Exploring Obstacles to Perinatal Care-Seeking Behavior In Women of Rural Odisha, India Using a Community Based Participatory Research Approach

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EXPLORING OBSTACLES TO PERINATAL CARE-SEEKING BEHAVIOR IN WOMEN OF RURAL ODISHA, INDIA USING A COMMUNITY BASED PARTICIPATORY RESEARCH APPROACH

By

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Submitted in Partial Fulfillment of the Requirements for Graduation with Honors from the South Carolina Honors College

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Our senior thesis documents our journey of partnership with ARM and our learning process, not only about factors contributing to our research questions, but also about that nature of partnership with a community and ethical decision making within this context. Rajendra, the founder of Alternative for Rural Movement (ARM), asked that we design a study to determine why women put themselves at risk and deliver at home with untrained traditional midwives instead of delivering in a clinic or a hospital. Delivering without skilled personnel present is a fundamental global health issue faced in many developing countries; labor and delivery is incredibly complex and complications occur spontaneously and without warning, causing many mothers and infants to die if they are not given adequate medical treatment. Many have attempted to explain the reasons women chose to take such a risk. The Three Delays Model, one such explanation, asserts that the decision to seek care, access, and the availability of care are the three most pertinent issues. The public health sector designed different solutions to address these problems, from training traditional birth attendants to offering incentives programs. However, an anthropological lens shows that cultural factors, such as the symbolic meanings attached to birth and a cultural tradition of female seclusion, and historical factors such as the mass sterilization campaigns of the 1970s may influence on the decision to seek care. A psychological lens reveals the tendency of Indian culture towards collectivism, a focus on sense of community, which may be causing an aversion towards delivering outside the home. I used the theory of Planned Behavior, a psychological framework, to design questions exploring the beliefs women
had about delivery in a clinical setting, beliefs about others’ opinions, and beliefs about their control over the situation. This framework allowed me to synthesize all that I had learned through the public health, anthropological, and psychological lenses and design a survey to determine if these factors are actually considered when a woman decides not to seek care. The underlying complexity of the issue makes community partnership essential, because only half of the knowledge needed to solve this problem can be found in the vast databases we have access to through our university. The other half resides within the community—with community health workers, village leaders, self-help group members, and villagers in general. Only they know the community and its special needs, strengths, and weaknesses. A partnership that places the voices of the men and women of Baliapal at a level equal to our own is taps into knowledge that is integral to the success of this project.

Sarah Law

After our partner community was devastated by Cyclone Phailin, Runjhun and I were forced to take a step back to reconsider our plans for this thesis. Research never goes quite the way you think it is going to, so adaptability and flexibility are key skills for those wishing to engage in any sort of research endeavor. We decided to postpone the dissemination of the preliminary survey we had drafted during our trip, and—upon reflection—this turned out to be a very good choice. During this interlude, I have had the opportunity to really dive in and develop our methodology more clearly. I learned about Community Based Participatory Research in Dr. Simmons’s Medical Anthropology class, and it quickly became clear that adopting CBPR principles would help keep our research in line with the guiding philosophies of both Alternative for Rural
Movement and GlobeMed. In my research, I learned about the historical and theoretical origins of the participatory research movement; explored the connections between CBPR, the Health Belief Model, and Feminist Theory; synthesized a list of twelve essential components of CBPR and explained how to incorporate those principles into the research design; and outlined the pros and cons of CBPR. It is my hope that this part of the thesis will give to the students who take over this project a good understanding of the attitude with which they need to approach social research. I also developed a Training Manual that will be used to teach the SHG leaders how to conduct surveys. A very important part of this whole process and of our GROW trip was when the SHG leaders told us they had little interest in participating in research without getting anything in return. By adopting and sticking to CBPR principles, breaking down the traditional walls between the “researcher” and “subjects,” building strong relationships, and demonstrating commitment to the success of this project, I think we—and the students who continue this project after us—will be able to repair that trust that other researchers have damaged and ultimately produce much better results that will actually help make a difference to these women.
ABSTRACT

This project resulted from collaboration between USC student organization GlobeMed and the Alternative for Rural Movement (ARM), a non-governmental organization in Odisha, India. Rajendra Rana, the head of ARM, expressed the need to delineate the factors underlying the tendency of rural Odishan women to deliver with unskilled birth attendants as opposed to institutionally. A literature review was conducted to explore possible economic, cultural, and social factors. During five weeks in Odisha, discussions with women's groups, community health workers, and ARM staff members built on the literature review. A preliminary survey and plan for its dissemination were developed. The community based participatory research (CBPR) method was researched and chosen because of its alignment with GlobeMed and ARM's goals of community empowerment and sustainability. Training for dissemination was scheduled to begin in January 2014, but a cyclone led to concerns about directing ARM's resources away from the disaster. Plans were postponed until May 2014. Principal findings are the possible factors that could underlie the decisions rural women make including: cultural preferences for delivering with family, power dynamics attached to the traditional birth attendant, cultural meanings attached to birth, lingering mistrust in health care providers due to the sterilization campaigns of the 1970's, cost, distance, and lack of knowledge. The issue is complex, and the right questions must be asked in order for ARM to solve this problem within its community. Through the project, the investigators strengthened the partnership and provided an avenue for learning for future students of public health at USC.
INTRODUCTION

Research Questions and Purpose of Thesis

Our essential research question explores, through interdisciplinary lenses, the factors that are contributing to the underutilization of skilled birth attendance and perinatal care by the women living in the villages of rural Baliapal, Odisha, India. We aimed to use an initial literature review to develop a survey that could be administered to determine the extent to which these factors are at play in women and their families’ decision-making processes. We developed a training manual to administer the survey and identified Community Based Participatory Research (CBPR) as an appropriate research philosophy and asked how we could apply its essential components to guide future research and collaboration with ARM. On the surface, the goal of our thesis is to help ARM determine how best to appropriate its resources to effectively improve safe birth in the area. However of equal importance is our underlying to strengthen our partnership with ARM and the people it serves; by exploring key principles to successful, equal, and ethical partnerships, we hope to become more useful to ARM and gain more from our thesis as a learning experience. Much of what we have learned about partnerships and ethics will enrich our future work in the fields of medicine and public health. Additionally, we hope to create an avenue through which future students in the Arnold School of Public Health can learn practical lessons about study design, interdisciplinary research, and ethics in decision-making. We envision the creation of future leadership that is able to conduct research in a thoughtful, ethical, and effective manner. Ultimately, we hope that our project is a challenge to turn the traditional research paradigm on its head and engage in a partnership with the community,
ensuring that it has a strong voice that permeates every aspect of the process, from the development of the research question and methodology to analysis and dissemination of the results.

**Background of Collaborating Organizations**

by Runjhun Bhatia

**The GlobeMed National Network**

After completing an intensive selection process including an application and an interview, I finally received the consent to begin a chapter as acting Co-President and founder at the University of South Carolina. Since then, the national office then provided us with an immense amount of support and training so that we can implement GlobeMed's unique model effectively. Essentially, at the chapter level, a GlobeMed chapter is an organization of university students dedicated to promoting and learning about global health. This is accomplished at the international level via a partner organization; each chapter has its own. At the campus level, students promote awareness of global health issues on in creative ways. They also participate in and lead weekly discussions and activities at organization meetings that explore a network wide topic such as "health as a human right". Students also use their campus to fundraise and as a source of other resources for their partners. Finally, the GROW coordinator and team organize a trip to work with our partner organization for 6-8 weeks during the summer. This trip has many purposes including project implementation, partner accountability, relationship building with our partner, and media collection for better advocacy.
The organization consists of a staff board of who populate the committees led by 11 executive board members. The GlobeMed model is a unique one in that it is marked by its non-invasive approach to global health. Our chapter was partnered with a community-based organization in Odisha, India that is using initiatives in health, education, agricultural, and general economic development to improve the lives of the people living in the communities it serves. This partnership entails frequent video conferencing with our partner to become aware of their model and their needs. A deep knowledge of their needs allows us to advocate for them effectively. Furthermore, as students of public health, this is long-term exposure to the inner workings of a successful NGO that serves health and development that we can learn from. This makes our education pertinent and useful in the present, rather than knowledge that is static and simply waiting to be used sometime in the future. We are able to tap into our education and influence the world of global health without being intrusive. What makes this powerful is that it creates an awareness about the interdisciplinary nature of global health, and allows students to be genuinely useful. We are not experts in the field of public health, and yet, we have the opportunity to make a measurable impact.

Through these initial video chats, we devise a Memorandum of Understanding (MOU). This is an ever-evolving contract with our partner that details our responsibilities to them as well as other aspects of our relationship. In this document, we determine the projects we are to fund, the impact and evaluation of these projects, the specific line-by-line breakdown of costs, when and where to wire the funds we raise, communication guidelines, and when we will complete our summer internship with them. We also agree to provide for them other resources within our capacity. After much thought, we realized
that the GROW internship was the perfect opportunity to use our university resources to
develop a project for our partner. We started by telling them that we had professors of
all disciplines at our university, and that as our senior thesis, we could design and
implement a project under the advisement of a faculty member. Mr. Rajendra Rana, the
Coordinating Member of ARM, expressed a need for a study exploring the factors that
contributed to women's failure to seek out delivery and care during the pre-natal,
pregnancy, and post-natal periods. He explained that there were many possible factors,
but there needed to be a study to discern the most significant factors so that ARM could
take an appropriate course of action.

Building a Partnership

Our relationship with ARM picked up at the end of another. Sarah Endres, our
chapter advisor, had an uncharacteristically serious look on her face during one of our
first advising calls as she told us, "Now, what you've got to understand about your
partner is that this is their second GlobeMed partnership. Their previous chapter failed
them; there was no communication, and in the last year, the chapter raised only $40. So,
you might have some trouble getting in touch with them, but be patient."

ARM's disheartening relationship with its previous chapter had been
characterized by a lack of commitment and communication on the chapter's part. I
learned later that this turned into a dissatisfying GROW internship, in which the interns
were unable to adjust to life in Odisha and unable to further their relationship with ARM
into one of trust, openness, and partnership. Rajendra, never one to speak an unkind
word, shook his head with disappointment as a clear look of displeasure crossed his
face when I asked about them. "It was not good," he said, "They were not able to fit in like you all have."

Angela, the Internal Co-president at the time, and I were handed this situation and told that we had to basically undo this damage and somehow establish a flourishing relationship through video chat. At first, we struggled. For more than three months, it seemed nearly impossible to get in touch with Rajendra and Sachi. We seldom received responses to our e-mails. When we did, and we managed to schedule a time to meet, there was an understandable guardedness about their manner. I wanted our new relationship with ARM to be defined by the idea that "humanitarian efforts" should not necessarily assign roles of giver and receiver, but rather create relationships founded on learning, respect, and equal partnership. This is a difficult proposition; the nature of the donor – beneficiary relationship is inherently unbalanced; by virtue of being a resource provider and by virtue of the beneficiary’s dependence, the donor creates a power discrepancy. This power discrepancy can often lead to the beneficiary’s reluctance to voice concerns about the donor’s suggestions and ideas. Although the donor may be well intentioned, the donor and beneficiary do not have a clear line of communication. This is problematic, because ARM, a well-established organization, has an expert knowledge of its community. This expertise is made completely unavailable in a power discrepant relationship which poses the risk that we make suggestions that are harmful or unsuitable to the community. A humanitarian relationship can quickly become toxic for the beneficiary.

At the Leadership Institute in Evanston that year, I spent a lot of time asking other chapters for advice on creating a strong connection with our partner. I was taken
aback to discover that few chapters had really close connections with their partners; even many older chapters faced similar communication issues. The two or three chapters who had been successful on this front advised me that once we got in touch, we should start by talking about simple and personal things, rather than delving into an overwhelming conversation about goal setting and fundraising. I approached Dr. Billings, my mentor, who advised that I be very respectful and humble in these conversations and focus on learning from our partner and listening to them. Finally, my linguistics professor advised that I speak slowly, enunciate clearly, and possibly even use an Indian accent if I could. I did all of these things. In an initial Gmail chat conversation, I asked Rajendra and Sachi questions about Odisha and its people, referring to the annual report and website to make it known that I had researched ARM thoroughly. I sent Rajendra pictures of our retreat, our organization fair, our first meeting, voicing our excitement about working with them and learning about them. I told them about how many people had shown interest in the organization. As I learned more about ARM's work, I made it known that I was impressed by how much they did. Since then, I have had a lot of great video conversations with Rajendra. I often leave my Skype up and Rajendra feels comfortable with calling or e-mailing me whenever he needs to.

When we left for Odisha, though I had done extensive research on the problems that accompanied a lack of skilled birth attendance, I left with an open mind. Our research project needed to engage the women, empower them, be sustainable, and give as equally as it took. I had only these simple values in mind, but made no plans. Plans and ideas proposed before we understood the community would be impositions, creating a power discrepancy between the villagers and us, placing our desire for
knowledge over their needs. Students, eager to apply new skills, are especially vulnerable to this frame of mind. My goal for our research project was for it to reflect the needs of the community, elicit their participation, and empower them in the process.

The Decision to Partner with Women’s Self Help Groups

When we went to India for six weeks on our GROW internship, Sarah and I started looking for feasible ways to explore this issue so that ARM would have a better understanding of which solution would best suit its community. Administering the surveys ourselves was an option crossed off early on; with the language barrier and our limited time and capacity, this simply would not work. To me, it also did not "feel right". The importance of partnership and empowerment and an aversion towards paternalism has been imprinted into my ethical standards through my various public and global health experiences. I felt that our senior thesis could be a chance to empower the very women we wanted to help. After spending four weeks getting to know the villagers, I finally saw that opportunity; in this society, women lacked power and independence, but they were beginning to claim it through micro-enterprise groups known as SHGs. Although these groups were intended to be used for income generation purposes, they had begun to turn their attention to social issues. They were involved in a political movement to criminalize alcohol, a drug that resulted in domestic abuse and was an outlet for men to use up much of their surplus income. I was struck by the resemblance of the SHG to the women's groups that had been the unit of many successful community participatory action cycle (CPAC) interventions, from Ekjut to Makwanpur and Bolivia. CPAC, which trained groups of women to explore, research, and come up with solutions to their own problems, seemed to fit extremely well into the GlobeMed
model of empowering the community and amplifying our partner’s voice and with much of the work that ARM already did within the community.

Such a partnership would allow our project to be useful for the community and for the women immediately and in the long term. In the short term, women would explore the significance of this issue for them and their community through discussion groups, becoming invested and engaged. In the long term, training and empowering SHGs to address the lack of skilled birth attendance would provide them with authority, resources, and skills that would aid their involvement in social issues. Because of short term and long-term impacts, this model seemed to be the most ethical and sustainable way to design the project. The infrastructure to train SHG leaders to administer surveys was already present. After discussing the idea with Rajendra, the founder of ARM, and then with SHG leaders themselves and seeing a strong interest in the project, we decided to take this route.

Alternative for Rural Movement

Before GROW, we had a hard time explaining the assorted work of ARM to the casual passerby. How could agriculture training and a primary health center be classified under a single mission? After experiencing villager life first hand, from speaking to self help groups from different villages to eating leaf plates sitting cross-legged on the mud floor of a villager’s home, we began to understand the answer to this question. We realized that ARM made low cost, high yield investments to improve basic quality of life. That's why they supported self help groups for the women and improved their position in society, worked to increase the income of a family or a village through vocational and agricultural training, and built latrines.
With little over $160,000 per year, they support initiatives for over 200,000 people spread across 12 villages in the Baliapal district in Balasore, Odisha, India. Much of rural India still lives in the past, lacking amenities such as basic health care and sanitation, education, means of economic growth, and women and children's rights. ARM recognizes that there are many contributing factors to the problems that rural India faces, and thus envisions reshaping their community with a wide spectrum of initiatives to promote development. An overview of ARM's main activities include a system for extensive community and maternal health care, an expansive education program with a resource development center, awareness, advocacy, and vocational programs for girls at risk for trafficking, micro-finance and entrepreneurship opportunities for women (tailoring training), women and children's legal aid and political empowerment, and sustainable agricultural education and research initiatives. This list is far from exhaustive.

Most pertinent to our study is ARM's extensive involvement in maternal care. ARM is sponsored by the Indian government to own and manage a public health center in Paschimabad. Through this center, it provides among other things an ambulance service, maternal care and delivery, family planning, immunizations, and health promotion programs pertaining to maternal mortality.

It is exactly this breadth that makes ARM so highly effective; because of their extensive involvement, they can create an environment conducive to health, and act as a valuable resource for the people of rural Baliapal. When I look at the public health literature, what pops out are the well cited example of a handful of low-income areas with good health statistics such as Cuba, China, Kerala, and Sri Lanka. Their success is
the result of government investment in projects encompassing sanitation, education, and nutrition. I think that ARM and increasingly the Odishan government are on the same path. People under the poverty line in the country have decreased by more than 20% in the last few years, a greater decrease in poverty than any other state in India. More than anything, the reason ARM does so much and has a successful model is because they are partnering with the community at an individual, face-to-face level.

LITERATURE REVIEW- UNSAFE BIRTH: A GLOBAL HEALTH PROBLEM

By Runjhun Bhatia

There are great social injustices and inequities in the world. Governments and organizations at the local, national, and international levels are striving to reduce human suffering, and improve the lives of billions of people living in poverty throughout the developing world. International organizations such as the UN are often required to set goals that coordinate efforts and guide the best use of resources put toward this effort. The UN Millennium Development Goals (MDGs) are such an effort to define specific goals and ways to monitor progress towards those goals. One of the keys to achieving MDG-5, which is directed at improvements in maternal health, is striving that all births be conducted with a skilled birth attendant (SBA) present. An SBA is defined by the World Health Organization (WHO) as “an accredited health professional who has been educated and trained to proficiency in the skills needed to manage normal (uncomplicated) pregnancies, childbirth and the immediate postnatal period, and in the identification, management and referral of complications in women and newborns,” (United Nations, 2012). Skilled birth attendance is used as one of two measurements of progress in maternal health. This is because the three major causes of global maternal
mortality are hemorrhage, infection, and eclampsia -- complications that are largely unpredictable but treatable with the appropriate medical care. Without a skilled birth attendant present, these complications turn into maternal mortalities (Canavan, 2009). Traditional birth attendants (TBAs), “not trained to proficiency in the skills necessary to manage or refer obstetric complications,” cannot address these complications satisfactorily (Canavan, 2009). As such, the gold standard in reducing maternal mortality has been to encourage and persuade women to have institutional deliveries in hospitals and clinics (World Health Organization (WHO), 2013, p.2).

