substantial problems regarding resource sharing, political turf battles, regulatory differences, and the like" (416).

All NGOs interviewed showed enthusiasm about working in collaboration with each other and finding potential areas of reciprocity in their networks. Many mentioned that, essentially, trust and relationships of reciprocity are built over time and that, eventually, they will make such a network more efficient and resourceful. Others have described attempts in networking but have also pointed out the need to build more satisfactory partnerships.

Though many of the NGOs interviewed expressed a willingness to share resources such as contacts and organizational strategies, the creation of a shared referral network is likely to require, at least to some degree, the sharing of more tangible resources like money, medicines, equipment and supplies as well as surgery slots and doctor time. Although not discussed in the interviews, these implications of collaborating in a shared referral network would have to be considered by all parties involved at all levels. Provan and Milward point out that, since the people served by organizations like NGOs are not usually politically powerful interest groups by themselves, "groups that represent the community's and clients' interests must be satisfied by network activities. In agency-theory terms, these are the principals, whose role it is to fund and/or monitor the activities of their agents (network agencies), who provide services to clients" (417).

Most of the NGOs interviewed reported that they receive a large part of their funding from private donations managed from an off-site headquarters, often located in Europe or North America. What this means is that collaboration would also have to occur on a larger, multi-national level even, where stakeholders such as funders might be involved not only in the decision to collaborate with other NGOs but also in the establishment of network goals. These are all matters that would have to be taken into consideration if the creation of a shared referral network were to be seriously pursued.

Another idea these analysts express is that a key advantage of a network is that it allows for "the provision of a broad range of services that collectively address the full needs of clients" (418). In building a shared referral system, the participating NGOs would have to decide exactly what aspects of the referral process to focus on and the best possible way to offer the necessary services. This means that considerable thought would have to go into deciding what NGOs would be included in the network and how. Provan and Milward explain,

> At one extreme, only a limited range of services may be offered by the agencies comprised by the network, forcing clients to go outside the formal network to meet their full treatment needs. At the other extreme, too many agencies and programs may be involved, resulting in a confusing array of services with considerable duplication of effort. Thus, network-level effectiveness can be judged partly by the extent to which services that are actually needed by clients are provided by the network. (418)

Although not all of the NGOs interviewed are directly involved in the provision of health care, each one does participate to some extent in the referral process. In some cases, their participation is as simple as telling someone to talk with an affiliate organization that might know more about how to access a surgery. If a shared referral network were to be created, all of these NGO interactions, no matter how minimal, would have to be considered. Potential issues, such as how to handle duplication of services, would also have to be worked out. That is not to say that all of the NGOs in the network have to offer distinct services. Indeed, having, for example, three NGOs that deal with the logistics of housing patients coming in for surgeries

could possibly enable the network to serve a wider patient-base. The idea, rather, would be for these three to collaborate in finding patient housing.

Recommendations and Potential Points-of-Entry for a Shared Referral System

One of the most important factors in creating a shared referral system is the willingness to share information and to acknowledge that the current system can be improved. Conferences, like the *Futuros Colectivos* conference in October 2011, is a prime example of an opportunity for existing networks to link up to share information. With respect to the conference registration fees, a sliding fee scale is available. Moreover, workshops and information will be available in Spanish, English and Kaqchikel. These two factors ensure that both local Guatemalan organizations and foreign NGOs will have access to the conference. Since NGOs have the desire to expand their network, it is also worth reviewing the particular departments within each NGO, its current network that is not working properly or that needs improvement, as well as identify areas that can be streamlined to disseminate information faster throughout the network as a whole.

Starting with the conference, holding monthly or bimonthly meetings of network members could be a productive step towards creating a shared referral network. Not only would such meetings providing each NGO with the opportunity to express its ideas and viewpoints, but it would also allow for the creation of both short- and long-term goals for the network. This would strengthen the direction of the network and provide guidance for its future trajectory. Clear action points should be identified to start the process. Email lists or a web-page for more frequent communications should also be established.

Trusted facilitators should be elected to guide the network's activity. Our research team believes that it would be wise to give credence and acknowledgment to the established NGOs that are already succeeding in Guatemala, especially the NGOs whose focus is in delivering medical aid to the local community. With that said, NGOs that have a smaller capacity or less experience with surgical referrals are advised look to the larger, more established NGOs for guidance in surgical referral procedures and, in this way, explore which aspects can be integrated or improved to streamline their referral process. The elected facilitators can be in charge of running meetings, making sure each idea gets fully consideration by all members and that the mutually-created network goals are always kept in mind.

