FORMATIVE RESEARCH AND PARTICIPATORY GIS MAPPING: ELDER WELL-BEING IN CHIAPAS, MEXICO

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Formative Research on Elder Health and Care in Comitán, Chiapas, Mexico

This article grows out of my (NG) ongoing research on well-being among older adults in Comitán, a small city in Chiapas, Mexico. This work has aimed at jumpstarting two interwoven processes: (1) obtaining, analyzing, and applying information on elder demographics, lifestyles, health, and care, and (2) engaging local stakeholders (elders, care providers, policymakers, social scientists, the media) in the process. The research has assumed a formative research dynamic, conceptualized by Nichter (2004) as a multi-stage participatory process that is iterative and draws upon multiple methods and actors to identify and define a problem, and then develop, monitor, and assess locally-congruent interventions. Fundamental tenets of formative research are that:

- The process should be a partnership, rather than a top-down study. This requires addressing hierarchies of power and authority traditionally framing researcher-subject relationships.

- The project should develop into a cyclical formative-reformative process. Growing insight and rapport among participants facilitate feedback, so that strategies are evaluated and improved in real time.
- The aim is to help meet local needs in a culturally-congruent way, requiring multiple methods, including qualitative research, to achieve breadth and depth of understanding.
- The project should benefit from ongoing participation of an invited social scientist.[1]

This formative research has been facilitated by my decade of previous research in Chiapas, and by the support of the Comitán Center for Health Research (CISC), a Mexican non-government organization (www.cisc.org.mx). With these assets, I conducted: (1) an interinstitutional elder health forum; (2) an elder health and care survey; (3) interviews with elders, care providers, and home-based caregivers; and (4) an elder care planning meeting, which spawned (5) an independent elder health working group. This chapter details how, with Ben McMahan's collaboration, GIS maps of survey data became a springboard for local dialogue and community-based problem-solving regarding elder health and care in Comitán.

Elder Health Survey Data in Standard Table Format

After applying a 339-variable survey to 300 men and women aged 50 and up in Comitán (stratified by age, gender, and neighborhood), I proceeded with standard data entry and statistical analysis in SPSS. I displayed results as percentages in tables distinguishing men from women and local from national rates. To exemplify, Table 1 illustrates the data display (translated from Spanish) for local responses to a survey question about hypertension. I then sent this extensive—hundreds of pages—data display document on CD to be distributed through CISC and the elder health working group to local professionals interested in elder well-being.

Elder Health Survey Data Reworked into GIS Maps

Critically examining my work, I realized that my tables provoked neither individual engagement, nor group interaction. It was then that Mark Nichter introduced me to Ben McMahan, a medical anthropologist with Global Information Systems (GIS) expertise. While commonly used in a more quantitative manner, GIS is also a useful tool for analyzing how different patterns (e.g. behavior, ideas, disease) spread across the social

Table 1. Standard Data Display for Survey Question Regarding Hypertension

Have you ever been told by a doctor or other practitioner that you have hypertension or high blood pressure?
(Valid % excludes values missing due to not responding or not knowing.)

Comitán		Comitán Men				Comitán Women				Comitán All			
		Frequency	%	Valid %		Frequency	%	Valid %		Frequency	%	Valid %	
	Yes-dr.	35	25.4	25.4	25.4	74	45.7	45.7	45.7	109	36.3	36.3	36.3
	Yes-other	1	.7	.7	26.1	3	1.9	1.9	45.7	4	1.3	1.3	37.7
	No	102	73.9	73.9	100.0	84	51.9	51.9	99.4	186	62.0	62.0	99.7
	Dont know	0	0	0	100.0	1	.6	.6	100.0	1	.3	.3	100.0
	Total	138	100.0	100.0		162	100.0	100.0		300	100.0	100.0	

Source: Salud 3E: Encuesta para el diagnóstico de salud & bienestar, cuidados & atención en personas de la tercera edad en Comitán, 2005, SB_9_HIPER:Q8a

and spatial landscape. A foundational tenet is that *where* things are (happening) can be just as important as *what* things are (happening), as well as how things change in place over time. In addition to visually representing health statistics and proportions of people, we can plot where the units of analysis (individuals, diseases, etc.) are located and how they appear, disappear, cluster, and move. This process can be conducted in a participatory manner, as stakeholders may design, direct, conduct, and evaluate data collection, display, analysis, and application. In doing so, participants both make their individual/collective voices heard and become invested in local problem solving. Here, we exemplify the process and products of this merger of participatory research and GIS mapping.