Researchers have studied traditional birth attendants (TBAs) and their practices around the world. Most have found that TBAs are often influenced by and base their practices on traditional beliefs. In an extensive examination of delivery practices in rural Nepal, many potentially harmful practices were found. For example, many TBAs advised that women delay breastfeeding by two to three days after birth, based on traditional beliefs such as the yellow color of colostrum being an indication of spoilage (Thatte et al., 2009). This practice is unarguably harmful because colostrum, the first breast milk produced during a women’s pregnancy and postpartum period, is the source of an infant’s first antibodies (Womenshealth.gov, 2010). Other harmful practices in this village included mustard seed oil massage of the infant, which may have toxic effects on the infant’s skin barrier (Thatte et al., 2009). A study in Mysore, India found that TBAs had little knowledge about complications such as “excessive bleeding, prolonged labor, and vaginal tears.” Of the TBAs interviewed, 13% felt it necessary to refer the woman to institutional care in the case of excessive bleeding (Madhivanan et al., 2010), even though hemorrhage is the primary cause of maternal mortality (Canavan, 2009). In
Jharkhand, a neighbor state of Odisha, a study investigating childbirth pointed out other harmful practices such as the use of oxytocin to accelerate labor and advising the new mother to abstain from food (Barnes, 2007). All of these studies, despite being conducted in different locations, point to the same conclusion; traditional birth attendants compromise the health of mothers and children when complications arise. TBAs can, however, be valuable in the support they provide to a woman (Canavan, 2009).

In addition, the idea that safe birth necessarily translates to an imperative to deliver institutionally is not unanimously held. The Comprehensive Rural Health Project (CRHP) in Jamkhed, India has produced relatively good maternal outcomes in an area where 81.5% of women still deliver at home by reducing cultural objections to obstetric care, increasing knowledge about common cause of maternal death, improving nutrition and pre-natal care, and training village health workers to assist at delivery (McCord, Premkumar, Arole, & Arole, 2001, p. 298, 301-302).

In fact, the promotion of institutional births in rural and developing areas without accompanying supply side changes may not be ethical; many health care facilities do not have well maintained equipment or a constant supply of water and electricity. The Common Review Mission (CRM) found that in India, basics, such as toilets and running water were not adequate in many areas (Nair et al., 2011). The WHO has recognized that institutional delivery does not necessarily equate to high quality care at the time of delivery (WHO, 2013, p.2). Therefore, it is working on a 29 item safe-birth checklist for SBAs to use to address the major causes of maternal mortality, stillbirths, and neonatal mortality (p.3). The items included in the list are believed to be absolutely necessary to
handle the complications during a delivery and field-testing and a pilot study in India indicate that the checklist is highly effective (p.4). The pilot study reported that the average rate of the use of essential safe delivery practices increased on average from 10 out of 29 to 25 out of 29 with the use of the checklist (Spector et al., 2012). I recommend that the researchers taking on this project enter into discussions with ARM about adopting this checklist for their PHCs and CHCs. The collaboration for this the safe-birth checklist initiative welcomes the participation of smaller organizations with limited resources (“Participating in the Collaboration,” n.d.). As I will discuss later in this section, this may be an important supply side intervention that will ensure that ARM’s exploration of the situation is ethical.

The Three Delays Framework – A Public Health Perspective

Public health research has demonstrated an extensive amount of research that is relevant to developing solutions for this important global health issue. One question that must be asked is why women make the decision to deliver with TBAs in place of SBAs. Then, targeted solutions can be developed to change this decision. A useful way of approaching this question from the public health perspective is by using the Three Delays Framework, which explains the delay in seeking life-saving medical treatment with the following three phases of delays: (1) a delay in care-seeking by the woman and her family (2) a delay in accessing health care (3) a delay in receiving proper care (Thaddeus and Maine, 1994, p.1092).

In the second delay, access is a key component; distance from clinics and hospitals, insufficient providers of skilled care, and financial concerns are (Family, 2005) mean that often, access is unimaginably difficult. In Odisha, families may have to carry
the pregnant woman in a basket to auto-rickshaws to access emergency services (Murthy et. al., 2002), and the average distance they travel for delivery is 15.8 km. In one heartbreaking example, a husband from Madhya Pradesh, another state of India, reported "we carried her on a cot for eight kms in the rain" (Murthy et. al., 2002).

The third delay is illustrated by shocking examples as well. Even after traveling such a distance, an inefficient referral system means that women with complications may have to travel to more than one facility. Out of the 98 women included in a study in the state of Andhra Pradesh, 60% traveled to two hospitals or more, and one woman visited nine hospitals before ultimately dying at home (Nair et al., 2011).

However, decision-making and behavior cannot be explained by access alone. The first phase of the three delays model encompasses the decision to actually seek care; perceived cost of skilled care, socioeconomic status, education about maternal health issues, and traditional beliefs about birth play significant roles in this decision (Metcalfe et al., 2012). Another factor is a lack of perceived need for SBA if complications are not perceived as present (Titaley et. al, 2010). This is problematic, because as mentioned earlier, complications in pregnancy are spontaneous and must be handled quickly. Making the decision to seek care after complications arise is often too late for women in rural areas in developing countries.

There has also been some mention of aversion to planning for the birth; birth is seen as an unpredictable event and decisions are often not made until labor begins (Family, 2009). There is some evidence that women themselves do not make decisions about seeking care; in a study in three Indian states, from 2000 – 2001, husbands played a large role in care seeking behavior, particularly in Odisha, followed by mothers...
and mothers-in-law. Women expressed little unhappiness about others making such decisions, even though “women themselves appeared to be more aware about postnatal complications, need for care during complications...but they were not the decision makers.” (Murthy et. al., 2002). I observed in Odisha that men and mothers-in-law are seldom the target for educational campaigns. An important question to pose to women, in this case, might be related to how much they perceive the husband knows when it comes time to make a decision of where and with whom to deliver.

**Critical Medical Anthropological Framework**

It is important to fully understand that the problem of unsafe birth does not exist inside a vacuum. The decision making process is complex and unless we understand the hierarchy and weight placed on the factors women and their families consider, we will fail to develop adequate solutions. Much of the public health research on this subject focuses on immediately apparent and individualistic factors in the decision-making process and fails to delve deeply into the history, politics, and culture that complicate the context in which a decision is made. Because they developed embedded and interwoven with the fabric of the community’s identity, decision-making processes can be viewed as an extension of this identity. The psychological notion of self-concept is useful here; it is defined in the well-thumbed paper by Markus and Wurf as “a dynamic interpretive structure that mediates most significant intrapersonal processes (including information processing, affect, and motivation) and a wide variety of interpersonal processes (including social perception; choice of situation partner and interaction strategy; and reaction to feedback)” (Markus & Wurf, 1987, p.300). Essentially, self-concept dictates that people will act according to certain beliefs
they hold about their identity. If we expect to develop interventions that fit with the community’s identity or the individual’s self-concept as a community member, we must understand these beliefs.

Experiences people have with institutions, policies, and health programs color their perceptions of the quality of care and affect their ability and willingness to demand better care or seek recourse for maltreatment. Cultural norms and traditions as well as societal rules and restrictions also affect the acceptability of care. In India, specifically, facility-based care neglects some of the symbolic and social roles that birth has in traditional societies. In this sense, the care provided may seem incomplete to rural Indians. Thus, I have chosen to examine the problem of unsafe birth in India through a critical medical anthropological lens. The critical medical anthropological (CMA) framework asserts that a person’s ability to seek out well-being is affected by “social inequality, class, gender…and other discrimination, poverty, structural violence,” (Singer, 2004, p.26). CMA asserts that fully understand ill health, one must understand the social, political and economic contexts and their contributions to illness as well as the meanings the sufferer and her community attach to illness (p. 26-27). Although Singer focuses on understanding disease, he exalts the WHO definition of health as general well-being that extends to one’s physical, mental, and social functions (p.26) and claims that CMA explores barriers to the achievement of this well-being. Thus, I have extended the framework in order to understand care-seeking, which by definition, is a decision to improve well-being (although I critically analyze whether it is viewed as such by rural Indians). A critical perspective allows us to examine the wider political context while also understanding the meanings that birth holds for women and their families. Both
lenses overlap to delineate a picture of what people expect from care and the significance of various factors in the decision making process.

**Political Context**

Odisha, a state in India, is a “high focus” state for safe birth initiatives. Odisha's maternal mortality ratio is 258 per 100,000, and infant mortality ratio is 57 per 100,000 (Government of India, 2012), the sixth the highest in India. Less than 50% of mothers in rural areas of Odisha had a birth attended by skilled personnel (Government of Odisha, 2008.) The area of our concern is the Baliapal block of District of Balasore. This area is served by the Alternative for Rural Movement (ARM), an NGO whose activities encompass the health and well-being of its partner villages, and range from agriculture, to advocacy, to the provision of primary health care. ARM runs a Primary Health Center in the area that serves 200,000 people.

ARM is the partner organization for the student organization GlobeMed, of which I am founder and president. GlobeMed’s relationship with ARM is that of a donor, but we also strive for an equal partnership. We have been a resource for ARM in more ways than just funding. As students, we also wish to learn from ARM and its model. I communicate with Rajendra, the head of the organization, every week. He expressed to me in video-conferences and in person, a strong concern about women in the community choosing TBAs instead of SBAs and a willingness to do something about it. Although the study we initially started researching and designing had a focus on institutional delivery, I have since shifted my attention to safe-birth in general. I am unconvinced, having considered the evidence, that institutional delivery is the most effective way of achieving safe birth in India.
Geographic Location

Odisha’s capital city is Bhubaneswar, the 58th most populous city in India (Census India, 2011) and houses the state government. The state is divided into thirty districts, and the district of interest is Baleshwar, which, with a population of approximately 2 million people, holds the position of fourth most populous district in the state (Government of India, 2011). ARM serves the Baliapal block in the Baleshwar district, a rural area with an agricultural economy. District level council is known as the zilla parishad, in which Baliapal, the community development block (administrative sub-district) has four representatives (Government of Odisha, 2007). These representatives are chosen by the panchayat samiti, the block government.

Government

The block that ARM serves contains 233 villages (Patnaik, 2012), which each have their own gram panchayat, or village level government. Each gram panchayat has a representative, or sarpanch, present at the panchayat samiti. The gram panchayat is an important political entity, especially as a political resource for women. Women have historically lacked political power and political involvement in India, just as they have the world around (Nandal, 2003, p.125). In 1992, as an attempt to increase political participation by women, the Indian constitution decentralized power via the 73rd amendment, and mandated that thirty-three percent of elected seats (p.123) be reserved for women and those in marginalized castes (Deininger, Nagarajan, & Paul, 2012, p.1). This amendment also established Panchayati Raj, “village level rule,” altering the function of the gram panchayat from a body responsible for implementing
state and national level policy, to a body with real governing power that create its own policies (Nandal, 2003, p.125).

Before this amendment, one or two women were voiceless and powerless members of a *panchayat* comprised of between fifteen to nineteen people (Nandal, 2003, p.125). The end result was that women were represented in name only. After the constitutional amendment, women still face this problem; sometimes women are elected because they are relatives of current leadership (Nandal, 2003, p.126; Vissandjee, Apale, Wieringa, Abdool, & Dupéré, 2005, p. 126, p.130) and may even be told what to do by these relatives (Vissandjee et al., 2005, p. 130), a problem which was also expressed to me by ARM staff during my GROW internship during the summer as I sat in on a meetings where these leaders were present.

Female villagers and even female leaders may not actually speak during village meetings, and may not even be in attendance (Kulkarni, 2012, p.160-61). The *gram sabha* consists of all the voters in the village and elects and regulates the gram panchayat (Kulkarni, 2012, p.153). In theory, women should have the most access to politics through the *gram sabha*, but this voter assembly, though in principle held every six months, may occur with larger gaps (Kulkarni, 2012, p.153). These obstacles to political power are relevant to the issue of safe birth, because they impact the ability of women to change the infrastructural and economic issues that impact the care-seeking and decision-making process in their families. In fact, nearly seventy-nine percent of ASHAs interviewed in a major study in Odisha were selected by the *gram sabha* (Uttekar, Uttekar, Chakrawar, Sharma, & Shahane, 2007, p.17). However, NGOs such as ARM can often be a source for this political power. They can provide training and
support that make women more successful in achieving and wielding political power (Kudva, 2003, p.446). This is often through basic means like increasing literacy through SHGs. Half of the women in Odisha are illiterate, so the status of women is low. 41.8% have a say in decisions within the household, and 38.4% experience violence from their spouse (Papp et al., 2012). It is important to examine the availability of political power to women, because these are the means through which women can ensure accountability of those with the responsibility of carrying out the interventions that are supposed to provide them with basic maternal health care. These systems provide them with an avenue to ensure that their rights are not violated.

*Provision of Health Care*

There are three levels of care in India. At the very top, tertiary health care is provided at the district hospital level (Government of India, 2013b). The Balasore area has one "district headquarter hospital," and one "sub-divisional hospital" (Government of Odisha, 2011). Secondary care is delivered to 120,000 people at the community health center (CHC). Ambulatory care is administered at primary health centers, which serve approximately 30,000 people, accompanied by sub-centers, serving 5,000 people (Government of India, 2013b). The Auxiliary Nurse Midwife (ANM) manages the sub-center level care, and her role is providing information about contraception, immunization, and delivering some maternal health care (Gautham, Binnendijk, Koren, & Dror, 2011).

However, in my personal experience in Odisha, PHC level care is understaffed, and a doctor is not often present. The literature supports this observation; at both the PHC
and CHC level, there are doctor shortages, but the difference is more pronounced at the CHC level, where 51.6% of specialist positions remain unfilled (Gautham et al., 2011).

Furthermore, according to the literature, PHC and CHC level care is often inconvenient, crowded, under-supplied, and understaffed. Poor, rural people are often mistreated at government run health facilities and often distrust government programs. Their interactions with government employees, such as doctors and ANM, may be characterized by physical hitting, verbal abuse, blatant disgust, and extortion and corruption (Jeffery & Jeffery, 2010, p. 1716). The experience of poor villagers in the public health system thus most likely elicits feelings of powerlessness and humiliation and this may be a contributing factor to a lack of care-seeking in the perinatal period.

Private care is expensive, so rural people often turn to quack doctors or traditional providers. In the ethnographic account of a maternal death, Jefferey and Jefferey describe the villagers’ reactions and explanation of Razia’s death; they view it as the result of her poverty and her husband’s resulting inability to provide her with private care, but they also believe that doctors gave her a deadly injection for not having enough money to pay, and having too many children. When I read about these reactions, the severity of the villagers’ conclusion struck me. It indicated that I needed to dig further.

**Historical Context**

This mistrust may arise, in part, from the sterilization programs of 1975-76. During a 19 month period of emergency rule declared by the Prime Minister Indira Gandhi between 1975 and 1977 (Gwatkin, 1979, p.29), within the context of an international focus on family planning (p.34), her son Sanjay Gandhi initiated an
aggressive sterilization campaign (p.35). Odisha gave out government loans only to sterilized people/small families. In some states, raises were awarded only to sterilized employees, and food rations were withheld from families of more than two children (p.38). This was often to fulfill sterilization quotas, which came with the threat of suspension from government positions. This campaign affected all areas of the government; teachers, railroad officers, and police were subject to filling these quotas. In some cases, this led to compulsory and coerced sterilizations (p.44). The widespread notion was that the government wants to restrict and harm people rather than help them (p.52). To what extent this attitude is still present needs to be determined.

It would beneficial to determine if NGO-run programs, such as the PHC managed by ARM, elicit the same attitudes for rural villagers. Villagers seem to trust ARM more than they might the government. ARM staff members come from the community themselves and are highly responsive and engaged with villagers, often bringing the doctor to them through health camps, and supporting almost every aspect of village life.

Current Policies and Programs

There are several policies and programs that have been designed at the national level that affect safe birth and institutional birth. The National Rural Health Mission (NRHM) was established in 2005 and the RCH- II program is the umbrella under which all maternal and child health initiatives are covered. It is supported by the World Bank and focuses on institutional delivery and access to emergency obstetric care (EMOC). The objectives of the program are reductions in the total fertility rate, infant mortality rate, and maternal mortality rate. Under this program, the government of India has established a financial assistance program known as Janani Suraksha Yojana (JSY)
and Accredited Social Health Activists (ASHA), community health workers with several roles and responsibilities, including escorting women to a delivery facility (Vora et al., 2009).

The ASHA worker program is financed by the NRHM; ASHAs are volunteer community health workers that are usually educated to at least the eighth grade and are married women between the ages of 25 and 40, often with children of their own (Uttekar, Uttekar, Chakrawar, Sharma, & Shahane, 2007, p.16) The function of ASHA workers is to disseminate health knowledge throughout the community, including reproductive issues to women and to distribute drugs and other supplies. They play a major role in immunization programs, accompanying deliveries to the hospital, and creating awareness about health issues. They also play a role in planning check-ups, calculating the date of delivery, and identifying the referral facility in the case of complications (p. 17) They are a part of the JSY program and receive around 600 rupees for transporting women to government institutions for delivery and no compensation if the mother delivers in a private facility. The women themselves receive 1400 rupees to for delivering in a government facility or approved private facility. If the woman delivers at home, with a skilled birth attendant present or a trained traditional birth attendant, she receives only 500 rupees, while the ASHA worker is not compensated.

A newer program, Janani-Shisu Suraksha Karyakram (JSSK) was started in 2011 and it covers the provision of free care, transport, food, c-sections, and drugs (Government of India, 2013a). Outside organizations like UNICEF and the World Bank are also operating in Odisha to train more SBAs and improve reproductive health,
respectively. There seems to be a lack of accountability amongst SBAs that contributes to the problem of accessibility (Campbell, Gogoi, & Papp 2013).

Many programs are implemented by ARM at the local level. One such program is the self-help group (SHG) program, which supports SHGs. These are groups of about 10 women from the village, that decide to create a voluntary group for the primary purpose of saving money and obtaining loans to generate income through micro-enterprise (Saha, Annear, & Pathak, 2013, p.2), which in rural Odisha, was often making baskets, leaf plates, crafts, or incense sticks. NGOs, such as ARM, play a role in training SHG leaders and providing groups with support in the form of resources. These SHGs can often be a target for health improvement interventions by NGOs. The groups also contribute to social capital by increasing bonds within the village as well as links to financial resources and as a result, often improve the uptake of health services by women involved, and improved health knowledge (Saha, Annear, & Pathak, 2013, p.2). Women in SHGs are more likely to have an institutional delivery and to use family planning (Saha, Annear, & Pathak, 2013, p.5).