A major concern for all of our participants is the lack of adequate post-surgical care provided by *jornadas*. To address this concern, the shared referral process must be a continuous one that ends only with the completion of follow-up care. One area worth exploring is the possibility of better preparing visiting medical teams and the government facilities they sometimes utilize. Many of the NGOs interviewed in this study mentioned that educating patients prior to their surgery is an important part of what they do. Along the same lines, this research team recommends that incoming *jornada* teams are also educated. Better preparation of the teams is likely to reduce communication issues and cultural misunderstandings.

Since quality of care in *jornadas* was a frequently mentioned concern of the NGOs interviewed, efforts could be made to approach the Guatemalan Medical Association and Ministry of Health about *jornada* oversight.

Technology

Technology is a powerful tool if everyone in the network has access to it. In analyzing how a shared referral system would work, ideally the flow of information would be secure, accessible, affordable, and easy to set-up and utilize. Thus, another topic that could be discussed at these meetings is the ability to share information in this way. The ideal technological network would involve software created specifically for the network with all users having the same technological access. This would, of course, require monetary resources and labor to initiate.
In booking and referring patients, most of our participants reported utilizing a calendar system. Since all of our participants have internet access, using online software is recommended. There are many open software companies that offer free, secure, accessible calendars that would enable other organizations within the network to view what surgical referral slots are available from other networks. Two such companies that offer these services are Google and Famundo. These two companies allow calendars that are private, semi-private (where an invitation and log-on is required to view the calendar), as well as public calendars. These calendars also allow for individuals with administrative access to view, edit and share the calendar with any given member of the users. One drawback of these calendars is that if local community health workers needed to view what surgeries are available, then they would need internet access; however, this may be avoided if they are given a printed copy of the calendar. Certain precautions may be taken to ensure that calendars are not overbooked during this period. Software training would have to be given to those participating in the network to ensure consistency, accuracy, and security. Further investigation into the integration of technology within each NGO is advised.

Another recommendation for NGOs in the sharing referral process is efficient patient identification and processing. Currently, it appears that each NGO has different systems for identifying patients. If this process were streamlined among NGOs, it would allow for a more holistic treatment of patients, one in which a patient's entire medical history could be taken into account as well as his or her background information (number of dependents, employment, income level, etc.). This would also help reduce patient confusion in the steps to be taken to receive a surgery, since they would become more standardized across NGOs. NGOs could reap the benefits of work done by one another in educating community members about the referral process if it were shared. Additional simple steps could further assist the NGOs in sharing patient information. For example, the network could create standardized triage forms and establish the specific medical terms to be used in diagnosis, tests, treatment and medication.

Conclusions & Areas for Further Investigation

When this study began, it sought to investigate the factors that NGOs identify as facilitators and barriers to quality of care in surgical teams. As the study progressed, common barriers to health care delivery and receipt were cited time and again (e.g. – money, transportation, racism and sexism); however, what also became apparent was a desire on behalf of the large majority of these NGOs to see a more efficient, permanent and patient-centered surgical referral process put into effect. NGOs and the people they help stand to benefit from the creation of such a system.

Ultimately, the participating NGOs discussed their capacities and willingness to reform the surgical referral system. Many of the NGOs looked at their role in the surgical referral process and the ways that they, in collaboration with others, could bring about significant change. Given

this willingness to collaborate, the next step will be to open up the communication between these players in order to seriously discuss the implementation of the ideas each has for improving surgical patient care.

With respect to future investigations, a follow-up study with an expanded sample size would be a useful tool to track the progress of the creation of a shared referral system. Moreover, the study could include patients' perceptions. Interviewing patients to understand their perception of health services provided by NGOs, their reasons for seeking health care through NGO referral, and their ideas about how services could be improved would greatly add to this study as well as broaden its scope.

This investigation could also examine the extent to which NGOs collaborate with the government and vice versa to get people the surgeries they need: how willing are NGOs to work with the Guatemalan government and in what capacity? It would be also be particularly useful to further investigate the role of health promoters in the surgical referral process, exploring how they are selected by NGOs, what their positions are in their communities and whether or not this has an effect on the way they recruit patients for surgical referral.