Because I had maintained the data from each survey linked to each elder's neighborhood, McMahan was able to enter this data into a GIS. The resulting maps provide visual clues and reveal patterns that are available, but less readily apparent, in tables. For instance, the map in Figure 1 displays data from the table in Table 1, circles for women with hypertension; squares for men, plotted over the city of Comitán.

Participatory Analysis of GIS Maps on Elder Health in Comitán

Using a few basic GIS visualization tools, we developed a set of maps showing elder health and care data with the aim of engaging local people in evaluating survey results and catalyzing problem-solving initiatives. Then, in summer 2006, McMahan traveled to Chiapas, where I arranged for him to share these maps with CISC personnel (who had helped design and conduct the surveys), and local social scientists and health care providers who had participated in the forum, interviews, planning meeting and/or the working group. McMahan showed a prepared PowerPoint® presentation as well as printed maps, and drew spontaneously on the GIS database. He met with people individually and in groups. On one level, the maps were efficient ethnographic elicitors, evoking direct observations on the data presented. At a deeper level, the maps encouraged appropriation of the research
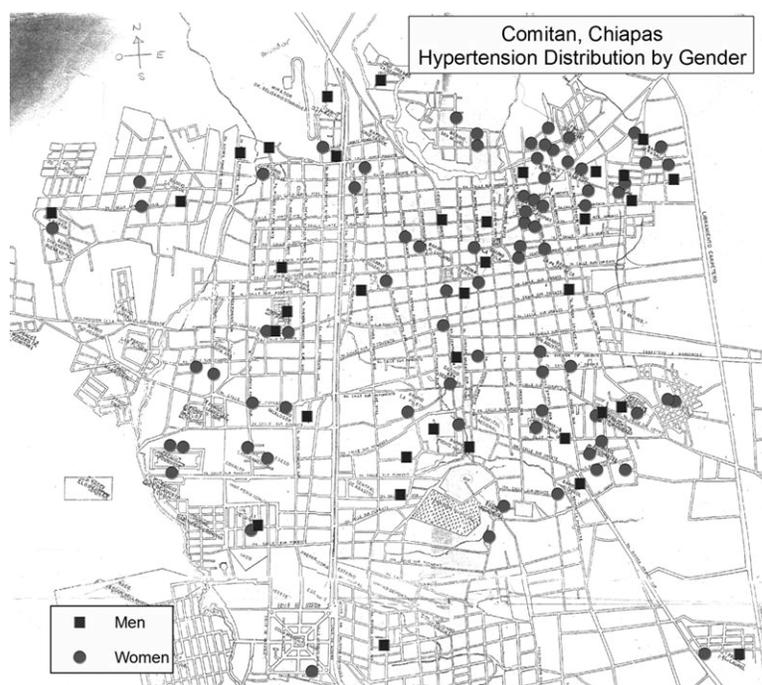

Figure 1. Data Display for Survey Question Regarding Hypertension Using GIS

products and process.[2] To illustrate, we share four examples.

1. Spatial Extent and Severity of Pain, Distance to Sources of Medication

In Comitán, chronic pain is not a focus of health services. Nevertheless, Figure 2 shows the widespread nature of chronic pain, much of it moderate and severe. When in pain, people want fast, convenient relief. So we plotted health care services (crosses), noting that elders live far from these services, and much closer to pharmacies, which are located within three blocks of every home and offer medication without the hassle, wait, or cost of a medical consult. McMahan also quoted from the survey that nearly 1 of 4 elders surveyed self-medicated at least once a week, and 1 of 10 did so over 3 times a week, often for pain. Providers did not anticipate the prominence of pain, and were struck by the distance between elders and services, underscoring the need to work with clinics and pharmacies to address elders' pain.

Further, participants said that maps made the distribution of vulnerable groups clear. Even before our examples spelled out disproportionate health problems in the

northeast quadrant of Comitán, participants held stacked maps to the light to look for clustering. At the same time, by looking at the outliers, participants noted negative cases, anomalies, and contradictions. They also appreciated the maps for demonstrating the severity or systematic nature of certain problems, the maps showing how, rather than clustering, some health problems—like chronic pain—are endemic and spatially widespread.