In my experience with SHGs, I found that the women were proud of and engaged in their groups. They were a major source of empowerment for them and pride for the community. Rajendra informed me that these groups were entirely voluntary; ten women banded together and decided to start an SHG. In one case, an SHG became a source of social and financial support for one of its members; she had a heart attack and the group raised enough money to pay for her transportation and care at the hospital in Bhubaneswar. SHGs in Baliapal had also started to become involved with social issues, particularly in trying to get alcohol prohibited in the district. Alcohol was
perceived as a major source of domestic abuse and poverty, since the men used disposable income buying alcohol. It is the display of this social initiative that cued me to consider that SHGs might be the best platform for carrying out a study.

**The Malfuction of Governmental Programs**

Although the above describes how JSY is intended to work, often it does not work in this way. First of all, the amount of money given by JSY often does not cover the cost of travel to a government clinic or institution; many families have to acquire additional funds by selling possessions or borrowing from neighbors (Das, Rao, & Hagopian, 2011, p. 295). Second, because of corruption, many women and ASHA workers are given JSY money months later. Third, staff at government facilities often asks for a cut of JSY money, even refusing to give families the baby without compensation. Finally, the number of institutional deliveries is over reported; babies delivered at home are recorded as having been delivered at institutions in order to obtain JSY payments (Jefferey & Jefferey, 2010, p.1717). Rajendra has expressed concern over this last problem to me personally; some of the other factors discussed in the literature may also be present; we need to determine to what extent.

**Cultural Context**

*Interlude – exploring psychological self-concept in a collectivist society*

While I am still operating under a CMA framework in examining the cultural context of rural Odisha, I introduce the idea of self-concept within a collectivist society in order to better understand the large role that culture plays in decision-making in rural India. The decision making process is complex and unless we understand the hierarchy and weight placed on the factors women and their families consider, we will fail to
develop adequate solutions. This is especially important because much of the public health research on this subject focuses on immediately apparent and individualistic factors in the decision-making process and fails to demonstrate an understanding that this decision-making process developed embedded and interwoven with history, politics, and culture. As such, this process should be viewed as an extension of the community’s identity.

The Collectivist Psychology of Rural India

Indian families traditionally are structured as joint families, with two to three generations of people living in the same household (Allendorf, 2010, p. 265). For the majority of people, this joint family is a form of social security; these are the people who will care for their needs in times of hardship (Kapadia, 1966, p.315). As such, Indian culture can be classified as collectivist – as opposed to individualist – (Berry, Poortinga, & Pandey, 1997, p. 22-24), which the well-cited study by Hui and Triandis defines as having the following seven characteristics:

(1) concern by a person about the effects of actions or decisions on others, (2) sharing of material benefits, (3) sharing of nonmaterial resources, (4) willingness of the person to accept the opinions and views of others, (5) concern about self-presentation and loss of face, (6) belief in the correspondence of own outcomes with the outcomes of others, and (7) feeling of involvement in and contribution to the lives of others. Individualists show less concern, sharing, and so on than collectivists (Hui & Triandis, 1986, p.225).

In rural Indian society, birth is an event in which many women find comfort in surrounding themselves with female family members and friends (Pinto, 2011, p. 41, 50).
Having seen the delivery room in the local primary health center in India, I know that there is little room for friends and family. Since access is difficult to facilities, the likelihood that close friends will accompany a woman to her birth is unlikely. In order to understand the significance of the stark contrast between the birth as a social and ceremonial event and the birth within a cramped delivery room, I find the analogy of marriage to be useful. Most people, even if they were told that a wedding ceremony, perhaps because of expense, would be detrimental to their health and well-being would not eschew this traditional rite of passage and opt for signing marriage papers at city hall.

This is a matter of comfort during birth; in one study, Nepalese women indicated “they were sometimes uncomfortable sharing everything with their husband and rather preferred to do that with close female relations” (Thapa & Niehof, 2013, p.5) and both women and their husbands reported feelings of shyness (p.5). It is not the husband that is generally involved in the birth; in fact, a pregnant woman may return to her maike or mother’s home for her first birth, where her mother, grandmother, and sisters-in-law are present to help her with the experience (Pinto, 2011, p.50). According to the ASHA workers that I spoke to, this presents a problem for the continuity of care. Additionally, making the decision to deliver institutionally may be seen to deprive female family members of involvement with this social rite and decrease the “feeling of involvement in and contribution to the lives of others,” one of Hui and Triandis’s definitions of collectivism (1986, p.225).

The psychological notion of self-concept is useful here; it is defined as “a dynamic interpretive structure that mediates most significant intrapersonal processes
(including information processing, affect, and motivation) and a wide variety of interpersonal processes (including social perception; choice of situation partner and interaction strategy; and reaction to feedback)” (Markus & Wurf, 1987, p.300). Essentially, self-concept dictates that people will act according to certain beliefs they hold about their identity.

Social responsibilities are seen by Indians as moral imperatives (Berry, Poortinga, & Pandey, 1997, p. 24), aligning with the moral and religious concept of dharma or duty. Hindus thus have a monistic self-concept wherein a person identifies as part of a social whole (Miller, 1994, p.15). In fact, one of the cornerstones of the Hindu religion is the Bhagavad-Gita which presents the story of Arjun, an extremely skilled archer, who spends the course of the epic poem debating a clash between two roles, that of warrior, and that of his social role of cousin. The epic poem is about Arjun’s inner struggle “on the field of dharma,” (Easwaran, 2007, p.267). The concept of dharma can be equated roughly to justice, duty, inner nature, or law, but dharma is also equivalent with unity. Evil or chaos is disunity, referred to as adharma (Easwaran, 2007, p.267). The Hindu sense of good and evil and morality and amorality, is deeply rooted within interpersonal duties and within this society, a person’s feeling of spiritual fulfillment depends on “meeting social role and status expectations,” (Miller, 1994, p.19). Although detailing the empirical evidence for the collective nature of rural India is beyond the scope of my paper, Miller reviews several studies to show that Indians do indeed view social obligations and responsibilities as moral issues (1994, p20-30). However, I have included the Communal Orientation Scale designed by Clark et. al (Clark, Oullette, Powell, & Milberg, 1987, p.96) to assess the presence of a collectivist identity in rural
India. Our survey must explore the hypothesis that a collectivist identity in rural Indians villagers leads to a lower likelihood of care-seeking behavior. This is integral if we are to develop interventions that fit with the community’s identity or the individual’s self-concept as a community member. Is the health system model too individualistic and does its failure to incorporate the collectivism of traditional birth and delivery structure affect women’s’ decisions to seek care? Finally, if this is an issue, could safe birth be presented in a collectivist light? A possible solution could be CBPR discussions and health camps that present delivering with an SBA as a social responsibility.

Factoring collectivist expectations of the birth experience is important if we are to truly develop interventions aimed at improvement of maternal health. The stress-buffering hypothesis asserts that social support during acute episodes of stress, of which labor and delivery are an example, can help alleviate the stress and reduce its physical and psychological impacts (Cohen & Willis, 1985, p.312). Thus, while the movement from a traditional home birth to an institutional or clinical birth will be effective in reducing mortalities from complications, it may lead to worse mental health and well-being or compromise certain aspects of physical health. There is evidence that shows that during delivery, a companion who provides continuous social support can reduce the number of medical interventions such as anesthesia, c-section, amniotomies required the time spent in the hospital (Sosa, Kennell, Klaus, Robertson, & Urrutia, 1980, p.598; Madi, Sandall, Bennett, & MacLeod, 1999, p.6; Hodnett, Gates, Hofmeyer, & Sakala, 2007, p. 6). Women also interact more with their babies (Sosa et al., 1980, p. 598-99) and have an overall more positive experience (Hodnett et al., 2007, p. 9). The effects on maternal health of continuous social support interventions is especially
remarkable within societies where there has been a recent shift from home deliveries with a lot of support from family members to institutional deliveries with little continuous support (Madi et al., 1999, p.4; Sosa et al., 1980, p.597).

In designing an intervention that aims to move women towards institutional births, then, it is important to both the ethics and the success of the program that there is provision of an option to bring along a female relative free of charge or provision of a doula type option within the clinical setting. There may also be some benefit to training and encouraging friends and relatives to provide each other support as Hodnett et al. suggest. There are multiple resources for such a program in Odisha, including the Better Births Initiative and a guidebook by Simkin (Hodnett et. al, 2007, p. 10).

Women within the context of the Indian family

A woman's marriage is generally arranged into a family from an outside village, as I observed in my time in Odisha and confirmed by the literature (Rahman & Rao, 2004, p.240; Kapalgam, 2008, p. 53), and the families are of the same caste (Kapalgam, 2008, p. 53). She resides in a joint family consisting of her parents-in-law and their sons and their respective wives. The family may become smaller as the parents die or when family moves away for work purposes (Allendorf, 2010, p. 265). As we sat outside a self-help group member's home, on a concrete slab, I asked the SHG leader a question, “Why are all women in the village not involved in the SHG groups?” She answered that the newly married women had household duties to attend to and did not have time to become involved in microfinance. This is corroborated by what Chowdhry asserts in her paper; as the woman grows older, her decision making power in the family increases. Mothers-in-law have more power than married women with children in the family, who in
turn have more power than newly married females without children. Post-menopausal women, especially the head female in the family, the mother-in-law are more involved in major decision making and decide how domestic work is managed and distributed among the women in the family. The mother-in-law may in fact act to enforce the patriarchy, acting to enforce purdah, seclusion, and the low place of the newly married woman in the family structure. She may even have more power than her son, the husband, as she can act to control her daughter-in-law's interactions with the husband. (Chowdhry, 1993, p.95). Sons are favored very clearly over daughters; infanticide is a problem, male children are favored during meals (Rahman & Rao, 2004, p.240), families invest in education for boys because the daughter will leave the family once married, becoming a part of their husband's family, and education is seen as undermining the control a family has over the daughter (Malhotra, Vanneman, and Kishore, 1995, p. 285).

Ghunghat and Female Disempowerment

_Purdah_, also called _ghunghat_, is both a set of physical and behavioral prescriptions from women so that they preserve the izzat or honor of the family. These include keeping the hair and face covered and are practiced by both Muslim and Hindu women in India (Jacobson, 1982, p. 132). The practice of covering the face has begun to fade in many parts of India (Chowdhry, 1993, p.93) and I seldom saw women with their entire faces covered in the villages of Baliapal block. In some cases, this is very much the result of practicality issues in women becoming the primary pool of agricultural laborers in rice paddy farming (Chowdhry, 1993, p.93; Bagwe, 1996, p.11; Malhotra, Vanneman, & Kishore, 1995, p.286) There is reason to believe that the principles behind the
ghunghat are still very much in place (Kapalgam, 2008, p.54). The ghunghat is a veil that symbolizes an ideology of female behavior that in order to preserve her family's honor, a woman should seclude herself from society, should avert her eyes in respect to dominant males and older females, and should limit her interaction with males, including her husband while in the presence of the mother-in-law (Sharma, 1978, p.218-219; Chowdhry, 1993, p. 91, 94). Thus, though the physical symbol of male dominance over women may be mitigated, the behavioral codes accompanying the practice of ghunghat still restrict behavior seen as compromising the family's izzat.

The practice of ghunghat and the favoring over male children over female children both contribute to inequality between the genders. Inequality, in turn, limits a woman's participation in the decision making of the family (Jejeebhoy, 2002, p.300), which I conjecture includes the decision of whether to seek care. Mobility restrictions limit the access that women have to health care (Jacobson, 1982, p.136). A study done exploring women's autonomy in 2,000 households found that only 43% of Hindu women and 38% of Muslim women in the village were permitted to go unescorted to the primary health center and even fewer were permitted to go further away, such as to an adjacent village (Jejeebhoy & Sathar, 2001, p.700). While the authors did not include community health centers or district hospitals in their survey, this level of care is even further from "local." Beyond the difficulty that distance poses in terms of travel time and transportation costs and availability, the requirement of a male escort is another inconvenience to overcome. These cultural issues are likely to persist over time; the preservation of culture and tradition is perceived as necessary by villagers to maintain a distinction between rural and urban life (Chowdhry, 1993, p. 91, 98) and since women
themselves participate in the perpetuation of such cultural norms as they grow older and become mothers-in-law.

*Implications of Family Dynamics and Disempowerment*

Female disempowerment and lack of autonomy impacts the voice women have to enforce social accountability, particularly in addressing some of the institutional corruption issues mentioned earlier in this paper. Social accountability is “a referee of the dynamics in two-way relationships, between often unequal partners,” (Campbell, Papp, & Gogoi, 2013, p.4), ensuring that responsibilities and services are carried out by officials, administrators, and other health system staff. Campbell et al. assert that community mobilization and female empowerment are necessary and that the “mindsets” of marginalized women and leaders play a large role in the success of social accountability (2013, p.14); the lack of mobility and voice encompassed by the ghunghat ideology is most likely the “mindset” they have observed.

*The Caste System*

Castes or jatis are different classes of people. Different castes have different roles and jobs in society, a division of labor referred to as jajmani. Historically, this caste system was overlaid by systems of bonded labor; lower caste people owed money to landowners, a debt incurred as a cost of marriage. In the 1960's bonded workers began earning wages. The caste system is very complex, with caste names varying from region to region. Often, one's surname denotes one's jati (Berger & Heidemann, 2013, p.70-71). The varna caste system is comprised of a hierarchy of five castes: Brahmins, Kshtriyas, Vaisya, Sudras, and Ati Sudras (or untouchables). This system indicated a person's spiritual and occupational place within society.
Brahmins were priests and teachers, Kshatriya warriors and royalty, Vaisya traders, merchants, and moneylenders, while the Sudras did manual labor and the ati sudras often did work involving bodily fluids or some sort of pollution (Deshpande, 2000).

Women within the context of the caste system

Low caste status often equates to inequity; for women, this fact is exacerbated by the state of being a woman. Shantabai, a dalit woman, describes that during her childhood, women received a small amount of grain for their work, which her mother fed to her husband and son. Her mother, her sisters, and she ate the grain from corn cobs half eaten by bulls that was covered with cow dung and had to be washed before use (Rege, 2006, p. 166). Low caste women often face violence; in one study of such attacks, women overwhelmingly explained the attack as a response to their asserting the right to do or use something. 27% asserted their right to access land or water, 19% asserted their right to dignity, 14% asserted their right to use the temple, and 13% asserted their right to vote (Kapoor, 2007, p. 617).

The Polluted Nature of Birth

Cultural beliefs and rituals surrounding birth are important in understanding the decisions that women make. The culture surrounding birth in India is particularly unique because traditional birth attendants (TBAs) or dais, as they are known in India, are low caste women whose work marks them as polluted (Rozario 1998, p. 145-146). According to one ethnographic account, there is a firm distinction between delivery and post delivery. Delivery can be done by anyone, including family members, whereas post-partum care is polluting and done by lower caste women. This distinction is not observed in all of the few ethnographic accounts that exist on the topic of birth in India,
but it is widely recognized that cutting the umbilical cord, cleaning the baby, and bathing the woman is extremely polluted work (Afshar, 1987, p.155; Rozario & Samuel, 2004, p.184). The polluted post-partum work of the dai is a part of the jajmani system, in which work and payment is based on pollution and purity (Pinto, 2011, p.64) whereby low castes perform unclean work that preserves the purity of high castes, receiving payment for doing so and high castes perform purifying work for lower caste individuals, receiving payment as well (Commander, 1983, p.286).

The ideology of ghunghat rears its head during delivery as well; the new mother and baby are isolated following pregnancy and must go through certain rituals to rid themselves of pollution before they can re-integrate into society. The mother is most polluted before the first bath and gradually becomes cleaner (Pinto, 2011, p.59).

*The Role of the Dai in Birth and In Society*

It is clear that the purpose of the dai is less to facilitate birth than it is to bear the burden of and deal with the pollution that occurs as a result of the birth (Rozario, 1995, S149). A dai is generally a lower caste woman who takes up her work out of necessity (Jefferey, Jefferey, & Lyon, 1987, p.57). She cuts the umbilical cord, cleans up the bodily fluids post birth, cleans the body, and disposes of the placenta (Pinto, 2011, p.41). The dai occupies not the position of a specialist, with esoteric skills and knowledge, but rather as the performer of a job no one else wants to do (Rozario, 1998, p. 150). This is distinct from the western biomedical view of a birth attendant as a specialist healer that is present to manage and guide the birth or to handle complications. Her status is lower than that of a person that deals with trash or cleans the streets (Pinto, 2011, p.102) and she often comes from the chamar or leather
workers caste (Rozario & Samuel, 2004, p. 183). This means that the *dai* is often of a lower caste than those she is serving, creating a power differential that is a reversal of that between the doctor and patient in biomedicine. *Dai*, unlike doctors, do not have any authority during the birth, but take orders from the family (Rozario, 1995, p. S149). While there has not been any literature on the matter, I conjecture that the reversal of this power differential during birth could be the source of some discomfort for women and their families.

**A Framework for Producing a Survey – The Theory of Planned Behavior**

Thus far, I have discussed three frameworks I used to expand on the single question that Rajendra first asked of me on video chat when he proposed this project. In order to create a working survey, however, it was necessary to bring in a framework that ties together these three different approaches. I needed to understand the relationships between them and how the plurality of factors at play in this complex problem interacted to affect behavior. I decided to use the Theory of Planned Behavior (TPB), one of the fundamental frameworks in public health and psychology. This theory asserts that a behavior, in our case, the behavior of delivery without a skilled birth attendant present, is affected by attitude towards the behavior, the beliefs a person has about others’ expectations, and the person’s beliefs about her control over the behavior in question (Ajzen, 2002, p.1). The three frameworks I used to analyze the problem initially fit nicely into this fourth framework; the issues brought up by the Three Delays Framework are related to women’s control over the behavior, the cultural and historical factors are about a person’s attitudes towards the behavior, and the collectivist theory is related to normative beliefs, or the expectations that others have, although there is of course,
overlap within the three. The TPB framework also plays the role of tying these diverse factors directly to behavior and thus, will provide an indication of which factors are relevant to the women of rural Odisha, India.

Figure 1: Theory of Planned Behavior

Personal Impact

This research project has provided me with a curricular theme in my last three semesters of college. The act of creating this survey has allowed me to engage with and draw connections between the materials in many of the classes required by my major. In keeping my research in the back of my mind, and using classes, professors,
and TAs as a source of guidance towards answering my question, I have learned more than I ever could have from merely listening to lectures and studying for exams.

This project has been more than just a capstone experience, however; it has altered the trajectory of my career and of my life. I have come to realize that health is a complex and intricate cross-section of all aspects of human life. I have come to understand how I can contribute to a world of healthier human beings, and I have gained a lifelong passion for learning, research, and activism. It has taught me to think deeply about each decision I make, and about the possible consequences of these decisions. They say the path to hell is paved with good intentions, and I have come to realize that one must be cautious and deliberate with decision-making in the humanitarian world because humanitarianism can create a dangerous power differential that allows the giver to decide what is best for a community that they know little to nothing about.