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Annexes

Annex 1: Study Team

Gelya Frank, Ph.D., is a Professor in the Division of Occupational Science & Occupational Therapy at the Herman Ostrow School of Dentistry and in the Department of Anthropology at the University of Southern California. She is a medical and applied anthropologist and a cofounder of the discipline of occupational science, at USC, in 1989. Dr. Frank's books include: *Lives: An Anthropological Approach to Biography* (Chandler and Sharp, 1980), *Venus on Wheels: Two Decades of Dialogue on Disability, Biography and Being Female in America* (U California Press, 2000), and *Defying the Odds: The Tule River Tribe's Struggle for Sovereignty in Three Centuries* (Yale U Press, 2010). Among Dr. Frank's awards and honors are the Eileen Basker Prize in medical anthropology and the 2010 Ruth Zemke Lectures in Occupational Science. Dr. Frank is the Director of the NAPA-OT Field School.

Sarah Garrett is currently a senior undergraduate student of anthropology at the University of Oklahoma. Garrett speaks Spanish, English and Portuguese. Garrett works part time, and writes a bi-weekly opinion column for the Oklahoma Daily Independent Student Voice. Her typical subjects include politics, imperialism, consumer culture and intersectional analyses of issues of gender and sexuality, race and class. Garrett is actively engaged in campus struggles to revise and remove discriminatory policies, and bring awareness to students of social problems on campus and beyond. Garrett is interested in understanding compounded forces of race, gender and class for women's reproductive health, health seeking, and sexual culture in Latin America. Garrett hopes to work professionally as an anthropologist, and writer.

Rachel Hall-Clifford, Ph.D, MPH, MSc, is Postdoctoral Research Assistant in Primary Health Care and Research Associate in the School of Anthropology at the University of Oxford, currently focusing on illness narratives and autopathography research. She is a medical anthropologist working at the intersections of anthropology and public health. Dr. Hall-Clifford also researches treatments for childhood diarrhea and the delivery of primary health care in Guatemala. She is interested in the measurement of long-term impacts of public health intervention and inequalities in the distribution of health and development funding. She has also held medical anthropology research positions at Harvard University and the London School of Hygiene and Tropical Medicine. Dr. Hall-Clifford is Associate Director of the NAPA-OT Field School.

Stephanie Roche is a recent graduate from Boston University with a double B.A. in cultural anthropology and Hispanic language and literature. After receiving a research grant from her university, Stephanie spent a summer in Quito, Ecuador where she served as a research assistant on a study of gender and sports in Ecuador. She then spent a year in Madrid as an international program coordinator, after which she relocated to Guatemala where she plans to conduct qualitative research on health care delivery. Ultimately, her aspirations include going to medical school and doing research on international adoption.

Linda Rylands graduated with a Bachelor of Occupational Therapy (OT) at the University of Queensland (UQ) Australia, in 2002. As an OT, Linda specialized in the area of mental health for 5 years. After spending time working and travelling abroad, she returned home to Brisbane in 2006 and joined a innovative and dynamic local network of OT's named Occupational Opportunities for Refugees and Asylum Seekers (http://oofras.com). This progressed to a case management role in a lead settlement service for refugees in Queensland where she was particularly interested in exploring the OT role during refugee settlement. Linda has been

humbled by the stories and journeys that she has been privileged to share with families settling in Australia. She is now currently pursuing a Ba of Anthropology at the UQ and is passionate to explore the fusion of Anthropology and OT frameworks in study and practice.

Max N. Sandoval is a senior at University of Hawaii at Manoa studying Anthropology. An Army veteran, Max received his Associates Degree at George Washington University in 2003. Max then branched out and pursued a career in finance, and utilized his network and financial abilities to raise monies for various non-profit health organizations in Hawaii. A recent recipient of the Best Presentation Award at the Latin America Symposium at the University of Hawaii at Manoa, Max is taking his passion for non-profit organizations and Latin American culture and pursuing higher education in the health sector. In his free time, he enjoys surfing, running, traveling, microlending and training for Team in Training events. To know more about Max, visit http://about.me/hawaiiinsomniac.

Annex 2: Interview Instrument in English

NAPA-OT Field School, NGO Networks 2011

Interview No.: _____
Date: _____
Interviewed by: _____
Notes by: _____ ☐
Data entry by: _____ ☐
(Tick box when tasks are completed.) ☐

Informed consent has been administered: YES / NO (If informed consent not attained, interview must not proceed.)

1. Name of organization
2. Year founded
3. Mission of the organization
    a. Goals
    b. Population served
        i. Geographic area
        ii. Demographic group
            1. Typical SES of population
            2. Language group served
            3. Gender or ages
        iii. Numbers involved in programming
    c. Source(s) of funding
    d. Affiliations (religious, governmental, other national or international groups)
4. Interviewee's role within the organization
    a. Position/title
    b. How long have you worked with the organization?
    c. What activities do you undertake in your role?

5. Describe the programs offered by the organization – for each, note:
    a. Type of service, program, or activity
    b. Number of participants or population served
    c. Number of staff and/or volunteers involved
        i. Permanence of the staff (temporary volunteers, staff turnover)
        ii. Language skills of the staff

6. What are health care needs of the population(s) served by your organization?
    a. Where do most people seek health care?
    b. Which elements of the health care system do you think are sufficient and which should be expanded?

7. **ONLY for NGOs NOT providing health services as a primary focus**

   Does your organization help people access health services?

   a. How?
      i. Provision of information, translation, transportation, funding, or a direct health service?
      ii. Are any services provided for the patient's family?
   b. Frequency of this type of assistance

8. Do you have experience in referring people who need surgeries?

If NO, complete Part a. and proceed to Question 9.

   a. If you did come across a case where you needed to help someone receive a surgery, how would you go about it?

If YES, complete Parts b. – f. and proceed to Question 9.

   b. How frequently do referrals occur?
   c. What surgeries are most frequently needed?
   d. To whom do you refer – private doctors, other NGOs providing services, government health services/hospitals, visiting medical teams?
   e. What types of assistance do you provide?
      i. Information, translation, transportation, funding, or a direct health service?
      ii. Are any services provided for the patient's family?
   f. Can you describe step-by-step how you connect a patient with a surgical service?
      - *Interviewer Prompt with 'first you…'; and 'what do you/they do next?' to ensure you have full chain of process*
   g. What are the costs associated with utilizing surgical services?
   h. Do patients face challenges in accessing surgeries? If yes, how so?
   i. Does the referral process meet the needs of patients? How could it be improved?

9. What are the reputations of visiting surgical teams in Guatemala (for example, doctors doing a *jornada* from the U.S.)?
   a. Do you think they provide the best option for patients needing surgical procedures? Explain.
   b. How do local people perceive the services they offer?
   c. Who oversees the quality of care provided by these groups?

10. Do you interact with other NGOs? Government agencies?
   a. For what purposes?
   b. How would you describe the interactions among NGOs in Guatemala?
   c. If there were a shared referral system used by other NGOs to help match health resources with patient needs, would your organization want to participate?

d. Do you have suggestions for how such a shared referral system should work?

11. Is there another key player that you think we should talk to about the surgical referrals?

12. Is there anything else about health care referrals or cooperation among NGOs that you would like to add?

Thank you for your participation! You and your organization will receive a copy of the report based on this study, and you will be invited to participate in a follow-up discussion with other NGO leaders in October 2011.

Annex 3: Interview Instrument in Spanish

NAPA-OT Field School, NGO Networks 2011

Interview No.: _____
Date: _____
Interviewed by: _____
Notes by: _____ ☐
Data entry by: _____ ☐
(Tick box when tasks are completed.) ☐

El/la participante ha dado su consentimiento informado: SÍ / NO (Si no, la entrevista no debe continuar.)

1. Nombre de la organización
2. Año de fundación
3. La misión de la organización
    a. Objetivos
    b. Población atendida
        i. Zona geográfica
        ii. Grupo demográfico
            1. Estatus socioeconómico típico de la población
            2. Grupo lingüístico
            3. ¿De qué género? ¿Edad?
        iii. Número de participantes
    c. Fuente(s) de financiamiento
    d. Afiliaciones (religiosas, grupos no gubernamentales y/o otros grupos nacionales o internacionales).
4. El papel del entrevistado dentro de la organización
    a. Puesto de trabajo / Título
    b. ¿Por cuánto tiempo ha trabajado con la organización?
    c. ¿Qué responsabilidades y tareas conlleva su papel?

5. Describa los programas ofrecidos por la organización - para cada uno, tome nota:
    a. Tipo de servicio, programa o actividad
    b. Número de participantes o la población atendida
    c. Número de personal y / o voluntarios que participan
        i. Permanencia del personal (voluntarios temporales, la rotación de personal)
        ii. Capacidad lingüística del personal

6. ¿Cuáles son las necesidades de salud de la(s) población(es) a las que se atienden en su organización?
    a. ¿Adónde va la mayoría de las personas cuando buscan atención médica?

b. ¿Cuáles elementos del sistema de atención de salud cree usted que son suficientes y cuáles deberían ampliarse?

7. **SOLAMENTE para las ONGs cuyos servicios NO son principalmente servicios de salud.**
¿Su organización ayuda a las personas a acceder a los servicios de salud?
   a. ¿De qué manera?
      i. ¿Se da información, traducción, transporte, financiamiento y/o otro servicio directo para la salud?
      ii. ¿Se proveen servicios para la familia del paciente?
   b. Frecuencia de este tipo de asistencia

8. ¿Ha referido alguna persona que necesite una cirugía hacia algún especialista?

Si NO, complete la parte A y continúe a la pregunta 9.

   a. Si usted se encontrara en una situación en la cual tuviera que ayudarle a alguien a recibir una cirugía, ¿qué haría usted?

En CASO AFIRMATIVO, complete las partes B-F y después pase a la pregunta 9.

   b. ¿Con qué frecuencia refieren ustedes a sus pacientes a un especialista?
   c. ¿Qué cirugía es necesaria con más frecuencia?
   d. ¿Adónde refieren ustedes a sus pacientes – a los médicos privados, ONGs, hospitales del gobierno, jornadas de médicos extranjeros?
   e. ¿Qué tipo de asistencia ofrece su organización?
      i. ¿Se da información, traducción, transporte, financiamiento o algún servicio directo para la salud?
      ii. ¿Se proveen servicios para la familia del paciente?
   f. ¿Puede usted describir paso a paso cómo ayuda a un paciente a recibir una cirugía?
      - *El entrevistador puede empezar con "Primero iniciamos con…", y "¿qué / qué se hace después?" para asegurarse de tener la cadena completa del proceso*
   g. ¿Cuáles son los costos asociados con la utilización de los servicios de cirugía? ¿Quién los paga?
   h. ¿Tienen algunos conflictos los pacientes al intentar acceder a las cirugías? En caso afirmativo, ¿cuáles?
   i. ¿El proceso de referir pacientes a otros especialistas satisface las necesidades de los pacientes? ¿En qué manera se puede mejorarlo?

9. ¿Cuáles son las reputaciones de las jornadas de médicos extranjeros en Guatemala (por ejemplo, de las que vienen de los EE.UU.)?
   a. ¿Cree usted que las jornadas son la mejor opción para los pacientes que necesitan procedimientos quirúrgicos? Explique.
   b. ¿Qué opina la población local de los servicios que ofrecen las jornadas?
   c. ¿Quién supervisa la calidad de los servicios prestados por estos grupos?

10. ¿Interactúan ustedes con otras ONGs? ¿Con agencias gubernamentales?
    a. ¿Con qué fines?
    b. ¿Cómo describe usted las interacciones entre las ONGs en Guatemala?
    c. Si hubiera un sistema específico para referir pacientes a especialistas utilizado por varias ONGs, combinando recursos para satisfacer a las necesidades de los pacientes, ¿estaría su organización interesada en participar?
        i. ¿Tiene alguna sugerencia de cómo tal sistema compartido debería funcionar?

11. ¿Hay otra persona clave con la que deberíamos hablar con respecto al proceso de referir pacientes para cirugías?

12. ¿Hay algo más con respecto al proceso de referir pacientes o acerca de la colaboración entre ONGs que le gustaría añadir?

¡Gracias por su participación! Usted y su organización recibirán una copia del informe basado en este estudio y se les invitará a participar en un debate de seguimiento con los líderes de otras ONGs en octubre del 2011.