2. Re-prioritization of Health Problems and Potential for Extra-clinical Care

The maps in Figures 3, 4, and 5 layer different kinds of variables to suggest a re-prioritization of interventions. Figure 3 shows instances of diabetes and hypertension, the most commonly diagnosed diseases among elders in Comitán, and those on which existing elder health services focus. Figure 4 plots cases of poor vision, hearing impairment, and dental problems, which are at least as common and limiting as diabetes and hypertension but not a focus of services. Figure 5 shows elders with vision/hearing/dental problems, limited physical mobility, and no access to their own vehicle. Practitioners discussed how
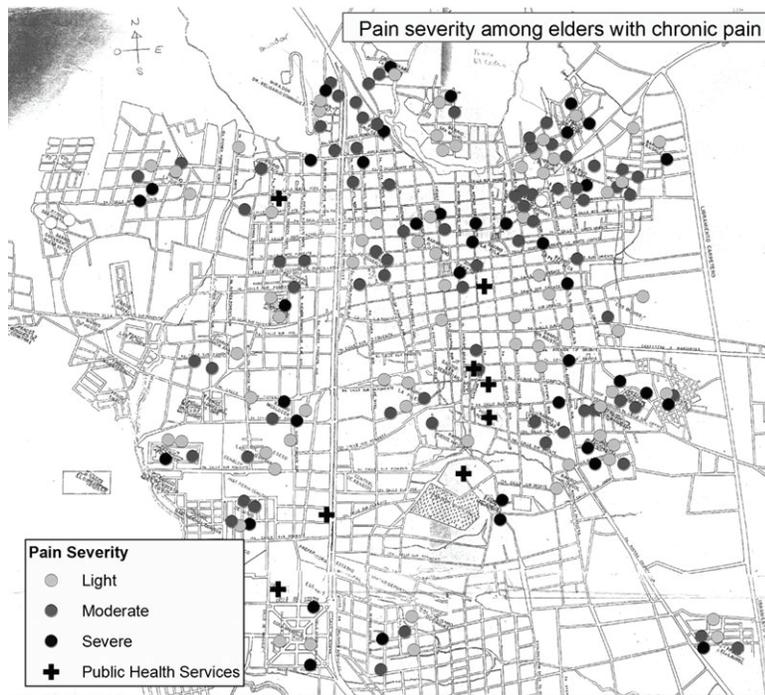
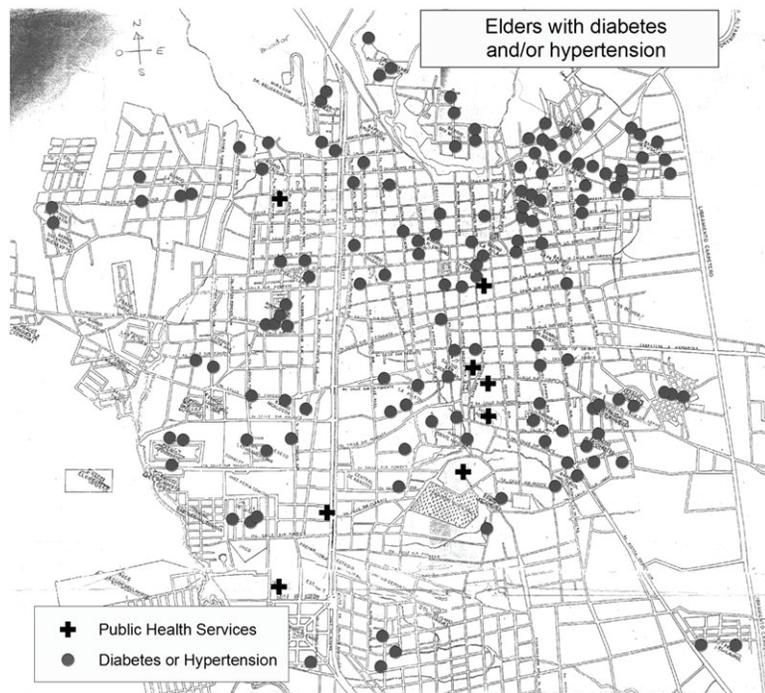*Figure 2. Map of Spatial Extent and Severity of Pain, and Distance to Health Services*

Figure 3. Map of Elders with Diabetes and/or Hypertension

vision/hearing/dental problems affect the quality of everyday life and require specialized medical attention, but can often

be screened for, diagnosed, and treated at home during easily pre-calendared home visits or a mobile clinic.

3. Formal Diagnosis Versus Projected Cases

Another set of maps compared current rates of disease to projected rates, and emphasized the connections between many diseases and exposures rather than single exposure-disease pairs. The map in Figure 6 plots the few elders with diagnosed respiratory illness (emphysema, tuberculosis, pneumonia). The map in Figure 7 shows these cases, plus elders who had chronic cough and/or (had) smoked a pack or more of cigarettes a day. This map identifies elders who likely have, or will develop, respiratory illness, and should be monitored.