I started my work on this project in spring of my junior year. I took a maternal and child health class taught by Dr. Billings during which I wrote three papers that explored our research question from a public health perspective. Just before I wrote my final paper, I attended GlobeMed’s global health Summit, a conference meant to inspire us to contextualize activism, our chapters, and our partners as part of a larger movement. This conference was important because it allowed me to step back and connect with my research and learn from it at a more fundamental level. Upon reflecting on my experience at the Summit, I found that three things had followed me home from Chicago. The first started as a mental itch, a restlessness that accompanied the documentary How to Survive a Plague. We watched the film on the opening night of
the Summit. The history of a movement led by those with HIV/AIDS flashed before my eyes. Their terror, their resignation, and their anger filled the screen. After the film was over, as my eyes adjusted to the lightened room, they settled on the Peter Staley sitting at the front of the room; he was older, grayer, but beyond that, looked very much the same. There was something else different about him -- he was not the angry young man he had been in the film (France et. al, 2013). This Peter Staley was calm, with kind eyes and a mild expression. There was something profound about this difference, but I could not verbalize it at that moment. I can only describe it as earthshaking; I could feel my perspective shift as suddenly as the ground shifts beneath one’s feet during an earthquake. I felt the sting of injustice. I felt the electric tingle of the beginnings of an idea forming in my mind. I felt excitement and anger. I felt sorrow and awe. The moment was, on whole, overwhelming. I spent the rest of the conference asking questions, trying to refine this vague conglomeration of emotion and thought and turn it into something useful and meaningful.

The next day, in a panel of personal narratives, was a speech by Dr. Rishi Rattan of Physicians for Haiti. The subject of his speech was the politically incorrect topic of “the power of the privileged.” He spoke about distribution of wealth in the world. He pointed out that many efforts at “help” for the developing world were neo-capitalist and paternalistic. He then showed us through a series of examples that a student’s role in activism is most effective when it capitalizes on the voice this inequality gives us. His drove home the point that it is best used for amplifying the voices of those with effective solutions to their own problems. He warned us not to cover their voices with our own. *Listen*, he said. Dr. Rattan’s advice was hauntingly reminiscent of Morton Schapiro’s
cautionary speech earlier in the conference. A famed economist, he told us of his regrets in life; the biggest was the arrogance he showed as a young man in providing recommendations to developing countries that turned out to cause more harm than good. His message was also listen and learn from our partner organizations.

Finally, Leymah Gbowee spoke, in a voice that resonated through the brightly colored church, about the movement she led in Liberia. This was a movement of women who had had enough, who were indignant, angry, and fed up with an environment that was unsafe for their families. Her humor and good nature on this occasion sent the same shiver through me; here was this shocking difference again -the angry Leymah we had seen in the documentary and the good natured Leymah that stood before us. Towards the end of the Summit, I began to realize that there was an underlying theme, a hidden thread that tied together all of the keynote and panel speakers, that wove through the conference and made its way into my project for this class. It gave me the sense that there was an unknown, but important, element to everything we were trying to accomplish, that if this element were missing, we would fail. Consequently, it was an epiphany that brought with it a sense of foreboding. As I descended deeper into my thoughts during the meditative act of writing my final paper for my maternal and child health class (which was to become a part of my thesis), I found the essence of why I do everything I do. It was anger, affront, and indignation. It did not belong to me, however; it should belong to the people who we serve through GlobeMed. You see, if we truly believe that each person has human rights, then in every case in which these rights are lost, the humans deprived of them should be angry. Anger is the appropriate response to loss that is caused, exacerbated, or could have been prevented by another. Let me
be clear: I am not condoning violence. When I refer to anger, I mean an emotion characterized by passion and aggression. Those on the “outside” of an experience, who are not deprived of their rights by it, can be angry about the loss of these rights as well, but this anger means less. It holds less power. Anger is the power of the oppressed, of those whose voice is otherwise unheard. Anger provides empowerment when one feels unheard and undervalued.

It all started with the documentary. We were introduced to Peter Staley, a gay stockbroker who contracted HIV, and as he wheeled down the road on his bike, a voice over told us, "Everything I read said I had two years to live, at most." I felt a strong emotion flood through me. My mind cycled through ancient moments of helpless loss. I could begin to grasp at the edge of emotions that those living with HIV/AIDS must have felt. It was enough to attach me emotionally to the issue, however and begin to imagine the reasons for their anger. I imagine they felt that their disease was not being prioritized or taken seriously enough. I imagine they felt that their country had resources to organize and carry out an effective campaign against the disease but was refusing to do so. The research was unorganized and insufficient, the drugs were ineffective and too expensive, and the conversation about AIDS was not taking place. I imagine they felt that their friends, family, and lives were being taken from them because of this negligence. I imagine they felt that were not valued. In fact, they thought, why was money more valuable than their lives? Their response was anger. My father, a psychiatrist, once asked me to ponder what the heart of all negative emotions was. The answer was loss. When one feels a sense of loss, anger is an appropriate expression of that loss, so their anger was justified.
The reasons for their anger should sound familiar; there are people all over the world with other diseases and ill health that who must afford exorbitant treatments or let their disease ravage them. The governments and NGOs of their country and community are often not doing enough to address the problem. They lose friends and family and opportunities. Dr. Rishi Rattan discussed many of these issues. In the US, for example, even though 80% of biomedical research funding comes from the National Institute of Health, the pharmaceutical company that has the license to produce the drug sets the price, which is often very high. This was the case with the drug stavudine, used to manage HIV/AIDS which made Yale billions of dollars. Because of its high price, it was inaccessible to the people living in South Africa, where the price of the drug was much higher than anyone could afford (Demenet, 2002). Often drugs rejected by the developed world are pushed off into the developing world. Stavudine is no longer used in developed countries, but it is the first line of therapy in developing countries. This is due entirely to high cost of other, more effective drugs (Zaidi, 2011).

This ideology, simple yet powerful, led me to an epiphany in the project we were designing for ARM. The most useful thing we could do is to link them up with a nearby NGO that had already had success in addressing ARM’s concerns. I was writing my paper about the community participatory action cycle, and on a whim, decided to research some of the ideology behind it. What I found was breathtaking. The concepts of Liberation Social Psychology and critical consciousness arose in Latin America to address its very specific and unique needs. It is the antithesis of individualistic Western psychology. LSP focuses on the community and it has two main components. First, oppressed and marginalized people must understand the mechanism through which
they are being deprived of their human rights. They can then appeal to those with a conscience within the system that is oppressing them and work with them to change these systems and processes (Burton and Kagan, 2013, p. 68). The success of both of the movements in Liberia and for HIV/AIDS (though they are both ongoing) is due in part to this self-awareness. Being aware of these systems produces anger and empowerment. The women of Liberia understood the role of Charles Taylor's government as well as the rebels in producing the violent situation within the country. They called upon international leaders, who were a part of the system but sympathized with the women because of their conscience, to work with them to create a solution.

Suddenly, I knew what was missing from the community participatory action cycle (CPAC) I wrote of in my paper. It was the ideology behind the program. The programs that succeeded, including the program led by Ekjut in Odisha and the Warmi Project in Bolivia were both intensely focused on this notion of critical consciousness. The CPAC was merely the platform through which women could discover these systems and processes of oppression and human rights denial. It was not just about going through the motions of CPAC, which some unsuccessful studies did do, but rather, about the purpose of the curriculum and meetings. CPAC is not the only platform for bringing about critical consciousness. In Latin America, community social psychology is such a platform, where the psychologist facilitates as the "conscientizator" by providing "expertise in investigation, an understanding of leadership and organization and group dynamics, and knowledge of the system," (Burton and Kagan, 2013, p. 70) which are some of the same goals of the women's groups in CPAC. In a way, ACT UP and other early HIV/AIDS movements did the same thing, but more organically. Perhaps the
reason this was able to occur organically was as Peter Staley put it, "We had a huge motivator--death" (France et. al, 2013). Death was literally staring this movement in the face, inciting it to act. It may have also been a product of a culture of protest in the US; perhaps our citizens understand better how to access the systems of change during times of desperation. Indeed, there is nothing in the definition of critical consciousness that excludes organic acquisition, and Leymah Gbowee's movement demonstrated another organic instance of critical consciousness.

In essence, this Summit and ensuing research has changed my perspective on how one goes about changing the world and solving its problems. I have never really understood the purpose of protests or understood their effectiveness, but now I do. I am a poet at heart, and I know anger is not a pretty emotion; it is more appealing to think that we can solve the world’s problems with love, but anger has its place in change. Looking back, there were so many opportunities and examples in my life for me to learn this simple fact, and I was a bit slow on the uptake. Aggression is a way of asserting oneself, making one’s voice heard when no one is listening; in fact, anger is a source of empowerment. It is strange writing this out, but the world needs more anger. I feel that I have to clarify once again, to avoid misunderstanding, that I am not at all implying that the world needs more violence. Ultimately, this means that those problems that do not personally belong to us require us to bring about the critical consciousness that ultimately leads to anger and empowerment.
LITERATURE REVIEW: COMMUNITY BASED PARTICIPATORY RESEARCH

By Sarah Law

Introduction to CBPR

The delays caused by the cyclone gave us an opportunity reevaluate our study as a whole as we debated whether or not to change the focus of our project and move in a different direction. We ultimately decided that because ARM had requested that we investigate a particular research question, we needed to press on; the leaders of ARM have recognized the underutilization of skilled birth attendance and perinatal care as a significant problem in the villages they serve, and Cyclone Phailin certainly did not improve matters. We realized that our study would still be relevant to the community after some time and disaster relief efforts help to re-stabilize the area and return people to their homes. In this interlude, as we debated the fate of our Honors Thesis, we realized that our methods were not very clear and could certainly use some revising. Since neither of us has ever conducted research of this nature before, we dove into the process without a clear idea of exactly how to do social research. I know I personally thought that we would do half of the research in the library through literature review, write and disseminate a simple survey, collect data, and develop an intervention in the course of a year or so.

A combination of factors helped me realize that this was not truly the best or most effective approach. The first factor was a comment one of the SHG women made to us when we were in India talking to them about conducting our survey. Rajendra was helping to translate and when he translated to one of the SHG leaders our request to have them as subjects in our study, she regarded us with a level of skepticism in her
eyes before responding to say that they would do the research, but we had to give something back to them. At the time, I imagined that what we would be giving back was an intervention of sorts. The second event was when we learned about a study method called Community Based Participatory Research (CBPR) in Dr. Simon’s Medical Anthropology class. To describe it briefly, this type of research emphasizes community involvement and seeks to break down the formal barriers between the researchers and subjects in order to establish a more equitable working relationship. As we learned about CBPR, I realized how essential it was for our research methods to mirror the values and model of ARM, which does everything by and for the people. ARM knows that it is the people who best understand their problems, not outsiders, so our initial approach to this whole process was totally off. It quickly became clear that CBPR was the perfect method for us to work with. But first, we needed to learn how to do it.

To this end, I have conducted a review of the literature on CBPR. I began the process imagining that I would find some glorious step-by-step guide to walk us through this study; but as it turns out, there is no such handbook. CBPR requires everyone involved to develop a unique system of operation that suits everyone’s particular needs. And it doesn’t ever stop. Conducting this sort of research will require constant collaboration and continual feedback from ARM, our SHG interviewers, and the women who volunteer to be participants. The students who take on this project in the next few years will have to constantly evaluate and reevaluate the decisions the group is making. It will certainly be time consuming, but this is truly the only way that we can constantly improve our study model, design appropriate and thoughtful survey questions, develop a comprehensive training manual, and ultimately create a survey that addresses the
needs of the ARM community which the women are more likely to participate in (Jason et al, 2004, pg. xvii).

Our study's objectives fall in line with a growing body of research that is attempting to place health-care-seeking-behavior in its socioeconomic context by examining community influences on individual health outcomes (Stephenson & Tsui, 2002, pg. 311). According to Stephensen and Tsui (2002), a community has the potential to influence the health of an individual in two important ways: the community’s attitude and practices toward health and the economic status of the community (pg. 311). Health and community are inextricably linked, especially in areas of the world like Odisha where the sense of community is so strong. I believe that by engaging these women in CBPR, we will all gain much more from the process. After all, the proverb says *It takes a village* …

**What is CBPR?**

With my background of conducting more traditional, scientific research, I began the process of seeking out resources on CBPR with the idea that I would find a step-by-step handbook to follow, but I simply could not have been more wrong. Traditional scientific research follows a specific formula, namely the scientific method, whereby the investigator makes an begins by conducting background research on a question they developed based on an observation, poses a hypothesis, makes predictions, tests the hypothesis with experiments, and then analyzes the data to draw conclusions (Science Made Simple, 2013). But, CBPR is not a method of research; it is in fact "an orientation to research (Cornwall & Jewkes, 1995) that emphasizes mutual respect and co-learning between partners, individual and community capacity building, systems change, and
balancing research and action (Israel, Schulz, Parker & Becker, 1998)” (qt. by Minkler & Wallerstein, 2010, pg. 2). Therefore, it makes sense that both Minkler & Wallerstein (2010) and Israel et al. (2009) state that there are no CBPR methods. The definitions of CBPR are many, but most are very similar.

According to the W.K. Kellogg Foundation’s Community Health Scholars Program (2001), CBPR is "a collaborative approach to research the equitably involves all partners in the research process and recognizes the unique strengths that each brings" (qt. by Minkler and Wallerstein, 2010, pg. 6; and Willging). Israel et al. (2009) expand on that definition to say that CBPR is "partnership research that equitably involves community members, organizational representatives, and academic researchers in all aspects of the research process" (pg. 6). The term CBPR has gained a certain about of respectability and attention in the health field in the last 10 years (Minkler and Wallerstein, 2010, pg. 26), and it has a number of definitions in its own right, but it can also be used as "an overarching term for a wide variety of approaches such as action research, participatory action research, mutual inquiry, and feminist participatory research" (Cornwall & Jewkes, 1995 qt. by Minkler & Wallerstein, 2010, pg. 2). The approaches listed here are just a few of the terms used to describe this participatory research paradigm, and deciphering the differences between all of these participatory approaches can be quite challenging (Minkler and Wallerstein, 2010, pg. 26). On approach that I found very interesting was Participatory Action Research (PAR), which is distinguished in that it "adds an element of social action that involves building sociopolitical awareness and facilitating social reform, policy reform, and other types of social or systemic change” (Jason et al., 2004, pg. 4).
According to Elden & Levin (1991), PAR is "a way of learning how to explain a particular social world by working with the people who live in it to construct, test, and improve theories about it, so they can better control it (qt. by Jason et al., 2004, pg. 19). Brown and Tandom (1983) say that "PAR combines social investigation, education, and social action to define and address social problems, particularly among disenfranchised and oppressed groups" (Jason et al., 2004, pg. 17). This describes well what we want to do in Odisha. It will not be enough to investigate the personal reasons that the women underuse skilled birth attendance, we have to investigate community-level influences as well. Although personal behavior change will certainly play a role in our eventual intervention, it is more likely the case that a policy change needs to be made on a higher level. A key point made by Minkler and Wallerstein (2010) is that PAR "is emergent and evolutionary: you cannot just go to a village or an organization of a professional group and 'do it'; the work either evolves or does not evolve as a result of mutual engagement and influence" (pg. 234).

Vital to the evolution of a participatory, collaborative relationship is a paradigm shift on the part of the researcher (Angie Reyes qt. by Israel et al., 2009. pg. 3) to stop portraying their participants as the other (Duran & Duran, 1995 and Walters & Simoni, 2002 qt. by Minkler and Wallerstein, 2010, pg. 36). Angie Reyes—the Executive Director of the Detroit Hispanic Development Corporation—describes the traditional view of subjects from a researchers perspective as people totally lacking in resources. Thus the researcher thinks they need to come in and save the community, but they completely neglect the fact that there are already members of the community who are skilled and educated and can be leaders (Israel et al., 2009, pg. 3). CBPR seeks to avoid this
othering and this white/Western man's burden (Dr. James Campbell) by uncovering and honor community explanations and narratives of the conditions of people's lives (Duran & Duran, 1995 and Walters & Simoni, 2002 qt. by Minkler and Wallerstein, 2010, pg. 36). Israel et al. (2009) explain that a CBPR approach is particularly applicable to four certain types of research:

First, a CBPR approach may be used to conduct descriptive research to identify multiple determinants of health...Second, CBPR is appropriate for conducting research to understand racial and economic disparities in health status and health-related risk, and in particular to examine the relationships between multiple factors and health disparities...Third, a CBPR approach may be used to conduct research aimed at defining and understanding needs, problems, resources and assets in specific communities...Fourth, CBPR is appropriate for efforts to design, implement and evaluate interventions and policies. (pg. 10-11)

It is essential to note that this "this orientation to research...cannot exist without its practical applications in the community. CBPR research, whether focused on disease causation or direct community improvement, always takes an intervention activist approach" (Minkler and Wallerstein, 2010, pg. 37).

CBPR and other participatory research approaches were developed in part in response to communities complaining about "helicopter research" or "parachute research" where the researchers fly in and take information without giving anything in return" (Deloria, 1992 qt. by Minkler and Wallerstein, 2010, pg. 31). In order to get an idea of the theory behind CBPR and how you go about conducting research without a method rule book, I will now explore the history and theoretical origins of CBPR, discuss
the theories that influenced my thinking about this process, elaborate on the essential components of CBPR, delineate the pros and cons of using CBPR, and offer advice to student researchers looking to take on this project and sustain its commitment to a CBPR orientation.

**Historical Origins and Theoretical Roots**

According to Minkler & Wallerstein (2010), the Participatory Research Group was created in 1976 by the International Council for Adult Education in Toronto and its network of centers in India, Tanzania, the Netherlands, and Latin America, and the first International Symposium on Action Research and Scientific Analysis was held in Cartenga, Colombia in 1977 (pg. 28). But, the search for new social theories and methods of inquiry had began in the 1960s (Minkler & Wallerstein, 2010, pg. 26) as people began to start challenging the positivist view of science that had predominated research since the Middle Ages (Jason et al., 2004, pg. 161). According to Jason et al. (2004), within the positivist paradigm "the goal of science is to seek the truth, of which there is only one version, [and] this goal is best achieved by an individual, working alone, setting aside all emotions and personal values" with no intent to apply that knowledge (pg. 161).

Minkler & Wallerstein (2010) state that within the search for new research methods, important issues included the "ownership of knowledge, the role of the researcher in engaging society, the role of community participation and agency, ... the importance of power relations, and the challenge to use knowledge to promote a more equitable society" (pg. 26). By putting their heads together, "social psychiatrists, psychologists, and anthropologists were encouraged to combine their skills to deal with
these issues and in this way 'a new action-oriented philosophy of relating psychiatry and the social sciences to society had become a reality in practice" (Heller, 2004, pg. 352). Earlier I mentioned that there is a long list of terms that fit under the CBPR umbrella, and according to Minkler and Wallerstein, a majority of these terms can be traced to one of two different historical traditions (pg. 27). The Northern Tradition is so named due to its origins in European and industrialized settings (Wilmensen, 2008, pg. 10). Within this tradition the goal is to reform organizations through collective problem solving (Heller, 2004, pg. 351) and a cyclical process of fact finding, action, and evaluation (Minkler & Wallerstein, 2010, pg. 10).

A pioneer in this field was Kurt Lewin, a social psychologist who is credited as being the first user of the term action research within the Northern Tradition (Minkler & Wallerstein, 2010, pg. 27). Lewin was very much a scientific pragmatist (Adelman, 1993, pg. 12). According to Hookway (2013), Pragmatism—which is a philosophical tradition that originated in the U.S. around 1870—has at its core a maxim that asserts that hypotheses must be clarified by identifying their practical consequences. Minkler and Wallerstein (2010) state that "Lewin rejected the positivist belief that researchers study an objective world separate from the meanings understood by participants as they act in their world" (pg. 27). In his acceptance of pragmatism and rejection of positivism, Lewin contributed to the development of participatory and action research approaches as tools to produce practical local-centric knowledge that is useful to people in their everyday lives, (Ledwith & Springett, 2010, pg. 199-200).

According to Cunningham (1993), "most social scientists trace the origin of Action Research to the period of the Second World War and its aftermath" (qt. by Heller,
2004, pg. 352). Even before the U.S. got drawn into WWII, we were sending supplies, including meat and butter, to the European allies and this required rationing on the part of civilians. The “critical gatekeepers” in this situation were housewives who made decisions within their homes about food (Heller, 2004, pg. 352). Lewin and his colleagues were trying to figure out how to solve the problem of persuading housewives to substitute beef hearts, sweetbreads, and kidneys for conventional cuts of meat and margarine for butter, so they conducted an experiment (Heller, 2004, pg. 352). They invited housewives to a meeting and divided them into groups: some groups of women listened to a lecture about rationing meat and butter and others participated in a group discussion. Lewin and his colleagues found that the group discussion model was more effective in producing changes in purchasing behavior (Heller, 2004, pg. 352). It was in conducting this experiment that Lewin began to realize the transformative power of dialogue: "Action research for Lewin became exemplified by the discussion of problems followed by group decisions on how to proceed" (Adelman, 1993, pg. 9). Lewin’s mantra and legacy for action research became: "No action without research and no research without action" (Adelman, 1993, pg. 9).

During the 1970s, a second wave of participatory research was rising in Latin America and Africa (Minkler & Wallerstein, 2010, pg. 28). Just as the Northern Tradition was named for its geographical origins, this tradition came to be known as the Southern Tradition (Brown, 1993 qt. by Heller, 2004, pg. 351). This movement was led by social scientists who were “influenced by Marxism and liberation theory who sought new practices for applications among populations vulnerable to globalization” (Minkler and Wallerstein, 2010, pg. 28). Accordingly, the Southern Tradition's epitomizing
characteristic is "an explicit challenge to the inequitable distribution of political and
socioeconomic power [and it] defies unequal access to, and participation in, the
production of knowledge in institutions of higher learning" (Scammell, 2004).

One of the most influential leaders within the Southern Tradition was Brazilian
philosopher Paulo Freire, author of many works—including the Pedagogy of the
Oppressed—which were banned during the Latin American military dictatorships of the
1970s; like his books, Freire was also exiled from Brazil during this time (Minkler &
Wallerstein, 2010, pg. 28). Whereas Lewin was greatly influenced by Pragmatism,
Freire gained much of his inspiration from Karl Marx and Marxist thinkers. Central
to Marx's political, economic, and social theories was "the belief that the struggle
between social classes is a major force in history and that there should eventually be a
society in which there are no classes" ("Marxism", n.d.). Thus, Freire's approach
became "firmly anchored in such traditions of emancipating workers, the poor, and other
oppressed peoples" (Wilmsen, 2008, pg. 9).

Freire was unique in that he wanted the process of social change to start with the
conscientization of the people themselves (Bower, 2004, pg. 120). He thought the best
place to start was with transforming the traditional approach to adult education: "The
goal of education is for teachers and students to work together to arrive at a synthesis
of knowledge in which the roots, processes and techniques of oppression are exposed"
(Freire, 1981 qt. Wilmsen, 2008, pg. 9). Freire acknowledged that reality has to be
looked at and understood through the lens of people's individual perspectives, and that
reality is not simply a collective of objective facts or truths (Freire, 1982 qt. by Minkler &
Wallerstein, 2010, pg. 28). He also acknowledge that people have different forms of knowledge to bring to the table and that dialogue is the best way to bring out ideas.

Park (2006) states: As people engage in dialogue with each other about their communities and the larger social context, their own internal thought patterns and beliefs about their social world change; their relationships to each other become strengthened; and ultimately, they enhance their capacities to reflect on their own values and to make new choices. These three dimensions have been called the 'power of competence, connection, and confidence. (qt. by Minkler and Wallerstein, 2010, pg. 33)

In addition to his strong opinions on dialogue, Freire "was very clear that a unity of theory and practice, praxis, is fundamental to understanding and transforming the power relations of everyday life" (Ledwith, M. & Springett, J., 2010, p. 172). According to Ledwith and Springett (2010), Freire believed that dialogue was the "basis of praxis, [and] this is an important insight for participatory practitioners [because] it identifies dialogue not only as [a] tool of democratic communication, but as the basis for the entire process of transformative change" (p. 134). Freire's legacy within participatory research is that his work resulted in "the transformation of the research relationship from one in which communities were objects of study to one in which community members were participating in the inquiry (Minkler & Wallerstein, 2010, pg. 28).

Participatory Action Research arose from the Southern Tradition. Elden & Levin (1991) say that PAR as learning can empower in three ways: (1) it helps people create better explanations for their social reality, (2) it teaches participants how to learn, and (3) it teaches participant how to transform their own social reality (Jason et al., 2004, pg.
According to Jason et al. (2004), "learning is, in effect, what Freire (1970) characterized as the necessary step to comprehending one’s potential to act to transform the world; therefore, the process of learning becomes a process of taking control conducive to transformative action (pg. 20).

Reflections on Influencing Theories

Critical reflection and transformative action are not separate processes: they are inextricably integrated as a unity of praxis. However, the trivialization of theory in current times presents us with a problem. Without theory there is no praxis, and without praxis our work becomes thoughtless action; it lacks criticality.


This quotation from Ledwith and Springett’s book Participatory Practice: Community-Based Action for Transformative Change marks a pivotal moment in my research process. Upon reading those words, I finally grasped the justification behind all of the books about CBPR, with their focus on the history and supporting theories of this movement, and behind my own (somewhat extensive) review of this research philosophy. My interpretation of this quotation is that action without critical thought and ongoing reflection is meaningless, because then you are simply acting for the sake of action itself rather than acting upon well-thought-out plans. As Minkler and Wallerstein (2010) remind us, "praxis [is] the ongoing interaction between reflection and the actions people take to promote individual and social change" (pg. 38).

Keeping this train of thought in mind, I spent some time reflecting upon the ideas and theories that have influenced me over the course of this project. Both the Health Belief Model (HBM) and Feminist Theory have certainly affected my thought process.
The HBM, which I have learned about and discussed at length in a number of my public health classes, suggests that people’s health behaviors are influenced by their health beliefs and their perception of the efficacy and accessibility of strategies to improve their health or avoid further health risks: "The HBM thus conceptualizes the decision to seek health care as a rational balance between perceived susceptibility, barriers, and benefits" (Stephenson & Tsui, 2002, pg. 310). To me, this model seems a clear fit for our study. The women are making health choices regarding the birth of their babies based on their own personal health beliefs, which are influenced by a number of interpersonal factors such as age, level of education, and socioeconomic status. In addition to these interpersonal factors, their perceptions of how good the health services are and how accessible they are (based on price or distance to travel) also influence how likely they are to utilize skilled birth attendance.

Feminist Theory (FT), on the other hand, is one of the supporting theories of CBPR, and as a feminist myself, I find that this philosophy influences my thinking on a day-to-day basis; clearly, then, FT has impacted my thoughts and actions during this project. FT asserts that giving the oppressed a voice is the basis for social change (Fowler, 2009, pg. 11). By tailoring this survey to the specific needs of the ARM community, involving the women in planning, implementation, and evaluation throughout the study, and collecting personal narratives, we are giving these women a chance to make themselves heard. Hopefully, this experience with CBPR will also be a catalyst for them to start discussing and addressing this problem and other problems that face their communities.
Health Belief Model

One of the most constantly re-occurring topics of study in my Public Health education has been the Health Belief Model (HBM). Naturally, then, this model was one of the first things that came to mind when I sat back to reflect on and consider the ideas that have guided me throughout this research. It was one of the very first models to examine health problems through the lens of behavioral sciences (Daniels, 2011), and despite the fact that it was developed many years ago (back in the 1950s) it remains as one of the most commonly used theories in health promotion and education (Glanz, Rimer, & Lewis, 2002 qt. by Jones & Bartlett). Social psychologists in the U.S. Public Health Service developed the HBM as a way to understand why and explain how preventative medical screening programs were experiencing such widespread failure in the 50s and 60s (Daniels, 2011; Schumaker, Ockene, & Rieker, 2008; Jones & Bartlett).

Later the HBM’s application was expanded to understanding patients' responses to symptoms and disease diagnoses as well as their ability (or willingness) to follow a prescribed medical regimen (Daniels, 2011; Schumaker, Ockene, & Rieker, 2008). According to Hochbaum (1958), "the underlying concept of the original HBM is that health behavior is determined by personal beliefs or perceptions of a disease [or health problem] and the strategies available to decrease its occurrence” (qt. by Jones & Bartlett, pg. 31). Thus, the HBM "provides a framework for us to understand the potential influences on an individual’s decisions to make use of available health services (Becker et al., 1977 qt. by Stephenson & Tsui, 2002, pg. 309). This is exactly what we are looking at in our study; we are trying to shed light on the factors that influence Odisha women as they make choices about utilizing skilled health care services during
pregnancy and delivery. The HBM itself is built on certain theories that hypothesize that behavior is influenced by two important factors: “(1) the value placed by an individual on a particular goal, and (2) the individual’s estimate of the likelihood that a given action will achieve that goal” (Maiman & Becker, 1974 qt. by Shumaker, Ockene, Riekert, 2008, pg. 21).

According to Stephensen & Tsui (2002), the HBM “postulates that three sets of factors—individual perceptions, modifying factors, and likelihood of action—contribute to an individual’s decision to seek health care” (pg. 309). These three postulates encompass four distinct theoretical constructs: perceived susceptibility, perceived seriousness/severity, perceived benefits, and perceived barriers (Shumaker, Ockene, Riekert, 2008). The first postulate states that "the individual's perceptions of his or her susceptibility to a disease and of the seriousness [or severity] of the disease act to provide the impetus to seek care" (Stephenson & Tsui, 2002, pg. 39). The construct of perceived susceptibility is a person's opinion of their chances of getting a certain condition (Daniels, 2011). In our case, perceived susceptibility would apply to a woman’s opinion of her chances of having complications during her pregnancy or delivery. Jones & Bartlett assert that "personal risk or susceptibility is one of the more powerful perceptions in promoting people to adopt healthier behaviors: the greater the perceived risk, the greater the likelihood of engaging in behaviors to decrease the risk” (pg. 32).

Perceived severity, on the other hand, is "a person's opinion of how serious this condition is and the likelihood of contracting the disease" (Daniels, 2011, pg. 37). McCormik and Brown (1999) state that although “the perception of seriousness is often
based on medical information...it may also come from beliefs a person has about the difficulties a disease would create or effects it would have on his or her life in general” (Jones & Bartlett, pg. 31). This statement reminded me of a TedTalk I saw by Sonia Shah. She was talking about why malaria is still a problem in developing countries, and one of her arguments is that in places where malaria is the most common, people see it as a part of every day life, and they don't care about it as much (Ha, 2013). She related this to the idea of the common cold in the United States; people do not perceive the cold as serious, and tend to go about their day, even if they feel terrible. Because the low perceived seriousness of the common cold, people don't take preventative methods like washing their hands, sneezing into their elbows, or avoiding sharing drinking vessels.

Following this argument for malaria, it might be the case then that because problems like low birth weight babies are so common, the women we are working with do not perceive such problem as serious. If this is the case, then it is possible that an additional benefit of our study will be to initiate conversations on why conditions like low birth weight and premature labor are conditions that ought to be taken seriously. Together perceived susceptibility and perceived seriousness comprise perceived threat, which can be a powerful motivator for behavior change; however, even perceived threat fails to motivate people in some situations (Stretcher & Rosenstock, 1997 qt. by Jones & Bartlett). We see this everyday when people smoke cigarettes. People know that they are increasing their health risk by smoking and they know that lung cancer is serious, and yet they still choose to engage in this unhealthy behavior.

The second postulate is that "a series of modifying factors influences the extent to which this impetus to seek care is translated into action" (Stephenson & Tsui, 2002),
The list of modifying factors includes personal characteristics such as age, gender, ethnicity, and socioeconomic status—to name a few—as well as social factors such as cues to action. Stephensen and Tsui (2002) defined a cue to action as “any external stimuli that alters an individual's perception of a disease or condition and influences [their] decision to seek care” (pg. 309-310). This would include mass media campaigns or advice from friends. For example, let’s say that you watch a commercial on television that advises you to ask your doctor about your prostate health. As the narrator describes the frightening prospects of prostate cancer, you might become concerned about your prostate health and remember to ask your doctor at your next appointment. If you are an older man, then you will have taken a successful step in advocating for your own health; however, if you are a woman, your doctor will have even better news for you: “No need to worry, you don’t have a prostate.” (This story is based on the real experience of a doctor I know, and was too good not to share). This postulate relates to our thesis for a number of reasons. First of all, ARM is currently engaging in health campaigns to advocate for skilled prenatal care and birth attendance. The main two forms that we observed were wall murals that showed women talking to ASHA workers about going to the clinic for delivery and the awareness camps that ARM hosted during which the health expert spoke about many issues, including skilled prenatal and delivery care. Also, this factor could come in to play for women whose mothers or sisters have had complicated pregnancies related to their experience with unskilled birth attendance: knowing others who suffered from complications could prompt a woman to seek care at the health clinic.
The final postulate is that "the likelihood of [a person taking] action is the product of the perceived benefits of seeking care minus the perceived barriers to doing so" (Stephenson & Tsui, 2002, pg. 310). Perceived benefits are a person's opinion of the effectiveness or usefulness of some advised action or new health behavior in decreasing the risk one will develop a disease or health condition (Daniels, 2011; Jones & Barlett). Perceived barriers are a persons' opinion of the concrete or psychological costs of this advised action (Daniels, 2011, pg. 37). I reviewed two studies where HBM was applied to women's health, just to see if I was on track with my thinking. The first was a study about the timely use of prenatal care by black women of low socioeconomic status in the South and their behavior's effect on their birth outcomes. Daniels conducted this study in 2011, seeking to "test the HBM...to explain timing of prenatal care usage, compliance, and birth outcomes for this group intersected by race, class, and region" (pg. 9). In her study, Daniels argued that "both the Intersectionality Framework and HBM can be used in health disparities research [because they] provide a [theoretical] foundation to explain how preexisting conditions in society can have an effect on one's beliefs and the choices that they make" (Daniels, 2011, pg. 9).

Daniels’ (2011) study found that: Knowledge and attitudes are key factors that shape one’s health beliefs. A woman's health beliefs are shaped by a number of factors. These factors can be either agency or structural factors and oftentimes both. In examining agency factors versus structural factors, the results show that agency factors such as family size, social support and knowledge/attitudes have an effect on prenatal care use and compliance. These are all individual factors that affect each woman individually. Some
may argue because they are individual factors that they can be easily changed. However, changing one's health beliefs and behavior is not something that is easily done or sustainable over time. (pg. 114-115)

These findings are consistent with public health literature, which states that the connection between a woman’s “lack of knowledge and [her] attitude about prenatal care is well cited” (Braverman et al, 2000; Hogue et al, 2001; Rowley et al, 2004 qt. by Daniels, 2011, pg. 40).

Daniels (2011) explains that: Lack of knowledge includes factors such as being unaware of the signs and symptoms of pregnancy, not knowing when or how to seek prenatal care, or the importance of prenatal care. Previous research has shown that women who are knowledgeable about prenatal care and adverse birth outcomes often times seek early prenatal care while women who are less knowledgeable seek late or no prenatal care. (pg. 40)

The other study I examined was conducted by Stephenson and Tsui in 2002 in regards to contextual influences on reproductive health service use in Uttar Pradesh, India. Their study investigated determinants of the use of four types of reproductive health-care services in Uttar Pradesh, India: “contraceptive services, antenatal care, delivery in a medical institution, and services dealing with reproductive tract and sexually transmitted infections” (Stephenson & Tsui, 2002, pg. 309). They found that there were a number demographic factors that increased the likelihood of health service use; these included low parity, young maternal age, woman's employment in skilled work outside the home, and husband's high level of education. Some related socioeconomic factors were cost, urban residence, household living conditions,
household income, occupational status, and woman's level of education. One of their findings was that “although demographic factors may shape a woman’s desire to…use…services (for example, younger women may have more modern attitudes toward health care), the socioeconomic status of an individual and her household determines her economic ability to do so” (Stephenson & Tsui, 2002, pg. 310).

But, Stephenson and Tsui found that demographic factors and socioeconomic status were not the only explanations for the health care seeking behavior they observed: "The results highlight strong community-level influences on service use [wherein] the role of some individual and household factors in determining a person's use of services is mediated by the characteristics of the community in which the individual lives" (Stephenson & Tsui, 2002, pg. 309). The community factors they found to be significant were “beliefs and opinions based on health-care-seeking behavior, childbearing preferences and sexual and reproductive health behavior, as well as traditional beliefs surrounding childbirth coupled with misconceptions about and fear of medical institutions” (Stephenson & Tsui, 2002, pg. 309).

Another significant argument in their paper was that women in South Asian cultures tend to think of reproductive health services as curative rather than preventative.

Stephenson and Tsui (2002) state: Goodburn and her colleagues (1995) note that in many South Asian cultures, the use of preventive reproductive health services (that is, routine antenatal care) is an alien concept, because such services are perceived as existing solely for curative purposes. This belief was also highlighted by Griffiths and Stephenson (2001), who found that women in
slums of Mumbai, India, would only avail themselves of antenatal care if they experienced problems during their pregnancies. (pg. 310)

This relates back to the HBM in our study because the women may not perceive the benefits of seeking preventative care if they think it is only curative, and on top of that they might not see a need for preventive care because they do not perceive common problems like low birth weight or premature delivery as serious or do not perceive themselves as susceptible to such complications.

Stephenson and Tsui (2002) conclude by saying that “the results [of this study ultimately] demonstrate the need to look beyond individual factors when examining health-care-seeking-behavior, and illustrate that there is no singular 'community effect on service use" (pg. 309). This is important as it relates to our thesis: we recognize that the community can influence an individual in many ways, and we are hoping to investigate those reasons. I will speak more about the affects of a community on health seeking behavior in the introduction to CBPR.

Feminist Theory

Feminism is a big part of my personal belief system, so I knew from the beginning that it would influence me throughout this process of studying women's health; however, I had no idea how perfectly it would fit with CBPR. But before we talk about feminism, we need a definition for oppression. Oppression has many faces: it can include exploitation, marginalization, powerlessness, cultural imperialism, and systematic violence (Iris Young, 1990 qt. by Haslaner, Tuana, & O'Connor, 2014). This description fits our participant population for a number of reasons: they have been exploited by past researchers who came in to take data but didn't give anything back;
women are often treated as second class citizens in Odisha—ARM even cites combating backwardness of rural women as a problem within their community (ARM, 2010)—and many of these villagers are of the scheduled castes and tribes, so they have been historically marginalized and still face significant disadvantages due to this history (Internet FAQ Archives, 2008). Haslander, Tuana, & O'Connor (2014) describe oppression as creating 'enclosing structures' that are part of a broader system that asymmetrically and unjustly disadvantage one group while benefitting another. Around the world women are oppressed by many social structures including sexism, classism, homophobia, racism, ageism, ableism, etc (Haslanger, Tuana & O'Connor, 2014). In this light, feminism can be characterized as an intellectual and political movement that seeks justice for women and the end of oppression in all forms (Haslanger, Tuana, & O'Connor, 2014).

That being said, it is important to note that there is more than one type of feminism. For example, consider liberal feminism and eco-feminism. According to Iris Young (1990), “eco-feminism is rooted in principles of harmony, co-operation and interconnection that challenge the perceived male principles of competition, 'discrimination, extremism and conflict'” (qt. by Ledwith & Springett, 2010, pg. 28-29). Liberal feminism, on the other hand, focuses on women's similarities to men and emphasizes equality (Rogers). These differing facets of feminism are united in their desire for social justice, and thus “feminist inquiry provides a wide range of perspectives on social, cultural, economic, and political phenomena” (Haslanger, Tuana, & O'Connor, 2014).
Until I began to study CBPR, I mostly thought about feminism in the realm of reproductive health care, rape culture, and double standards that are so ingrained into our American society. But, as I found out through my investigations "feminists have a number of distinct interests in, and perspectives on, science [and] tools of science have been a crucial resource for understanding the nature, impact, and prospects for changing gender-based forms of oppression" (Wylie, Potter, & Bauchspies, 2012). According to Haig (1997), there are "five common features of feminist methodology": the rejection of positivism, the pervasive influence of gender relations, the value-ladenness of science, the adoption of a liberation methodology and the pursuit of non-hierarchical research relationships" (Punch, 2005, pg. 136). Feminists reject positivistic science for a number of reasons. First of all, they do not believe that the one-size-fits all approach of conventional research is the basis for sound methodology (Wyatt, Potter, & Bauchspies, 2012). Second, according to Hesse-Biber & Yaiser (2004), feminism asserts that the positivistic paradigm reinforces social dominance in two important ways: “(1) research is carried out through social relationships of differential power with the attendant risks of exploitation and abuse; (2) research is inherently political in facilitating particular structures of power within the larger society" (pg. 13).

Hesse-Biber and Yaiser (2004) explain a big issue that feminists see with positivistic science: "positivist science assumes a subject-object split where the researcher is taken for granted as the knowing party...[and] by privileging the researcher as the knowing party a hierarchy paralleling that of patriarchal culture is reproduced" (pg. 12). Another problem I thought of while investigating feminist perspectives on research is one that I learned about in a Health Psychology course:
most health and medical research used to be conducted nearly exclusively with male subjects because scientists did not recognize that women's differing physiology warranted separate study (Society for Women’s Health Research). Jason et al. (2004) argue that “this silencing of voices is not just a matter for theoretical discussion. It is a matter of passionate interest for the members of the silenced groups, and for those who believe that all of humankind benefits from diversity” (pg. 164). Because women have been historically excluded from research, feminists place greatly emphasize the importance of giving women a voice to speak of their own experience and reality, and this has been very influential in shaping the work of many participatory researchers" (Minkler and Wallerstein, 2010, pg. 10).

Another important aspect of feminist science is that they recognize that science is not value-free, as positivism would have you believe (Punch, 2005, pg. 48). Hesse noted that "the attempt to produce value-neutral social science is increasingly being abandoned as at best unrealizable, and at worst self-deceptive, and is being replaced by social sciences based on explicit ideologies" (Hesse, 1980 qt. by Punch, 2005, pg. 48). Liberation of the oppressed from exploitation and hierarchical social institutions also factors into feminist methodology: "Freire called for 'intervention,' 'liberation,' and 'transformation'; he called for the 'oppressed' to rescue themselves with the help of his liberatory pedagogy" (Bowers, 2004, pg. 120). The last common feature that Haig mentions is the pursuit of non-hierarchical research relationships: "feminist research typically involves...a radical redefinition of research roles,[a] refusal to ignore the emotional dimension in the conduct of inquiry, and [an] acknowledgment of the role of affect in the production of knowledge" (Punch, 2005, pg. 138). Dr. Jason Campbell
explains what a non-hierarchical relationship looks like when he says "the researcher becomes a participant of the research and the participant becomes a researcher."

This non-hierarchical research relationship is empowering to the ‘subjects’ because it gives them a chance to be heard, when in the past their experiences have likely been ignored: "one of the central findings of feminist research has been that alternative voices, particularly those of oppressed groups, are often silenced in mainstream constructions of reality” (Jason et al., 2004, pg. 164). This statement really reminds me of an article called Body ritual among the Nacirema by Horace Miner (1956). This study describes a tribe living in North America that views the natural state of the human body as unsatisfactory, so they expend great effort in collecting potions for their charm chest and worshipping daily at the water temple. My interpretation of this satirical article, which describes the typical American's bathroom habits and practices, is that when Westerns do anthropological research, they often make their subjects into "others" and interpret their findings without acknowledging their own cultural bias.

Minkler and Wallerstein (2010) sum it up nicely when they say that activist feminist research requires "researchers [to] develop a negotiated stance, being implicit about their own identity, and creating through dialogue."

**Essential Components**

Although CBPR is not a method, there are still a number of essential elements that a study must have in order to fit the description of this type of research. In my literature review, I came across a number of lists of that described the most important characteristics of CBPR. Israel et al (2009, pg. 8-10) developed a list of *Eight Key Principles of CBPR*, and Minkler & Wallerstein expanded upon this list, adding a 9th
characteristic (2010, pg. 49-52). In her presentation on CBPR (citation needed), Minkler again described this list as lacking an essential component, that of cultural humility, so she essentially added a 10th element. In their book, Jason et al (2004, pg. 107-110) outline a list of the 10 characteristics of collaborative university/community partnerships, and in his review of Participatory Action Research, Dr. James Campbell outlines four tenets of PAR. For the purposes of this project, I thought it would be wise to develop a compilation of all of these elements to help guide us in our research so that we make sure we are truly adhering to the most important aspects of CBPR philosophy.

The Twelve Most Important Elements of CBPR: A Compilation Based on Characteristics Described by Israel et al (2009), Minkler & Wallerstein (2010), Minkler (2010), Jason et al (2004), and Dr. Jason Campbell

1. Developing a relationship based on trust and mutual respect, with a focus on alliance building

2. Recognizing the community as a unit of identity and learning about the community's unique culture

3. Practicing cultural humility by respecting and celebrating diversity

4. Maximizing the use and exchange of resources to build upon the strengths of the community

5. Promoting collaborative, equitable partnerships in all research phases and involving an empowering and power-sharing process that attends to social inequalities

6. Creating a two-way learning-relationship to promote co-learning and capacity building among partnerships, which are multidisciplinary in nature
7. Integrating and achieving a balance between research and action for the mutual benefit of all partners

8. Collectively committing to engaging an issue or problem identified by the community by emphasizing public health problems of local relevance and also ecological perspectives that recognize and attend to the multiple determinants of health

9. Using both qualitative and quantitative research strategies

10. Establishing open lines of communication for collective reflection to develop systems through a cyclical and iterative process

11. Disseminating findings and knowledge gained to all partners and involving all partners in the dissemination process

12. Sharing accountability of partnership success and opportunities, and committing to a sustainable, long-term process

In the following pages, I will discuss each of these twelve principles in depth. I have also provided a chart of the principles that I used to develop this list for the sake of comparison.
### Table 1: Essential Principles by Israel et al., Minkler & Wallerstein, Jason et al., and Dr. Campbell

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<tr>
<td>1. CBPR recognizes community as a unity of identity</td>
<td>1. CBPR recognizes the community as a unit of identity</td>
<td>1. Develop a relationship based on trust and mutual respect</td>
<td>1. Collective commitment to engage an issue or a problem</td>
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<td>2. CBPR begins with and builds on the strengths and resources that exist within the community</td>
<td>2. CBPR builds on strengths and resources within the community</td>
<td>2. Maximize, use, and exchange resources</td>
<td>2. Collective reflection</td>
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<td>3. CBPR promotes collaborative and equitable partnerships in all phases of research</td>
<td>3. CBPR facilitates collaborative, equitable partnerships in all research phases and involves an empowering and power-sharing process that attends to social inequalities</td>
<td>3. Build a two-way learning relationship</td>
<td>3. Mutual benefit</td>
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<td>4. CBPR facilitates co-learning and capacity building</td>
<td>4. CBPR promotes co-learning and capacity building</td>
<td>4. Establish open lines of communication</td>
<td>4. Alliance Building</td>
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<td>5. CBPR integrates and creates a balance between knowledge generation and action for the mutual benefit of all partners</td>
<td>5. CBPR integrates and achieves a balance between research and action for the mutual benefit of all partners</td>
<td>5. Respect and celebrate diversity</td>
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<td>6. CBPR focuses on the determinants of health from a local standpoint within a context of a broader ecological approach</td>
<td>6. CBPR emphasizes public health problems of local relevance and also ecological perspectives that recognize and attend to the multiple determinants of health and disease</td>
<td>6. Learn about the culture of the organization</td>
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<td>7. CBPR disseminates findings to all partners and involves all partners in the dissemination process</td>
<td>7. CBPR involves systems development through a cyclical and iterative process</td>
<td>7. The research collaboration is based on the needs of the community</td>
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<td>8. CBPR promotes a long-term process and commitment to sustainability</td>
<td>8. CBPR disseminates findings and knowledge gained to all partners and involves all partners in the dissemination process</td>
<td>8. Understand the multidisciplinary nature of partnerships</td>
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<td></td>
<td>9. CBPR requires a long-term process and commitment to sustainability</td>
<td>9. Use both qualitative and quantitative research strategies</td>
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<td></td>
<td>10. CBPR requires researchers to practice cultural humility (Minkler, 2010)</td>
<td>10. Share accountability of partnership success and opportunities</td>
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Developing a relationship based on trust and mutual respect, with a focus on alliance building

If you will recall, one of the biggest problems that we had when first establishing contact with ARM was that their previous GlobeMed university partner had really let them down. The leaders of ARM did not even want to talk to us at first, and it took persistence on the part of our two co-presidents to break down that wall. We demonstrated our commitment to the relationship by keeping in frequent contact with ARM throughout the school year, but I truly believe it was our GROW experience that helped us build such a strong relationship with Rajendra, Sachi, and Krishna. Two of the most important aspects of a successful partnership are trust and commitment, but both of these take time to develop: "Establishing trust is a necessary foundation for creating a successful partnership" (Jason et al., 2004, pg. 107) and "the development of a collaborative relationship takes time and commitment to the partnership" (Mattessich & Monsey, 1992, qt. by Jason et al., 2004, pg. 107).

Because of the short length of time available for the GROW Trip, it is critical to begin fostering that trust as soon as possible; thus, the personality and conduct of students who go on this internship is of the upmost importance. At the end of our time there, we had a final meeting with Rajendra and Sachi, and they told us what it was they liked so much about us. They were truly impressed by the way that we had engaged with the community and they appreciated the fact that we handled our conflicts well and amongst ourselves. During our time there, we were blown away by their generosity towards us and their dedication to helping the people of Odisha. Now, as Jason et al. (2004) state, "partnerships within the community imply a diverse set of stakeholders"
Currently, the list of stakeholders include ARM, undergraduate student researchers in GlobeMed at USC, the SHG women, and the women who volunteer. During this summer's internship, it will be critical to identify any other stakeholders so that they can be brought into the partnership.

An impediment to building trust with our stakeholders, besides ARM, is the 8,300 miles that separate us for all but about six weeks out of the year. In order to establish the optimal relationship between ourselves and the community, our student researchers would need to live in Odisha for a number of years, and that is simply not possible for undergraduate students. It is fortunate, then, that ARM is so well known and respected by the community members. By maintaining a high level of trust with ARM through constant communication and collaboration and by setting up a system whereby ARM is constantly involving community members, we should still be able to have success in this endeavor. To this end, while our student researchers are in Odisha for the GROW Trip, they will need to focus on alliance building, particularly with the SHG leaders.

According to James Campbell, alliance building requires the researcher to believe that the people are smart enough to engage in research and the participants to feel that the researcher actually cares and understands; this requires the researchers to take a step back and recognize that they are there to help, not to impose their Western beliefs about how things should be (Jason Campbell). I will never forget how Rajendra described ARM's mission: he said that the people know the problems best, and thus they know how to fix them. We are just there to aid the transition of their ideas to reality. Lastly, significant time must be devoted to hosting focus groups with the SHG women this summer to establish trust with these women by "[identifying] a common vision and
goals for the partnership, [clarifying] expectations, and [discussing] the time commitments and resources needed to develop ownership over the collaboration (Jason et al., 2004, pg. 107). With these women you will clarify the essential research question, share the results of this thesis, and hone the training manual and survey instrument to fit the needs of the people.

*Recognizing the community as a unit of identity and learning about the community's unique culture*

Israel et al. (2009) state that "CBPR recognizes community as a unit of identity" (pg. 8), but defining that *unit of identity* can sometimes be tricky. I have been collectively referring to our future participants as "the women," but perhaps there are other social divisions that we are not recognizing or there is a better way to refer to our participants. (This should be discussed in the focus groups with the SHG women.) Sharing an cultural identity implies not only shared norms and values or common language and customs, but also similar goals and interests and a desire to meet shared needs, topped with a sense of emotional connection (Israel et al., 2009, pg. 8). Another goal, therefore, of the focus groups will be to engage in dialogue with the SHG women about whether they truly feel like they represent a *unit of identity* and how they would describe the norms, values, interests, and goals that bring them together. Understanding (to the extent possible) and respecting the culture of these women and how they relate to one another (Suarez-Balcazar et al., 2002 qt. by Jason et al., 2004, pg. 108) and to the group as a whole will truly aid in the collaborative process by giving us a better understanding of where they are coming from.
Practicing cultural humility by respecting and celebrating diversity

The previous element and this one are very much connected. You may have noticed that I added *to the extent possible* right after *understand* in the last sentence of that section. I added this because there are many who believe that it is not possible to truly understand a culture to which you are an outsider (Minkler, 2010), and I think that they might be right. However, regardless of how well one can come to understand a different culture, it is always essential to practice cultural humility. Tervalon & Garcia (1998) define cultural humility as "a life long commitment to self evaluation and self critique to redress power imbalances and develop and maintain respectful and dynamic partnerships with communities" (qt. by Minkler, 2010). Israel et al. (2009) explain that what researchers need to reflect on and evaluate is their own "privilege, values, belief systems, and patterns of unintentional and intentional racism and classism" (pg. 35). (Here you can see how well Feminist Theory fits into our discussion.) In other words, our student researchers will need to reflect upon the ideas, opinions, and reactions they have as they go through this process to understand why it is that they feel the way that they feel. According to Marin (1993), "respecting diversity also includes the development and use of culturally sensitive and appropriate research instruments and protocols" (qt. by Jason et al., 2004, pg. 108). This objective will be met by involving the SHG leaders and participants in the development of our instruments and materials and interpreting the results of our data analysis.
Maximizing the use and exchange of resources to build upon the strengths of the community

Those who have not heard of or studied CBPR before might be skeptical about using community members as co-researchers, but both academic researchers and community members have skills and resources to bring to the table. As you might expect, researchers provide access to resources, such as grant funding and technology, along with their knowledge of research literature and methods (Jason et al., 2004, pg. 107). The community members, on the other hand, bring a different type of knowledge: experimental knowledge of the issues involved, the specific area or population of interest, and the cultural and contextual characteristics of the setting and community (Bond, 1990; Jordan, Bogat, & Smith, 2001 qt. by Jason et al., 2004, pg. 107). Suarez-Balcazar et al. (2002) point out that community members also "provide access to key informants, community leaders, and networks in the community as well as program participants" (qt. by Jason et al., 2004, pg. 107). In other words, the community members have a lot to offer in terms of improving the quality of the research materials and the ease of accessing participants.

We are obviously conducting the research because ARM has identified a problem, but focusing simply on the deficits without recognizing the strengths of the community is negative and not empowering. Rather, we need to acknowledge and build upon community strengths such as "knowledgeable, engaged, and committed community members and leaders; resources and services provided by community and faith-based organizations; and supportive social networks (Israel et al., 2009, pg. 4). It will be important for the focus groups to assess community strengths and dynamics;
questions to help lead this discussion include: "What are the strengths and resources in the community? What are the influential organizations? Where’s the power in the community? Who needs to be involved to ensure community buy in?" (Israel et al., 2009, pg. 4).

Promoting collaborative, equitable partnerships in all research phases and involving an empowering and power-sharing process that attends to social inequalities

According to Israel et al. (2009), the process of promoting collaborative and equitable partnerships in all phases of the research involves the identification by community members of the issues and concerns to be addressed (pg. 8). Thankfully, it was ARM that approached us about conducting research and not the other way around; if we had approached them, this could not be in line with CBPR principles. But, it will be essential to use the focus groups with the SHG women to get their opinions on the research questions being addressed; to that end, they need to be involved in every step of the project from here on out, including redefining the research question (if necessary); designing and implementing data collection; and interpreting, disseminating and translating the findings (Israel et al., 2009, pg. 8). A certain level of inequality between researchers and participants is inevitable, but engaging the community members at every phase of the research to make sure their voices are heard is a step towards decreasing that inequality (Israel et al., 2009, pg. 8) and making sure that community members feel that they are valued team members.
Creating a two-way learning-relationship to promote co-learning and capacity building among partnerships that are multidisciplinary in nature

Because both community members and researchers have different skills and resources to bring to the table, these two groups can learn from each other. In a two-way learning relationship, "each partner comes to the partnership ready to learn as well as ready to guide" (Jason et al., 2004, pg. 108). We can learn more about the issues at hand, and they can learn more about conducting evaluation and research (Israel et al., 2009, pg. 8). Under the traditional paradigm of research, the knowledge of community members is often devalued by the illusion of the superiority of academic expertise; but in truth, different forms of knowledge are complementary rather than antagonistic (Bond, 1990 and Serrano-Carcia, 1990 qt. by Jason et al., 2004, pg. 108). In regards to capacity building, it is one of the very long-term goals of this study to give the SHG women (and the women participants) the knowledge, skills, and—most importantly—the confidence to initiate their own research or evaluation of community problems and other issues of concern to them. While we were in Odisha, one of the meetings we went to was of a large group of women who were working to ban the sale of alcohol in the area because alcohol-fueled instances of domestic violence by husbands to their wives is a problem of great concern to them. We know that these women already have the ability to make great changes to their communities, and we want to help add to the arsenal of skills they possess.
Integrating and achieving a balance between research and action for the mutual benefit of all partners

A very important distinction between traditional research methods and CBPR is that CBPR is not focused on simply generating knowledge; there is a commitment to translating the research findings into practical applications such as intervention strategies or policy changes to meet the needs and concerns of the community (Israel et al., 2009, pg. 9). The intervention strategy or policy change is what is given back to the community members in return for their engagement in the process. According to Dr. James Campbell, mutual benefit happens when the researcher immerses themselves into the community as much as possible, so that "wins" for the community are "wins" for the researchers, and vice versa. Although our ability to immerse ourselves into the community is limited, ARM is well immersed since many of the leaders, including Rajendra—the chair/founder—are from the community. This means that mutual benefit can be created between ARM and the community, and thus our student researchers by extension, since aiding the well-being and success of ARM is at the core of our GlobeMed chapter goals.

Collectively committing to engaging an issue or problem identified by the community by emphasizing public health problems of local relevance and also ecological perspectives that recognize and attend to the multiple determinants of health

This element emphasizes once more that in CBPR the research question or issue to be investigated must be identified by community stakeholders rather than the researchers. CBPR requires a lot of time and commitment from everyone involved; thus,
the results must be translatable to real, practical, and impactful action items. Here, Dr. James Campbell draws the concept of *white man's burden* into the conversation; simply put, this concept describes the flawed idea that it is the obligation of the privileged group to alleviate those who are suffering; he says that this is absolutely not the way to approach CBPR. This concept would violate a previous concept that requires the researcher to truly believe that the people are smart enough and capable enough to do the research and change their own society for better. I had a thought at one point in our research process that if researchers approached me and told me that American women go about childbirth all wrong and I was making the wrong choices about my health care, I would be angry and think they were arrogant to tell me something that was so contrary to what I knew about the way of life. This is exactly what happens when Western researchers try to impose their values on vulnerable, non-western populations. In his video about participatory research, Jason Campbell rants about the traditional researchers' tendency to waltz in and say "We heard you have problems in your third-world community and we are here from the first-world West to tell you what to do."

Israel et al. (2009) explain that the emphasis placed on the "local relevance of public health problems acknowledges that issues need to be identified and understood within, and interventions need to be tailored to, the local cultural, historical, political, and socioeconomic context in which the community is embedded" (pg. 9). This helps ensure that the questions that are asked and the interventions that are eventually developed are in line with the values and relevant to the needs of the community. Israel et al. (2009) also state that "the ecological model reminds us that the actions we take as individuals are influenced by many things in our environments" (pg. 9); this is exactly
what our research question is addressing: the women are taking certain actions in regards to choosing unskilled birth attendance rather than skilled birth attendance, and we need to figure out what all of the "things" (also known as influential factors) are.

Using both qualitative and quantitative research strategies

It is my thought at this time that a closed-ended survey, focus groups, and open-ended interviews will provide us with an abundance of data, both qualitative and quantitative. Getting data from different sources should help us get a better perspective on the whole situation:

Jason et al. (2004) argue: As community researchers, we are not only interested in numerical data descriptive of participants but also the rich stories and voices of the people of concern is consistent with the key principles of the field of community psychology (Rappaport, 1981; Serrano-Garcia & Bond, 1994; Trickett, et al., 1994). Qualitative methodologies underscore the development of trust and rapport with participants to gain access to their personal experiences (Tandom, Azelton, & Kelly, 1998). In addition, community partners appreciate the use of both strategies and are likely to have previous experience with public forums, focus groups, listening sessions, personal interviews, and other qualitative methods. (pg. 109-110)
Establishing open lines of communication for collective reflection to develop systems through a cyclical and iterative process

Earlier in this section we discussed the formation of partnerships, but it is essential to remember that relationships do not simply maintain themselves once formed. They require lots of work. Additionally, since CBPR is a philosophy or orientation towards research and not a methodology, we need to continuously reflect on and evaluate how well we are living up to the standards of conduct that are set at the beginning of the study. Thus, communication is key: "for a relationship to be successful it is essential to establish open and frequent communication by providing updates, discussing issues openly, and conveying all information to one another as well as to others outside the team (Mattessich & Monsey, 1992 qt in Jason et al., 2004, pg. 108). These open lines of communication can facilitate collective reflection. Dr. James Campbell emphasizes the idea that what is at stake in this type of research is the process of the research itself, therefore, we need to always be making sure that we are adhering to our CBPR principles.

Disseminating findings and knowledge gained to all partners and involving all partners in the dissemination process

There is a significant barrier that exists between academia and the rest of the world. By this I am referring to the fact that there is a lot of research that only gets published in academic journals, and is never made available to the general public. Even the most insightful social research is not helpful, if the results are not publically shared. According to CBPR principles, Israel et al. (2009) insist that researchers not only feed
back the results to their community partners, but also include those partners in "the interpretation of findings, deciding what results to share, and deciding how the results need to be distributed more broadly" (pg. 9-10). Involving our community partners in decisions about the dissemination of our results will be absolutely critical in this project. A challenge that faces us is figuring out exactly how to disseminate the results; this should be a topic of discussion in the focus groups this summer. Two ways that ARM currently distributes health information is through mural art and through health and awareness talks; incorporating our results into these mediums might work well, but it will be important to get input from the SHG women in this matter.

*Sharing accountability of partnership success and opportunities and committing to a sustainable, long-term process*

Depending on how much longer this project goes on, it may change hands a few more times on the side of the student researchers. A benefit of this is that it could allow for increased ownership of the project by ARM and the community stakeholders. Despite student turnover, all parties involved need to be held accountable for ensuring the success of the project in the long term. Making sure that the action portion of the project is sustainable is critical, because it would be unethical to leave these women without the tools they need to take the knowledge we generate in this study to make permanent changes within their communities. Also, according to Blake & Moore (2000) "In partnerships developed with low-income communities or grassroots groups where levels of resources are disparate, sharing the credit for accomplishments and successes is even more important" (qt. by Jason et al., 2004, pg. 110). What this means
to me is vulnerable populations, like the women we are working with, really need to leave research endeavors feeling like they gained from it and had a positive and successful experience. If they have a negative experience or feel that the researchers don't credit them with helping to make the study a success, that could be discouraging or disempowering and it might turn them off from doing research again, which is the opposite of what we want to do. Jason et al. (2004) reminds us that just as we must celebrate successes, we must also look to failures as opportunities to reflect and learn. Clearly, not everything is going to go smoothly during CBPR, but rather than fretting or become discouraged by setbacks or mistakes, we need to look at what went wrong and figure out how to not repeat those mistakes down the road.

**Challenges of Conducting CBPR**

As with any type of research, there are a number of challenges that are faced by those wishing in engage in CBPR. First of all, there is not a single or simple set of one-size-fits all CBPR principles that can apply to all partnerships (Minkler & Wallerstein, 2010, pg. 53). Every setting, culture, and community is going to have different needs, so the development of CBPR principles has to fit each individual situation (Minkler & Wallerstein, 2010, pg. 53). In addition to establishing the principles, there is the ongoing challenge of following them throughout the whole research process (Israel et al., 2009, pg. 90). If you start off by calling a particular study participatory but don't follow through, you may contribute to the ‘tyranny of participation’:

Ledwith and Springett (2010) assert this position: We have to be mindful to claims to participatory practice that are superficial, giving lip service by using the language of participation but not following the process through. Taking a partial
perspective is dangerous, and can reinforce the very system that it seeks to change, creating what Cooke and Kothari (2001) call the 'new tyranny of participation'. The path to participation is a fine line to tread: it is the line that marks the interface of liberation and domination. Dangers arise when transformative concepts are not fully understood and embodied in the theory and practice. (p. 81)

Minkler and Wallerstein (2010) advise that those in CBPR partnerships handle these challenges by developing procedures to ensure CBPR principles are followed and to continually evaluate how well those CBPR principles are being followed (pg. 59-61). Additionally, the research design and methodology plus the appropriate size of the partnership are points for discussion amongst partners because these are not dictated by CBPR principles alone (Minkler and Wallerstein, 2010, pg. 59-60). Having all of these principles and agreements down on paper and produced through focus groups is great, but Jason et al. (2004) remind us that "difficulties...arise when working in real-world settings" (pg. xvii).

Challenges also arise in deciding how the CBPR partnership defines its "community" and whether or not that community represents a community of identity (Israel et al., 2004, pg. 93). Minkler & Wallerstein (2010) offer a number of questions for partners to consider as they attempt to outline the community of interest, concerning who represents the community, whether community members will be involved as individuals or as representatives of community based organizations, and who is being defined as "outside of the community and not invited to participate?" (pg. 53). This question is important for us to consider because we are doing a study that concerns
women's health, but men in the villages might want to be involved to, since their wives will be answering some personal questions about their family life. To what extent can or should these men be included? Are they being defined as part of the "community?"

Literature on CBPR emphasizes collaboration and equitable participation, but all partners in a CBPR study have to agree on what exactly is meant by these terms and how the implications of these terms will be carried out. Minkler and Wallerstein (2010) state that "every partnership needs to ask itself whether members are true partners or just part of the partnership—in other words—are all partners ready and able to share power? This requires considerable time and attention from all involved" (Israel et al., 2001 and Lantz et al., 2001 qt. by Minkler and Wallerstein, 2010, pg. 54). Another challenge is achieving an equitable distribution of power and control. Researchers and partners, especially when they are from different countries, often have some real inequalities to deal with, which may include race, gender, social class, socioeconomic status, and level of education, to name a few (Israel et al., 2009, pg. 91). And these inequities, according to Minkler & Wallerstein (2010), can and often do come up and cause tensions, even as partners strive for equity (pg. 55). They suggest that partners acknowledge and address these inequities so that they can figure out ways to reduce the impact that the inherit power imbalances can have on the working relationship between partners (Minkler & Wallerstein, 2010, pg. 55).

A related obstacle is language, and—of course—this goes both ways. Within our partnership, we speak English and so do the leaders of ARM, but the women speak Odia. Having conversations can and will be challenging. Also, in our materials that we distribute, such as the training manual, survey, and any written materials for the focus
groups, we need to be able to phrase things in culturally appropriate ways and avoid using jargon. Of major concern to this project is finding a good translator to use and coming up with the funds to pay for his or her services. Another challenge is to recognize and embrace the unique strengths and resources that partners can contribute (Green et al., 1995, qt. by Minkler & Wallerstein, 2010, pg. 48). Researchers need to be receptive to these different forms of knowledge, and all partners need to have patience with the time necessary to effectively manage and synthesize diverse insights and perspectives (Israel et al., 2009, pg. 92). Minkler and Wallerstein (2010) state that the presence of multiple perspectives...require[s] the development of a common language, trust, and mutual respect; an understanding of the various cultures; and the recognition that different participants may have different goals and agendas and also different experiences with and degrees of commitment" (pg. 58).

Another challenge is accepting the fact that not everyone will be involved in the same way in all activities (Minkler & Wallerstein, 2010, pg. 56). For example, because of our university resources, the student researchers are going to be the ones exclusively doing the literature reviews. The community members simply do not have access to such resources, or the skills or time to devote to library research. On the other hand, the SHG leaders are going to be the ones ultimately going around and disseminating the surveys; our student researchers cannot participate in that for a number of reasons: the SHG leaders wanted to start in December last year, and that will likely be their preference again this year. Our interns won't be there in December. Also, the women who volunteer as participants would likely give different responses if student researchers were interviewing them as opposed to SHG leaders from their own
communities. Nina Panvelker experienced this first hand when she was trying to conduct a survey on dental health habits: people answered questions as a group even if she was trying to interview them separately and they kept giving her answers that seemed further from the truth and closer to what they thought Nina wanted to hear. A related challenge is that with CBPR the process is almost as important as the results that are obtained, and it can be difficult to balance the responsibilities of each of these tasks.

Israel et al. (2009) state: Some partners may be more interested in the processes involved, such as how decisions are made and how relationships are established, whereas other partners may want to focus primarily on the tasks at hand, such as collecting data; in addition, some partners are more committed to conducting basic, etiologic research, and other partners are more concerned with taking action through interventions and policy change. (pg. 91)

Minkler & Wallerstein (2010) say that "decisions regarding partner's specific roles...and where their respective energies can be best applied need to be made through open dialogue and consensus" (pg. 296). A good example of a phase of the process where researchers might not be inclined to seek community participation is data analysis. Minkler and Wallerstein (2010) state that "participatory data analysis is very difficult to achieve, [especially] in the case of qualitative data [when] the mountain of transcriptions to be examined can be daunting...and time consuming" (pg. 36). There is never a perfect equilibrium of power or participation in CBPR, and all research efforts undergo cycles of participation and questioning by community members, brining greater or lesser participation and greater or lesser ownership" (Minkler & Wallerstein, 2010, pg.
Because this is so, it will be an ongoing challenge for all partners to assure that participation occurs in ways that maximize informed input while minimizing the burden on the partners" (Israel et al., 2009, pg. 90).

Related to the issues of inclusion in processes like data collection and analysis is the discussion of the dissemination of results. Even if community members are involved in data collection, the "participatory process of feeding back results and jointly interpreting their meaning and prioritizing the findings in terms of broader dissemination and action planning can be overwhelming" (Israel et al., 2009, pg. 93). Additionally, at this point in the process, researchers need to be wary of spending too much time focusing on writing academic papers for publication (or in the case of our student researchers, the senior thesis) and not enough time on figuring out ways to broadcast findings to the participants and the communities as a whole (Israel et al., 2009, pg. 91). Israel et al. (2009) also remind us that "there can be a long time lag between collecting data, analyzing it, feeding back the results to all of the partners involved, and disseminating the findings more broadly" (pg. 93). Since the women are already hesitant to participate in research where they might not get anything in return, it will be the responsibility of our student researchers to work hard to accomplish these tasks in a timely manner, keeping the women as involved as possible, and keeping in constant communication with them through ARM so they don't feel like they are abandoned at the end of the process. Additionally, there will be the challenge of us figuring out exactly what mediums to use to distribute the findings (Israel et al., 2009, pg. 91) and we will need to avoid using jargon so that the findings can be easily translated and understood (Minkler & Wallerstein, 2009, pg. 93).
Making sure to "recognize and value priorities identified by the community can be a challenging part of CBPR" (Minkler & Wallerstein, 2010, pg. 57); figuring out how to balance academic priorities with CBPR endeavors is a challenge for researchers because "academic institutions often place higher value on publishing in peer-reviewed journals and receiving grant funding from federal agencies" (Israel et al., 2009, pg. 93).

Now of course, on our level, we are not publishing in peer-reviewed journals or bidding for federal grant money, but our student researchers will be under certain pressures to get what they need for a senior thesis. Fortunately, the senior thesis is very open, and the school simply wants us to have a good learning experience; the same goes for the Magellan Scholar award. However, students who work on this research in the future will need to be flexible to the needs of the community if they need to change deadlines or alter the process at any step. If any other students wish to do research with the community in the future, it will be important that it is the community that comes up with the research idea, not the student; because, if the student comes up with the idea, the community might not see it as important or worthy of such time investment. Back in November when Odisha was devastated by Cyclone Phailin we almost changed the focus of our research; however, I am so glad that we did not since that would not have been in line with the CBPR principles we are now trying to abide by. Additionally, it will be important in the focus groups to ensure that skilled birth attendance is an issue the SHG women care about and perceive as a problem in the community, not just one that ARM has chosen (although their opinion is very important).

Lastly, time and commitment to the relationships and sustainability of the project are big challenges to face (Israel et al., 2009, pg. 90). When there are more opinions to
listen to and more people to involve in making group decisions and taking care of tasks, it can really slow a project down, and that can be frustrating to all involved: "the active involvement of all partners in different phases of the research process requires a tremendous commitment of time in order to create a research design, and collect, interpret, and disseminate the data" (Jason et al., 2004, pg. 90). Arguably the most important aspect of CBPR is the development of a trusting and committed relationship, and that truly takes time, especially in communities like ours where there is already a level of mistrust with outside researchers. Jason et al. (2004) remind us that "many participating communities are underserved, marginalized, or are by nature vulnerable, lacking a voice as well as sufficient influence. Negative experiences in controlling relationships cause many marginalized individuals to be wary of institutions, authority figures, and outsiders" (pg. 223). The best way to establish that level of trust is by spending time in the communities talking to and engaging with the people (Jason et al., 2004, pg. 223).

Additionally, CBPR requires a long-term commitment to making the study and any programs, interventions, or policy changes that come out of it sustainable, even when the grant money runs out (Israel et al., 2009, pg. 91). This is definitely a concern for us since we have very little funding, but there are certainly costs for materials (paper and ink for the training manuals and surveys), incentives for the SHG workers and participants, and the cost of a translator.

**Benefits of Conducting CBPR**

Despite the many challenges and rather intense time commitments, there are even more significant benefits to pursuing a study endeavor based upon CBPR principles.
Unfortunately, there are many people in academia who doubt the legitimacy of CBPR as an approach to research, but rest assured, "CBPR can be both community driven and scientifically sound" (Minkler & Wallerstein, 2010, pg. 6). A key strength of CBPR is that it brings together people from different backgrounds, with different skills and expertise to address complex public health problems that are of significance to community members (Israel et al., 2009, pg. 96). A mutually reinforcing partnership is developed when researchers combine their knowledge of theory and method (Minkler and Wallerstein, 2010, pg. 6), with the experiential knowledge of community partners (Jason et al., 2004, pg. 20). Elden & Levin (1991) remind us that "those who live in a particular community get to know more about it and have more ways of making sense of their world than would be possible for any outsider to appreciate" (qt. by Jason et al., 2004, pg. 20). Willging describes this aspect further by saying that "the researcher might know about evaluation design or how to create the best data collection instrument; but, without the perspective of local community people, this research design can't be brought to life."

Also, by respecting the ideas, opinions, and concerns of the community members and including them in every stage of the research process, they can being to develop a sense of ownership of the research effort (Fawcett et al., 1994; Serrano-Garcia & Bond, 1994; Suarez-Balcazar, Balcazar & Fawcett, 1992 qt. by Jason et al., 2004, pg. 106).

Elden & Levin (1991) praise the ability of the CBPR process to alter the research paradigm: "The insiders are not simply sources of data, but they actively help create new meanings for the information generated in the research process; they become co-creators of knowledge; The professionals are not the liberators; they are merely the
facilitators in a struggle in which people seek to liberate themselves" (qt. by Jason et al., 2004, pg. 21)

According to Israel et al. (2009) CBPR can enhance the quality and validity of the research process and the relevance and use of data (pg. 94). Jason et al. (2004) state that "community participation holds much promise in strengthening the research designs by more accurately describing the population...and by identifying the actual community practices, prevention strategies, and resources" (pg. 55). Additionally, training community members to disseminate the surveys can significantly improve the response rate. In a study by Israel et al. (2009), community members were hired and trained as interviewers; the result of this was that due to the better rapport between interviewer and participant, they had an 81% response rate and they obtained very good quality data (pg. 94). I think this will be true for us too, especially after seeing the struggles our friend Nina faced in getting answers to her survey. Additionally, improving the quality of research methods and data collection increases the potential for translating the findings into interventions that are actually appealing to community members and that can be sustainable and guide the development of policy change (Israel et al., 2009, pg. 96).

Public health interventions are less effective when they are not tailored to the concerns and culture of participants and when they only address individual behavior change (Israel et al., 2009, pg. 5). It is very important to look at health in context, taking into account where "individuals reside and the extent to which broader social and structural conditions impact an individual's health and ability to adopt new behaviors" (Israel et al., 2009, pg. 5). Involving the women throughout the research process will help us pick up on cultural nuances we might otherwise miss and will assist us in putting
the issues of seeking skilled birth attendance into the cultural context of these rural Odishan villages. This will be helpful when the time comes to choose appropriate and acceptable actions to take once the data has been analyzed and conclusions have been drawn.

Another important benefit of using a CBPR approach is that "working in collaboration with the community provides unique opportunities to identify and build on the assets and resources that exist within the community" (Jason, 1997; Ostrom, Lerner, & Freel, 1995 qt. by Jason et al., 2004, pg. 106). Obviously the knowledge gained and interventions conducted can benefit the community (Israel et al., 2009, pg. 95), but new resources within the community can be skills that are learned when community members are tried as project managers, outreach workers, community organizers, and interviewers (Israel et al., 2009, pg. 96) such as planning intervention programs, learning to identify resources, and becoming "better problem solvers who are more likely to manage future challenges and issues" (Jason et al., 2004, pg. 5).

Gaining these new resources and skills can be very empowering for community members in three ways, according to Elden & Levin (1991). First off, engaging in participatory research helps community members recognize their own potential as they become more self-aware and are better able to understand their social reality. Second, it helps people learn how to engage in dialogue with each other and learn from one another in new ways. Third, It helps them learn how to transform their own social reality. To summarize, as they become more aware of their position in society, and they become more confident in questioning that position and the way things are, they will be
more likely to engage with each other in meaningful dialogue, which can be a basis for social change.

Scholte (2000) states: Through dialogue we are able to begin the process of questioning the taken-for-grantedness of everyday life. This is not only the starting point for critical consciousness, but also the motivation for collective action. As we become skilled in the practice of dialogue, we deepen our capacity for critical thought, questioning everyday experiences, challenging false consciousness to reach new insights into the political nature of personal lives. As we begin to see the world in different ways, we change how we act in the world. People join together to act collectively for social change, fired by a sense of justice and a hope for a better world. (qt. by Ledwith & Springett, 2010, p. 24)

Even more important than the eventual intervention or policy change or program that is developed from these research findings is the sense of accomplishment and empowerment that will hopefully be gained by all who engage in this endeavor. One way that we can do this is by making sure this research experience is really positive on a personal level; what I mean by this is, I want them to feel like we kept our promises, cared about them, included them, and that they gained from this experience. Israel et al. (2009) say that "the use of a CBPR approach enhances trust and bridges cultural gaps between academic institutions, health service agencies, and community-based organizations" (pg. 96). This is so important because of the history of traditional research being conducted under the 'parachute model' whereby "the researchers drop in, collect data, and disappear without any feedback of the results to the community" (Israel et al., 2009, pg. 5). This type of research has caused so much distrust in
vulnerable populations, and we have a chance to start changing that due to the unique nature of the GlobeMed and ARM partnership. We are with ARM for the long haul, and we are devoted to the success of this organization and the people it serves. I am confident that engaging in CBPR with these women will do so much more than we ever could by just taking a survey or doing library research ever could.

IMPACT OF CYCLONE PHAILIN

Implications for Rural Odisha

by Runjhun Bhatia

Every college student recognizes the crunch before any break. Professors tend to time assignments and exams to be due the week before break, and most of us have to buckle down for a couple of weeks before our time off. This usually means getting off Facebook, online streaming, and even slacking off a little in our extracurriculars. Generally, I speak to Rajendra at least every two times, although it is frequently more often. With the pre-fall break crunch, I had no contact with Rajendra for a couple of weeks. "I have a really busy week Rajendra! I'll call on the 16th, if that's okay!" I replied to his message requesting that we Skype. I would beat myself up for not taking 30 minutes out of my "busy life" to make the call. When he e-mailed me on the 14th of October telling me about the cyclone that had hit Odisha, I tried to Skype him, but failed to get in touch. Nearly three days passed until I was finally able to get in touch. As college students, we consider ourselves the center of our universe; every experience and class is important because we see it as an opportunity to grow. We are told to focus on ourselves. They tell you to put your grades first, put your career first. We so often lose touch with the feeling of having a real responsibility to others. My self-centeredness
hit me in the face. I prided myself on putting my commitments to others over my own ambitions. But there I was, unable to contact Rajendra. Needless to say, I have learned a huge lesson. I have learned that it is important to frequently take a step back from the bubble we encompass ourselves in as students, no matter how busy. The needs of others may not often be convenient or even apparent, but it is important to attend to them anyway.

From October 8th to 14th Odisha was ravaged by Cyclone Phailin. The storm had a wind speed of 205 km/h and was classified as a very severe cyclonic storm. It affected around 20,000 people in several districts of Odisha, including Balasore. The disaster was managed extremely well by the state government and only 38 people died. The UN decided in December to globalize Odisha's model (Mishra, 2013 December 21) This is a huge improvement in lives lost compared to the super cyclone of 1999, which left 10,000 people dead (Elliot, 2013 October 14). At least two rounds of flooding and heavy rain throughout the rest of October caused several more deaths (Jayaram & Sahu, 2013 October 25), more evacuations and a difficult recovery period (Sahu, 2013 October 27). Even taking into account the low death toll, multiple disaster scenarios have had severe repercussions for the people of Odisha. While research on cyclone Phailin has not been released, we can look to research done after the super cyclone of 1999 to understand the situation on the ground in Odisha in the weeks, months, and years following cyclone Phailin and the ensuing floods.

A study on the effects of the cyclone ten years after the 1999 super cyclone occurred points to its long-term effects. Because of the lack of "physical, economic, social, and political" resources available to people in rural Odisha, the disaster was hard
to bounce back from. It led (Chhotray & Few, 2012, p. 696). It led to long term food and income insecurity due to the salination of the land, lack of knowledge about how to farm this land, and additionally, a lack of employment in the area or skills other than farming (p. 698). This demonstrates the sheer depth of poverty that influenced recovery in the period; poverty extended to skills and knowledge as well as resources which led to income insecurity and food insecurity. Government rebuilding programs require that villagers received the money in two parts; after the use of the first part, the progress was assessed and the second half of the money was provided. Without additional income to supplement the insufficient government aid, most did not have the resources to build permanent, stable shelters and some ended up living in tarp houses for a year or more (p.699). This lack of housing made them more vulnerable to the frequent flooding in Odisha (p. 700). Many of the problems presented in the study have been ARM’s focus for a few years. With its vocational training programs and women’s self help groups, ARM has ensured that more people will have alternative vocations rather than being entirely reliant upon agriculture. With the NABARD infrastructure, a system for knowledge and agricultural technology and techniques dissemination is present. This system can be used to help people deal with the salination of the land. Finally, ARM has already initiated donor-sponsored construction of concrete houses. This study then demonstrates that ARM’s everyday activities have most likely increased the resilience of the community to disasters. We also hope that with all the rebuilding going on, the women may have the opportunity to influence factors that affect their access to care and the quality of their care. Going ahead with the discussions and the study could have a potentially positive effect, even as little as a year after the disaster.
Because this is the view that ARM holds as well, we have come to the mutual decision to continue with the study with the understanding that there may be more issues to work out as we proceed.

**Implications for GlobeMed at USC**

By Sarah Law

The devastation brought upon our partner community forced our GlobeMed chapter to refocus its fundraising efforts for the year. We changed our MOU, attempted to start a school-wide campaign, and started promoting awareness of the cyclone through social media. On an even more personal level, Cyclone Phailin meant that we had to change our research plans. The infrastructure for conducting the survey had literally washed away, and we knew our partner community needed to work on rebuilding. We considered the possibility of looking into how a health care system could be reassembled in the aftermath of a natural disaster, but ultimately decided that the original research questions were still worth pursing. In this process we learned the importance of being flexible and adjusting to the needs of our partner community.

**MATERIALS AND METHODS**

**Training Manual**

by Sarah Law

When we were discussing the creation of the Training Manual, Dr. Billings gave me a great piece of advice when she said that there was no need to recreate the wheel: there were plenty of survey training manuals available for me to base ours on. I ended up finding a training manual that was designed for the Consumer Operated Services Project (COSP), which was coordinated by the Missouri Institute of Mental Health. I
kept most of their document, but revised it to suit the needs of our study. The training manual that I have developed is a work in progress. This summer the students who take over our project are going to need to develop this document further by filling in specific information about project logistics and making the document more culturally appropriate. There are a number of examples incorporated throughout this training manual, but they have to be relatable to the women for them to work. Taking part in focus groups to edit the training manual and the survey are going to be an excellent opportunity to start engaging our community partners as co-researchers rather than simply the subjects of our study.

Survey
by Runjhun Bhatia

In order to create the survey, Sarah and I established some straightforward basic background questions to understand the general practices and experiences women had before, during, and after delivery. The second half of the survey has been developed using the theory of planned behavior framework. Questions corresponding to each of the factors that arose in my literature review have been created. The questions are worded to assess the beliefs and feelings of women answering the question. A seven-point Likert Scale has been used. The format of the question was adapted from *Constructing a Theory of Planned Behavior Questionnaire* by Dr. Izeck Azjen of the University of Massachusetts (2002). The Likert scale should be adapted this summer with the aid of ARM to use pictures instead of numbers. Discussion groups conducted this summer will allow our successors to present several pictures and judge which is most easily understood by the women. A chapathhi, smiley face, and money scale were
tested by Rao, Peters, and Bandeen-Roche of the Johns Hopkins Bloomberg School of Public Health and the money scale was found to be most appropriate in northern Uttar Pradesh, a state in the northern part of India (2006, p.415). The challenge for our successors will be ensuring that these questions are interpreted correctly so that the information obtained is an accurate reflection of beliefs.

CONCLUSIONS: A ROAD MAP FOR THE FUTURE

Younger female undergraduate students have been recruited and trained to carry on this research project. Starting in May they will need to:

• Develop a working partnership with Rajendra and the community that is respectful and inclusive of the voices of the women and men who live in the villages.
• Work with all involved parities to develop a set of research guidelines and policies that incorporate the 12 Essential Components of CBPR. These guidelines will determine: how power differentials will be dealt with, how group decisions will be made, to what extent partners will be involved in each step of the research, etc.
• Translate the survey and training manual and hold focus groups with the SHG leaders, community health workers, and ARM staff to revise these materials.
• Compile any baseline data ARM has on health statistics in the area.

Once a timeline has been set for the rest of the project, the researchers will need to:

• Provide final copies of the survey and training manual to ARM so that SHG leaders can be trained to conduct the surveys
• Develop an evidence-based discussion guide requested by SHG leaders so that they can discuss issues surrounding safe birth and explore the significance and importance of these issues to them and their communities.
• Refine the data collection procedures and explore methods of data analysis.
• Determine how to involve community partners in the interpretation of data analysis and how results will be disseminated to the communities
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APPENDIX

Survey

1. How old are you?
2. Can you read? (Yes/No)
3. Can you write? (Yes/No)
4. What is your highest level of education? (What standard?)
5. What village were you born in?
6. Where did your mother give birth to you?
7. How many brothers and sisters did you have?
8. At what age did you marry?
9. Do any of your children live in the same home as you? (Yes/No)
10. Do you live with your husband? (Yes/No)
11. Does anyone live in your home besides your children and husband?
   a. Mother in law (Yes/No)
   b. Father in law (Yes/No)
   c. Other (Yes/No) __________________

What is your or your family’s occupation/how do you manage your livelihood?
   (check all that apply)
   i. Agriculture
   ii. Fish Farming
   iii. Daily labor
   iv. Craft making
   v. Other: __________________
At what age did you have your first baby?
How many pregnancies have you had?
How many living children do you have?
What are the ages of your children?
What is the gender of each child?
  . First Child (M/F), Second Child (M/F), Third Child (M/F), Fourth Child (M/F), Fifth Child (M/F), Sixth Child (M/F), Seventh Child (M/F)
What time of day did you go into labor during your most recent pregnancy?
Did you know your expected date of delivery? (Yes/No)
Where did you deliver your babies?
  . (PHC/CHC/Sub-divisional hospital/District level Hospital/Private hospital/Home)
If at PHC or CHC
  . How did you learn about the PHC or CHC? (check all that apply)
    1. ASHA worker
    2. Anganwadi Worker
    3. Friend or Family Member
    4. ARM Awareness Camp
    5. Awareness poster or mural
    6. Other: __________
      a. How did you travel to the PHC or CHC when you were going to deliver?
        . Ambulance; How long did you wait for the ambulance to arrive? __________ in
          minutes
        i. Bicycle
ii. Motorcycle

iii. Walking

iv. Other ____________________

b. Did an ASHA worker accompany you to the PHC or CHC? (Yes/No)

c. Did your husband accompany you to the PHC or CHC for delivery? (Yes/No)

d. Did any other family members or friends go with you to the PHC/CHC for delivery?
   1. Mother in law? (y/n)
   2. Father in law (y/n)
   3. Brother (s) (y/n)
   4. Sister(s) (y/n)
   5. Friends (y/n)

e. Did you go to the PHC or CHC for a checkup before delivery? (yes/no)
   1. If Yes:
      1. At what time in your pregnancy did you first go to the PHC or CHC?
         1. 1st Trimester
         2. 2nd Trimester
         3. 3rd Trimester
         4. For Delivery
      2. How many times did you visit the PHC or CHC during your pregnancy? #___
      3. Did the ASHA worker accompany you each time? (Yes/No)
4. Did your husband accompany you each time? (Yes/No)

5. Who made the decision that you would go to the PHC or CHC for checkups before delivery?
   1. Me
   2. My husband
   3. ASHA worker
   4. Other: _______

6. How did you travel to the PHC or CHC for your checkups?
   1. Walking
   2. Bicycle
   3. Motorcycle
   4. Ambulance; How long did you wait for the ambulance to arrive? __________ in minutes
   5. Other __________

7. Were you able to remember the advice they gave you during your checkups? (Yes/No)

8. Did you understand the advice that they gave you during your checkups? (Yes/No)

9. Did you dislike any of the advice that they gave you during your checkups? (Yes/No)

10. Did you follow the advice that you received during your checkups? (Yes/No)
1. If not, why not? (check all that apply)
   i. Cost
   i. Could not understand
   i. Could not recall
   i. Did not see benefit of advice
   i. Conflicting advice from other
   i. Against personal/religious beliefs
   i. Other:____________

11. What sort of advice did you receive from the doctor during your checkups? (questions below)

   1. Diet

      1. What foods were you advised to eat?

   2. Water

      1. How much water were you advised to drink in a day? (In L)

      2. Did you know how to judge how much water __ L is? (Yes/No)

   3. Exercise
1. Were you advised to avoid heavy lifting during your pregnancy? (Yes/No)

4. Vitamins

1. Were you advised to take vitamins during your pregnancy? (Yes/No)

5. Medicines

1. Were you advised to take any medicines during your pregnancy? (Yes/No)

6. Other

1. Is there any other advice you were given during your pregnancy? (Yes/No)

2. Please describe this advice. (ask Dr. Billings how to process this data.)

If at Hospital

1. Why were you referred to the hospital?

   a. Who referred you to the hospital?

   b. When were you referred (at what time in your pregnancy)?

   c. How did you travel to the hospital?

      1. Ambulance; How long did you wait for the ambulance to arrive?
         __________ in minutes

      2. Bicycle
3. Motorcycle

4. Walking

5. Auto rickshaw

6. Other

d. How much did it cost you to deliver at the hospital?

e. How many days did you stay at the hospital?

f. What complications were you treated for?

g. What complications was the baby treated for?

h. Who delivered your baby?

   1. Nurse
   2. Doctor
   3. ANM
   4. Other

   If at home or mother’s home or other

. Where did you deliver your baby?

   1. Home
   2. Mother’s home
   3. other

a. Who was present in the room during your delivery?

   1. Mother in law
   2. Husband
   3. Dai
   4. Friends
5. Female family members

2. How many people were present in the room during your delivery?
   1. 1 or 2
   2. 3 or 4
   3. more than 4

b. Who delivered your baby or caught the baby?
   1. Husband
   2. Sister, female friend, or other female relative other than mother-in-law
   3. ASHA worker
   4. Anganwadi Worker
   5. Dai
   6. ANM (Auxiliary Nurse Midwife)
   7. