

Health Horizons International
Tufts University Public Health Team
2012 Public Health Trip Research
Assessment of Perceptions of Factors Related to Non-Communicable Diseases

Introduction

Health Horizons International (HHI) works to provide a system of primary health care and builds capacity for improving community health on the Northern coast of the Dominican Republic. To this end, HHI has developed partnerships with four communities: Arroyo de Leche, Negro Melo, Pancho Mateo, and Severet. While engaging these communities, HHI's International Programs Team (IPT) found that Non-Communicable diseases (NCDs) are a key health concern. Their field research was corroborated by a health mapping survey conducted by the Tufts Public Health Team in January 2011.

In September 2011, the UN convened a summit on non-communicable diseases, emphasizing the cyclical link between poverty and chronic disease. Rapidly developing countries, such as the Dominican Republic, frequently bear a dual burden of disease: both communicable and chronic. The Dominican health system has made significant gains in its capacity for surveillance and control of infectious diseases, but has not yet developed an integrated and effective strategy for addressing NCDs. This leaves a critically important gap in NCD prevention and provision of NCD prevention measures. Since 2008, the global health community has pledged to bring better prevention and management strategies to communities in which long-term health is often neglected.

HHI strives to meet community need and the WHO's commitment to fighting NCDs. Accordingly, the Tufts University Public Health Team designed a research project to engage communities in identifying their own health problems, and thus enable them to participate in solving the issues they identify. In January 2012, the Public Health Team launched a week-long Photovoice project in Pancho Mateo and Severet to achieve these two goals. In this project, the Public Health Team engaged participants to critically reflect on health issues in their community, through photography and discussion of the photographs, as well as reflection on the process of photography.

Methodology

Methods Rationale

The principal modes of data collection in this study were Photovoice (also known as Picturevoice or digital storytelling) and focus group discussions. Photovoice is a technique that enables community members to use photography as a means to explain and demonstrate that which is of most importance to them in regards to a specific topic. For the purpose of this document, community members who directly participated in the study will be referred to as "participants." Ordinarily, participants are given the opportunity to take photos for weeks, even months; this project shortened that duration, in accordance with obvious time constraints.

Photography is here employed with two purposes in mind. The first is to deepen qualitative discussions (focus groups, in-depth interviews, etc.) by providing material that may not have arisen in ordinary focus groups. By adding this layer to each participant's engagement in the subject, each participant is more likely to have deeper input. Further, other participants may agree, disagree, or qualify the original interpretation of a given photo. Thus, the multi-layer effect that results from standard focus group discussions is amplified. Ultimately, participants used photography to document and discuss the means by which they feel hypertension and

diabetes and hypertension are prevented and promoted. This information, included in the results/conclusion section, is meant to a foundational basis for HHI’s Healthy Lifestyle Initiative. With the input and participation of the communities, the initiative will be based in community priorities and community-held norms and standards. Further, because of their direct participation in creating this initiative, participants may be more likely to engage with the initiative modules.

Second, Photovoice intends to provide the participants with a sense of self-efficacy in identifying issues and assets in their communities. In an conceptual sense, Photovoice enables self-representation that may lead to self-advocacy. By identifying issues themselves, participants may gain a sense of empowerment and solidarity among their fellow participants. Ideally, participants will discuss these issues with their fellow community members, spreading the awareness of issues, concretizing norms, and setting the foundation for community-based action for change. Obviously, one week of Photovoice is not sufficient to incite this cascade of action, but it can serve as a sort of “educational seed capital.” In conjunction with sustained action, Photovoice has the potential for empowerment of community participants, and those connected to the participants.

Methods

The project was executed in two of HHI’s partner communities, Pancho Mateo and Severet, because of their accessibility by truck. In each of the two communities, 3 participants were recruited from an established youth group, and 3 were recruited from an established group of chronic care program (CCP) patients. However, in Pancho Mateo, no chronic care patients were recruited; the participant group was completely comprised of youth. Two extra participants in Severet asked if they could take part in the project, and they were accepted. One of the original Severet participants dropped out after camera difficulties. The final participant groups (after dropouts) were as follows:

Community	# of Participants	Chronic Care/Youth	Females/Males
Severet	7	4/3	6/1
Pancho Mateo	6	0/6	1/5

Day 1 - Orientation, Discussion and 1st Assignment

On the first day of the pilot study, consent forms were administered, and facilitators demonstrated, through interactive activities, how to use the cameras. Among the topics discussed were ethical issues surrounding the taking and the use of photographs, methods of asking permission, contexts in which consent is required, and how to ensure the highest quality of the photographs. Participants were directed by HHI facilitators to take photographs of objects, actions, and situations over two days. Instructions for the first day were as follows: “Take pictures that best represents what is important to you, or has an impact on your daily life.” After 24 hours with this assignment and the cameras, participants had discussions with facilitators, who asked questions designed to create captions (1-3 sentence descriptions) for each photograph. These photos were uploaded, in some form (see challenges section), to facilitator computers.

Day 2/3 - Captioning and Second Assignment

Following the completion of this process, participants were given the second photography assignment. Instructions for the second assignment were to answer the question, "Take pictures of that which prevents and that which promotes both hypertension and diabetes." After another twenty-four hour photography period, the new photos were uploaded and captioned. Participants then each selected three photos that they felt represented the best response to the assignment (best represented factors relating to diabetes and hypertension). The instructions for this second assignment were carefully withheld until after the first captioning process in order to minimize participant bias in photography.

Day 4 - Captioning and Focus Groups

Next, three semi-structured focus groups were held in each community to allow participants to explain the significance of their photos, and to discuss themes related to NCDs in their communities. Photographs were shown on a laptop to their fellow participants. The first two focus groups were separate meetings of each sub-group (CCP and youth group), in which some questions were tailored to that group. In addition to general discussion, facilitators asked the participants, as a group, to rank three selected photos in the order of certain criteria, including healthiness, relevance to daily life, etc. From the nine total photos discussed by the group (3 selected photos x 3 participants), the group selected 3 "finalist" photos that would be discussed with the larger focus group. Finally, the participants then took a short break before beginning the final focus group.

The third and final focus group brought all participants together for a larger discussion. One facilitator from each focus group took observational notes on the narratives. Each smaller focus group brought its three selected photos to the larger discussion for a combined six photographs. Larger group discussion was facilitated by Public Health Team members and Tracy Kaye. Participants discussed similar themes to those that were discussed during the smaller focus groups, but debates and differing opinions surfaced as a result of the more heterogeneous composition of the group. Before the conclusion of the discussion group, participants discussed what they would say in the following day's presentation to the community.

Day 5 - Community Presentation

Participants created a poster including the "finalist" photos discussed in the large focus group. They presented their findings and the major points of their discussion to an audience of community members. Additionally, participants presented recommendations for how community members might prevent diabetes and hypertension, and how they might become healthier in general. The intention of this step was to incite participant empowerment. By disseminating their findings to their communities in a public forum, in which they had organized and recruited audience members, this step was intended to engender sentiments, as well as practical trajectories of self-efficacy for the involved participants.

General Notes/Analysis

The note-taking facilitator recorded the group discussions and overall discussion. During captioning, some sessions were recorded, while other captions were recorded simply by paper notes. Data was also collected from the discussions in the form of audio recordings, which were later transcribed for further analysis. Once transcribed, each document obtained from the project was critically read for salient points, which were input into a separate analysis template. From these analysis templates, the findings were compiled in the conclusion section of this document.

Challenges

Our group encountered several challenges while implementing this project. In this section, we will: (a) make recommendations on how to address these problems in the future and (b) explain how they may have influenced the data collected and analyses.

Technical Problems

Given a limited budget, the group opted to purchase inexpensive cameras. Despite testing of 3 of the 14 cameras before the trip, several unforeseen technical problems arose. For example, when batteries were removed, all photos were erased from the camera. This problem was brought to the Public Health Team's attention at the first captioning meeting. This frustrated participants, and all but one continued participating after this occurred.

Uploading photos posed an additional problem. For instance, some photos appeared white once uploaded to the camera manager software. In order to retain these photographs, the PHT photographed the display screens on each dysfunctional camera and added these images to the data collected. These pictures were then uploaded to PHT computers. Although these retaken pictures were of lower quality than the original photos, they still served as useful discussion starters for the focus groups. Going forward, we recommend that higher-quality cameras should be used if the PHT organizes a photography-based project.

Recording captioning sessions and focus groups was challenging given outside sounds. However, this is a difficult circumstance to overcome because the space was communal. If a more private space were possible for such a project, it would present potential for improving the clarity of data collection, and more importantly, for the focus of facilitators and participants alike.

Language barriers

Of the 11 PHT members, only 4 were fluent in Spanish and could conduct full interviews with participants. This circumstance potentially created a time constraint, making interviews be more rushed than anticipated. Going forward, the PHT should select team members with a heavier focus, even a requirement, on conversational Spanish ability. With more Spanish-speakers, logistics and roles would be easier to coordinate, and team members could be more independent during the course of the project. Centralization of control in the Spanish-speakers was problematic for smooth group functioning in the unpredictable situations that inevitably occur during such a qualitative investigation.

Conveying Assignment Topics to the Participants

Due to the novelty of the research project, some participants were confused about their tasks and their responsibility with cameras. Despite facilitators' reminders to take meaningful photos that represent the participants' communities, some participants took many photos of family and friends. Although it was valuable to know that family and friends are integral to participants' lives, more photographs pertaining to the assignment would have been preferable. Before performing such a project as this one, the research team must understand that the novelty of cameras in low-resource settings may lead to "socially-focused" photography, as in cases where participants took photographs of friends and family members.

Substantial efforts were made to reduce biases in giving PhotoVoice prompts. Mention of "health" was minimized during the provision of the first assignment, which was simply targeted at important parts of daily life. However, bias toward health was inevitable. First, it was known that we were working with Health Horizons International, and thus, that our focus would

be associated with health in some way. Second, the purpose of the study was stated in the consent forms, as mandated by the Tufts IRB. Third, some facilitators may have mentioned something about NCDs while building rapport with the community members, in order to more fully explain the project. Finally, to help participants focus on the assignment, the Director of Public Health, Tracy Kaye, explained to the participants our goal to understand their perceptions of what causes hypertension and diabetes. This led participants to take more health-related photographs during the first, non-health assignment.

Additionally, the PHT worked to minimize biases that might be conferred by “western” perceptions of diabetes and hypertension. In providing the prompt for the second assignment, the PHT stated: “Tira fotos de ambos lo que promueve y lo que previene la presion y el azucar,” which can be interpreted as: “Take fotos of both that which promotes and that which prevents hypertension and diabetes.” However, the vagueness of this prompt necessitated further explanation, as some participants were confused about what the prompt was asking. In some, but not all cases, examples of possible photography subjects were given, introducing that bias into the photography process. In order to partially mitigate this bias, the PHT worked to make it clear that pictures could include anything related to diabetes and hypertension.

Retention Rate

Attendance was inconsistent due to scheduling conflicts, such as school or familial obligation. This was challenging because it was difficult to maintain, correct or reschedule the agenda (i.e., a captioning session) when conflicts like this arose.

Recommendations/Results/Conclusions

Below are listed the findings of the research project. At present, statements that were echoed multiple times across different documents are notated with a “+x,” where x is the number of times this theme was articulated **in addition to the first mention**. To be clear, a statement followed by a “+1” was articulated twice, while a statement with no “+x” was mentioned only once. It is our intention that these findings not only serve as the basis for HHI’s Healthy Lifestyle Initiative, but also as the basis of further, more complex investigations that lie outside the scope of this research. Points that merit further exploration are indicated as such.

Objective Findings:

- Diet
 - Cooking Practices
 - Participants noted that adding salt to foods contribute to diabetes, as do some fruits, and other sweet foods. +3
 - A participant noted that a woman got very sick from eating food heavily cooked in oil, and had very bad pain all over her body, and was forced to stay in bed.
 - That woman then felt better after counseling and advice from participant #11 (a chronic care patient).
 - Participants stated that cooking methods are closely related to the development of chronic disease. +4
 - Foods

- There is a consolidated community awareness that the eating of sweet items, such as cakes, or very sweet fruits, contributes to diabetes. Some participants stated that it “causes” diabetes. +3
- There is a sentiment in Pancho Mateo that youth must be given “food to improve them.” This may suggest a concern with malnutrition in youth.
- Sugarcane is consumed in large quantities by all members of the community on a daily basis. It can serve as both a snack and a meal.
 - Participants agreed that it provides energy, is readily available, and cheap, if not free (given the ability to cut it from the cancha).
- In Pancho Mateo, one participant stated that the majority of fruits (cahuiles, tomatoes, cherries, mangoes) come from a garden or individuals’ personal gardens. +2
- Meats
 - Participants stated that chicken is eaten frequently and is a staple the customary diet. +2
 - Participants said that “Bird meat” is a good, healthy food. +1
 - Participants noted that pig meat has more health benefits than that of a duck, and duck meat has more health benefits than chicken meat. Participants did not articulate specific benefits that these meats have. +2
 - Participants noted that pork is the least healthy meat and Haitians do not eat it because it is unhealthy. While some pork meats are fatty, other cuts of meat are lean.
 - Beef is eaten daily in the community and it gives people fuel and energy.
 - The most favored form of cooking meat is through frying.
- Fruit
 - Participants identified mangoes and plantains as beneficial for health, although people with diabetes cannot eat all of these fruits. However, it is not clear whether or not people eat these because they taste good, or because they are simply available. It is also not clear whether or not the participants consciously thought about what health benefits were being provided as they purchased/consumed them.
 - Oranges, lemons, papaya, and bananas are protective against diabetes. +1
 - Participants noted that oranges that are very sweet contribute to diabetes. This is an interesting finding in that sweetness of foods appears to be associated with diabetes development. In separate discussions, sweet cakes and pastries are separately noted as being strong contributors to diabetes, although their taste makes them strongly desirable.
 - Participants noted that tomatoes can cause “problems with the body.” This is an interesting finding, given the anti-oxidant and heart-health benefits that western medicine identifies in fruits such

- as tomatoes. The problems with the body were not fully explained by the participants. They instead gave a vague feeling that there can be negative health consequences associated with eating tomatoes. +1
 - Participants stated that people with heart conditions should eat fruits to become healthy. +1
- Other Foods
 - Pasta and yucca are sometimes combined by participants to make a soup, which was labeled as inexpensive and filling, although it was often difficult to make enough to feed the entire family and does not taste good.
 - “Moro” is a common rice dish made with rice and black beans that is frequently eaten in both Pancho Mateo and Severet. +1
 - Women frequently cook beans together, in pairs of mother-daughter or other female-female grouping.
 - Yucca was
 - identified as a healthy food that can help prevent diabetes, as was cassava.
 - There are many people who grow yucca, but it is not clear who grows it, or where they grow it.
 - Participants noted that it is very important to the community, and people cook it frequently by either boiling with salt or by frying it.
 - Rice and beans was identified as a common dish that is easy and inexpensive to prepare.
 - Participants noted that foods high in fat are potential causes of diabetes and hypertension. +1
 - Participants stated that eggs are important to their diet and can be used to make desserts, bread, soup, and other foods.
 - Vegetables are lower in calories and help to reduce cholesterol. High cholesterol was noted as a problem in the community. Participants also noted that people do not eat a lot of vegetables but should eat more. They suggested buying more or growing them in a home garden.
 - Vegetables, if consumed at all, seem to be incorporated into sauces that accompany meat.
- Participants stated that most food is bought at the local “colmados” which sell rice, beans, some vegetables, meats and other necessary items for cooking. Participants also mentioned that people frequently buy sodas at the colmados. +2
- Some vegetables and fruits are available in the markets of Pancho Mateo and Severet on a weekly basis.
- Consumption of fruits and vegetables may have been over-exaggerated in the focus groups. Most photos of fruits included raw items in the

- marketplace, while very few photos showed the fruits included in meals, or being eaten. However, this may be a result of the short shelf-life of foods, or of their commonality; if having fruit in the house is exceedingly common, participants might be less likely to deem them “photo-worthy.”
- A common breakfast food identified by the participants was white bread with “chocolate,” or a hot chocolate drink. +2
- Availability
 - Participants stated that people in Severet primarily eat mangoes and bananas. They enjoy eating them, but eat them only “sometimes, not frequently.” The frequency of consumption also depends largely on the season, which determines their availability. Mangoes and oranges are in season from June to August.
 - Fruits available in colmados tend to be expensive and participants stated they have their own gardens so that they do not have to buy the more expensive fruits.
 - Participants have specific provisions on different days and their diet may be limited to the foods available to them on a day to day basis.
 - There is a truck that brings food such as bananas, plantains, tomatoes, yucca, and cajuiles (a fruit) from Pancho Mateo to Severet. Participants noted that it comes frequently, but nothing said about where food is distributed to.
 - *“El azucar y la presion dependen mucho de como se alimenta, pero a veces, come todo lo que aparece, porque no tenemos más.”*
 - Participants understand that diet plays a major role in the development of diabetes and hypertension, but because the availability of food is often low, they are forced to eat whatever they can find and afford.
 - Exercise
 - People with diabetes and hypertension must be kept cool, and thus exercise is not healthy for them. It is considered dangerous.
 - One participant stated that she and a friend walked daily for 3 hours in the morning to get adequate exercise. +2, (3 days a week.)
 - It may be beneficial to start a community walking group. Dora would likely be excited to organize such a group.
 - Participants noted that exercise is a way to reduce your weight, combined with reduced consumption of foods high in fat.
 - Some people are reluctant to exercise because of “sweatiness”, indicating that rehydration after exercise may be unmanageable due to lack of access to drinking water.
 - In Pancho Mateo, there are differing opinions on whether or not youth should exercise.
 - Both note that the youth do play ball frequently, go to school, and wash their hands. There is a tone that suggests that the youth are taking initiative with respect to their futures.

- Access to clean drinking water is very limited.
- Some youth within the community are currently in the process of designing a project to facilitate the transportation of water from a nearby mountain to the community.
- Trash
 - There is no system for garbage disposal. Trash could be seen everywhere on the road and by the river bank.
 - Community members understand that trash is bad for their health.
 - In Severet, people would collect trash together and burn them when they exceed a certain amount. People understand that burning trash causes pollution.

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