4. Impact of Infrastructure on Production of Health

Participants, most trained as physicians, were much more accustomed to looking at individual-level data, such as a patient's chart. Viewing issues from a city-wide perspective offered a new orientation. Individual medical troubles became community problems. For instance, they were aware of health problems provoked by water quality and supply, but the maps encouraged discussion of wider societal issues. In response to the map in Figure 8, showing the 18% of elders without an indoor water faucet, participants offered up their own knowledge.

Participants discussed how the need to carry water made washing dishes and clothing, cooking, bathing, flushing toilets, and house cleaning difficult, and how, due to the gendered nature of everyday tasks, water supply challenged women more than men. They pointed out to McMahan that the question of indoor versus outdoor faucets is moot because Comitán's water supply is eternally limited, and that this is due more to politics than to the water table. They indicated on the map other influential factors: if you lived along the PanAmerican highway or downhill from the mayor's house, you always had water, but the recently settled outskirts of town never had water. The hospital, perched atop a hill, rarely had water and relied on expensive tanker trucks. In this way, the maps triggered reflection on factors beyond the scope of the data presented.

Participatory Mapping as an Ethnographic Elicitor

As ethnographic elicitors, the maps inspired insightful observations about the data presented and an appreciation of value added by spatial information and visualization. People asserted that maps were much better than exhaustive statistics and tables for exploring problems, envisioning solutions rooted in time and space, and conveying messages. For instance, a working group member said, "These maps are very evocative and impressive. They really help describe the problem in a way that is easy to understand, much easier than a series of tables and statistics." Presenting a sequence of successively more detailed maps was also deemed useful for considering multiple complementary and interrelated variables at once. Syndemics, or co-occurring problems, became apparent as well. As CISC's Director explained while holding maps to the light to see overlap, "The visual display of the results helps to understand the interaction of the different diseases. We can't necessarily treat these as individual diseases, because clearly many interact with and affect each other." A local demographer similarly observed, "I really like how the maps allow us to see how the data are distributed, especially the interaction between diseases. And also the gender differences that the data can demonstrate." Further, the maps challenged participants' expectations. For example, providers expected to see a relationship between the use of wood for cooking and respiratory illness, yet were surprised that the maps did not evidence a correlation. Conversely, service providers did not anticipate pain as such a prominent problem, yet could not ignore the abundance of dots on the pain maps.

Participatory Mapping for Appropriation of Research Products and Process

Beyond eliciting reactions to the data, the maps also inspired the appropriation of research process and products. This began with an altered nature of the
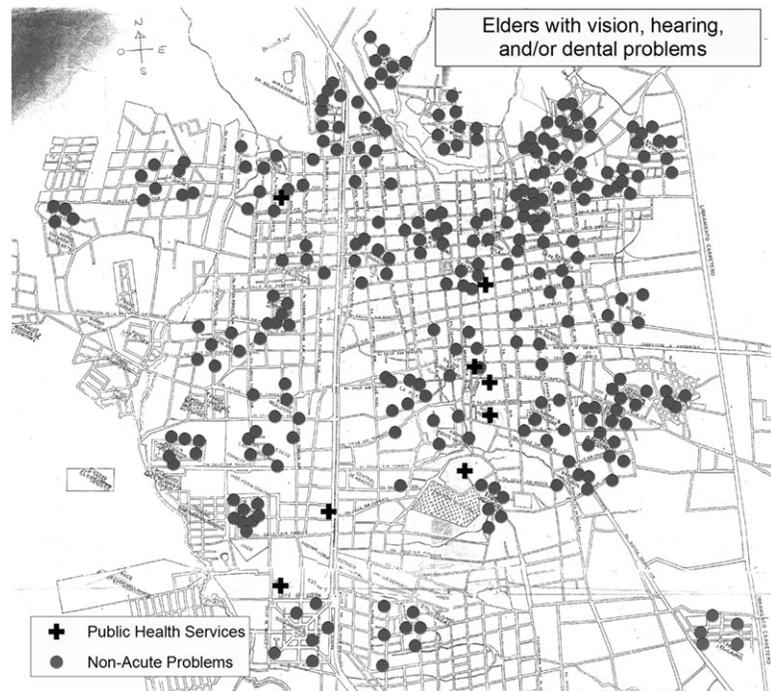

Figure 4. Map of Elders with Vision/Hearing/Dental Problems
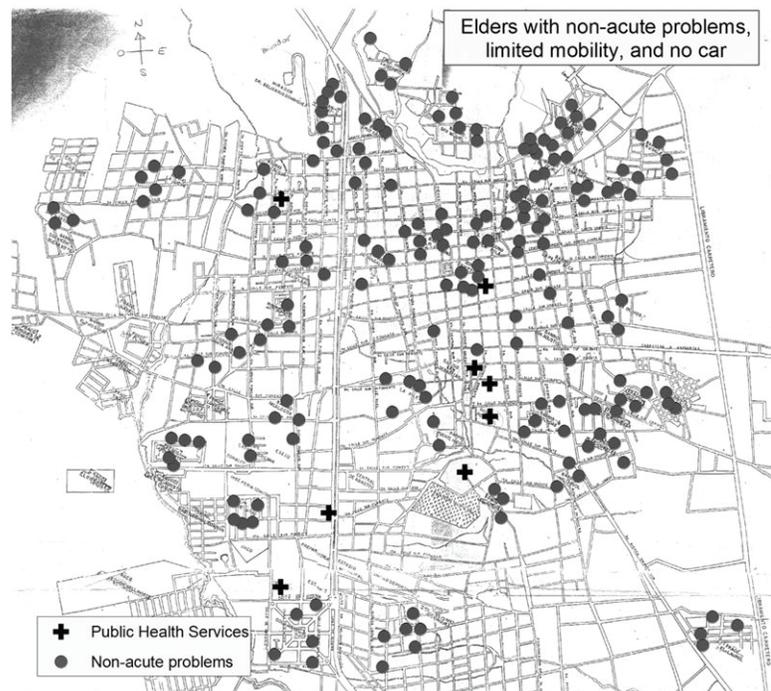

Figure 5. Map of Elders with Vision/Hearing/Dental Problems, Limited Mobility, and No Car

researcher/informant dynamic. Rather than a vertical "dumping" of results, presenting the maps was a horizontal exchange, and sometimes even a vertical exchange with participants orienting the presenter. The maps encouraged
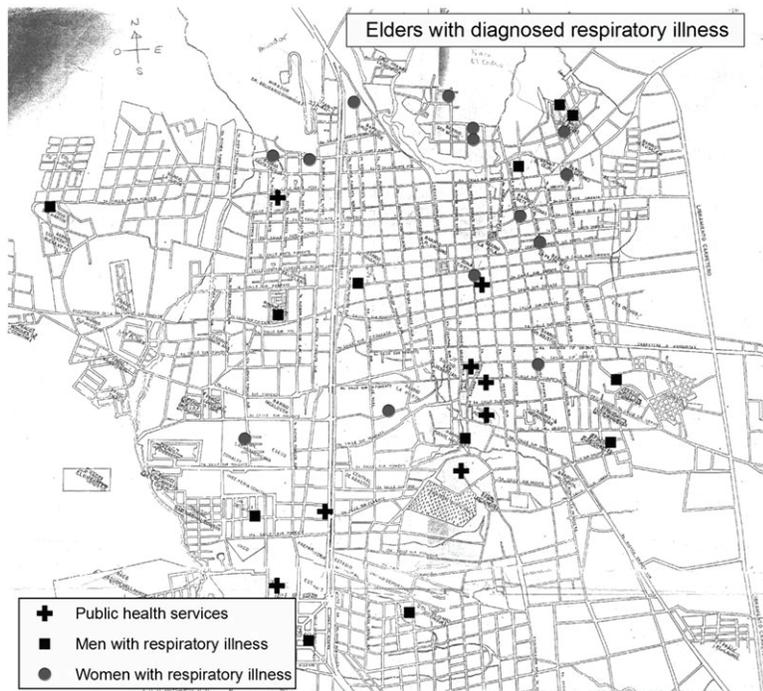
Figure 6. Map of Elders Diagnosed Cases of Respiratory Illness
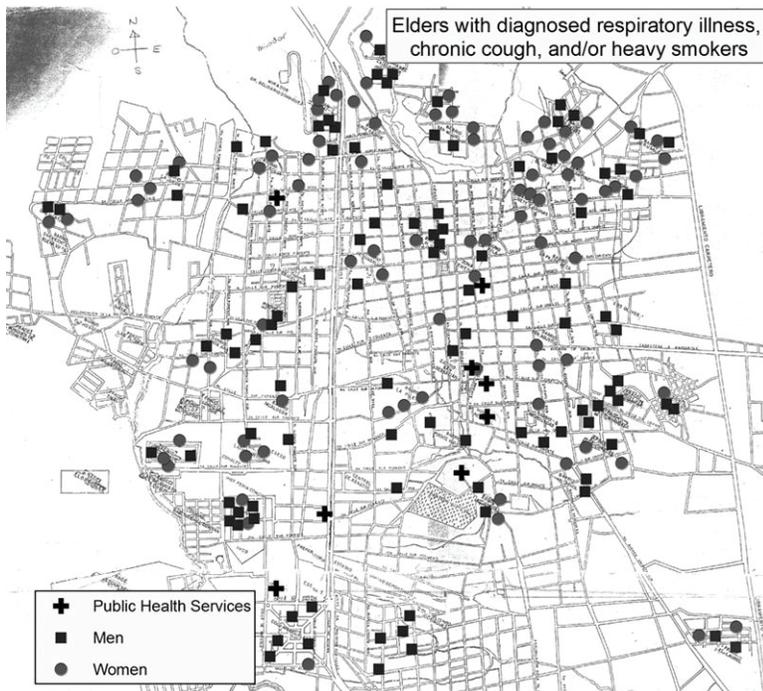

Figure 7. Map of Projected Cases of Respiratory Illness

process, our approach was to focus on the community-based nature of both the maps and the information that went into producing them.

Exposure to the maps awakened informants' desire to pull in additional data to better address problems. Health service providers wanted to overlay the locations of water lines, transportation routes, pharmacies, and the topography of Comitán with the survey variables. Participants provided McMahan with insight unavailable to analysts, for example, the information garbage disposal, air quality, and water supply. Rather than controlling for sex or residence, the maps inspired people to wonder about each location and population sub-group. For instance, a local demographer dedicated to gender and health requested maps distinguishing men from women, to visually evidence local women's plight. Additionally, working group participants noted that Comitán extends far beyond the limits of the survey, and suggested that the city's swelling perimeter be added, with the conviction that residents of the fringes would be especially challenged by health problems, reduced mobility, and limited infrastructure. Practitioners emphasized social structural factors as part of the cause of problems, which propelled them to consider innovative political and judicial approaches to the remedies.

Not only did the maps fuel desire for additional data regarding elder health, but they also inspired brainstorming about other issues to address with GIS tools. Participants expressed a genuine curiosity about how the process works, the types of variables one could map, and how this might work in future endeavors. They began to talk among themselves about how this method might be implemented for other diseases/variables and other groups of stakeholders. For instance, a local epidemiologist and coordinator of the elder health working group, observed,

How do you think we can use the maps as part of research/interventions? They have to be more than just pictures of the data.... One of

people to share their knowledge and expertise, to increase the accuracy and breadth of map content, as well as to

refine the questions asked to produce the maps. While maps are often viewed as a technical result of an expert driven

the big problems we have encountered is the lack of perception of risk in 'at-risk' communities and how this affects behavior and response to these risks. Maybe if we took maps and showed them to people to generate a sense of risk, this might help motivate behavior change… to make people think about diabetes. They are at high risk but they are unaware or ignorant of these risks. These maps might display visually what tables and statistics are often unable to convey… [i.e.] "*you* will become one of these dots if you fail to do x (or if you keep doing y)."

Further, participants realized that the maps could be used from the research planning stage. Another working group participant asserted,

We should use maps to design our future studies to make sure that we accurately represent the entire region. Maps could be used in sample/research design as well as analysis. This way we would be sure to cover all areas, especially the northeast of the city where lots of growth has occurred and residents are far away from services.

People also suggested using maps to keep track of progress and distributions of people/patients visited and to visit. Participants went beyond suggesting variables and issues that might be mapped to considering the possibility of learning how to do GIS analysis themselves. One, for instance, asked,

How easy is this to learn? Because this is a tool that would be very useful, especially if researchers could learn how to analyze and explore the data. If we were able to analyze our own data over time, we could think about new questions to ask with the data. And we could always be thinking about how our data might fit into the maps.

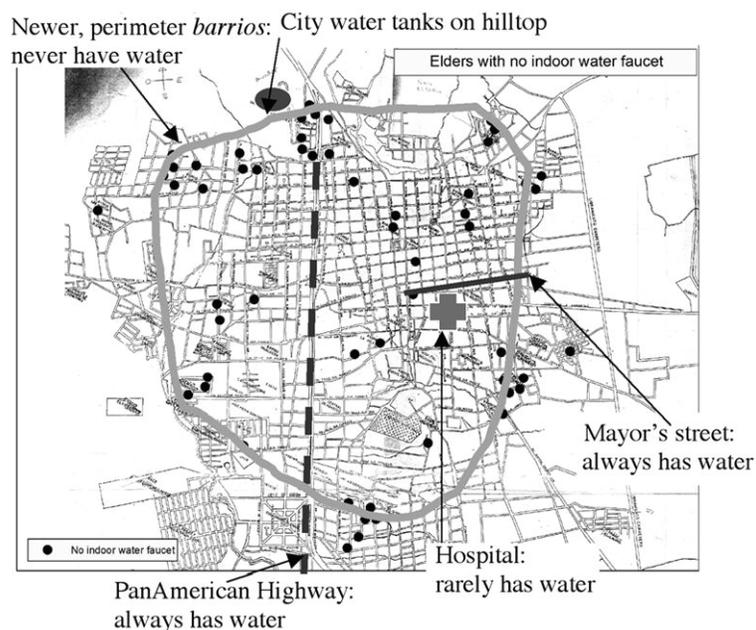People wanted to understand and manipulate the technology—a real

Figure 8. Map and Notes from Discussion on Water Supply

Figure 9. Photo, Water Storage

possibility, given that no high-level GIS skills are required for basic map creation and manipulation. Much GIS work is based in conversion of non-GIS data into a usable format in order to then fill and maintain a database. Once the data is ready to be manipulated, anyone with intermediate computer skills can learn how to do the basics in a fairly short period of time. Key capabilities are then to ensure that the data that goes into generating the maps is not flawed and to develop an accurate interpretation of the maps. If local people acquired these skills, outside researchers (such as ourselves) could then retreat into an advisory role, perhaps assisting via Internet between in-person support sessions, while local actors perform data collection and analysis.

Figure 10. Photo, Comitán's Hilly Terrain

Figure 11. Photo, Tanker Truck Pumping Water into the Comitán General Hospital

The map presentation also piqued interest in merging with other local researchers and projects. Participants noted the existence of other local mapping efforts. Most, however, were conducted at the municipal and state levels, moving participants to realize that they could incorporate information from these larger-scale projects to contextualize local findings, and produce more locally-relevant information. A nurse was excited about approaching the hospital's statisticians: "You should really meet with the statistics people at the hospital. They might have some information that you could use with the maps, like where people are coming from and what sorts of problems they are experiencing."

In general, participants were enthusiastic about sharing findings in this format. CISC's Director said encouragingly, "I think it is very important to present this information to some local leaders. This information could be really useful and I think that there should be a public presentation of this information." They even suggested sharing results with the general public—via a public presentation, an Internet Map Server (IMS), or a similarly organized website.

A final noteworthy instance of appropriation of the research process and products was the reaction of CISC personnel, among whom seeing the maps reaped satisfaction of a job well-done. Having participated in development of the survey questions and data collection, they were pleased with the visual demonstration of work completed. CISC's Director commended,

> These are really just representations of the information collected as part of the survey. In order to generate maps such as these, there is a lot of work that goes into data collection in order to have data that is possible to map.... So it's nice to see the outcome of the survey put into maps. There was a lot of work put into the survey, and these help to display the problems that we are dealing with.

In sum, sharing GIS maps was useful—much more so than sending tables—on a number of fronts. With my initial tables, survey information was transferred from informants' words to paper, becoming personal and private. With visual sharing of the maps, in contrast, all present could see, point to, discuss, and perhaps even manipulate and alter representations. The presentation complemented other means of ethnographic elicitation (e.g. interviews, forum) by inspiring participants to reflect on, question, debate, request, and share information. Because visualization is not a neutral language, interpretations varied, provoking rich discussion. Yet rather than inciting a quagmire of critique and politics, the data, presented in this non-threatening way, became a springboard for stakeholders to address realities collaboratively. Participants engaged with the maps and their colleagues, discussing potential interventions as varied as mobile clinics, research protocols, community health workers, local policy change, and a community elder center. They were able to look "upstream" at matters of prevention and risk communication, and "downstream" at distribution of patients, resources, and needs. The maps motivated people to explore, analyze, and represent their perspectives in their own terms and in a format that was visible, semi-permanent, and public. Information was cross-checked, verified, amended, added to, and owned by the participants. Local people became analysts, while our role was to use the maps to catalyze engagement, and then retreat into a less prominent, less invasive role of observing, assessing, documenting responses, and facilitating appropriation of process and products. Figure 13 contrasts my initial strategy to share data via a CD of tables with our subsequent sharing of data via a participatory GIS dynamic.

Potential Expansion of Formative Research-GIS Map Merger

The participatory nature of this research was largely limited to local involvement in data gathering and reaction to completed maps. However,

participants' response to the maps is indicative of the potential to make all stages participatory, and in line with the iterative tenet of formative research. One could imagine a project in which research design, data gathering, analysis, and mapping stages are all iterative and participatory, characterized by on-the-fly development and modification based on negotiation and dialogue among all involved. Even the final stage of data presentation and discussion could take place within a public context in which additional feedback might be recorded, thereby improving both the quality of research and community engagement in research process. For instance, local stakeholders could go on transect walks in the city to guide research design; construct, embellish, and edit maps; present results to residents, etc. Spatial information might be combined with chronological information, such that series of maps can show locally-relevant trends and historical patterns, by week, season, year, generation, etc. Local people might take up the mapping technique and use the method for themselves, interpreting, applying, and adapting the method themselves. Their appropriation of the method would be a true affirmation of local people as knowledgeable actors, and of researchers as learners and facilitators. Further, maps made by different groups of stakeholders would likely evidence key contrasts in perspectives.

Stepping back to gain perspective on the participatory GIS mapping experience inspired questions about relations of power between researchers and local people. McMahan reflected:

When someone asked, "is it possible to display the data based on gender differences?" I was able to respond by modifying the data/display/representations/etc. Yet the dynamic went beyond participants' requests and my manipulating the data in response. Some people were very excited and energetic to discuss and interact with the maps. They picked them up, flipped through them,

	Sharing results via tables	**Sharing results via PGIS**
Outsider's roles	Investigator/Analyst	Initiator/catalyst/facilitator
Outsider's mode	Presenting results	Facilitating discussion
Outsider's intervention	Total while producing tables	Initial and then reduced
Insider's roles	Reader	Analyst
Insider's mode	Passive and/or reactive	Creative
Personal contact with others	Low	High
Medium & material are those of	Outsider	Insider
Detail influenced by	Etic categories	Emic perceptions
Information flow	Sequential	Cumulative
Accessibility of info to others	Low & transient	High & semi-permanent
Initiative for checking lies with	Outsider	Insider
Ownership of information	Appropriated by outsider	Owned & shared by insiders
Utility for spatial, temporal, causal analysis, planning, monitoring	Low	Higher

Adapted from Chambers 1994: 1264.

Figure 13. Table Data Display Versus Participatory GIS Data Sharing Modes

and returned to previous maps to compare them. This speaks to the methodology of the participatory research process. Although we have the technology to present the maps digitally, it makes sense to also make paper maps that are left with the participants. That way, viewing the maps is not centered on the technology of—and access to—the computer. Instead, the maps become property of the partners, to do with as they please, to return to other ideas, etc. The linear nature of a PowerPoint® presentation is good for organizing a narrative for presentation to a group, but it limits the crucial ability of the group to interact and modify the order of discussion. The possibility of making the project overly-technological is certainly a risk. If we show up with computers and information,

how do we convey this information to partners without dominating the process? This goes beyond a question of computer literacy, as most/all partners are computer literate to varying degrees. It is a question of expertise and how to convey that expertise (in this case GIS) without obfuscating the real reason of making the maps: to solve a problem. (McMahan, Personal communication, 2007)

In closing, we call for colleagues to explore three key questions:

- How do maps help generate questions or lead to solutions of existing problems?
- How do maps spur local involvement in a research process?
- How do maps foreground problems and power relationships that might otherwise be obscured?

The answers have as much to do with the interaction with maps as the actual maps themselves.

Notes

[1] Regarding formative research, see: Nichter 1990, Nichter et al 2002, 2004.

[2] Chambers (1994) and Cornwall & Jewkes (1995) provide insightful reviews of the process, advantages, and challenges of participatory, community-based visualization of data.

References

Chambers, Robert
1994 "Participatory Rural Appraisal (PRA): Analysis of experience." World Development 22(9): 1253-1268.

Cornwall, Andrea and Rachel Jewkes
1995 "What is participatory research?" Soc. Sci. Med. 41(12): 1667-1676.

Nichter, Mark
1990 "Eight stages of formative research." Retrieved March 8, 2003 from www.medanthro.net/academic/tools/nichter_formative_research.pdf.

Nichter, Mark, et al.
2004 "Qualitative research: contributions to the study of drug use, drug abuse, and drug-related interventions." Substance Use and Misuse 39(special issue): 1907-69.

Nichter, Mark, et al.
2002 "Using qualitative research to inform survey development on nicotine dependence among adolescents." Drug and Alcohol Dependence 68: S41-S56.

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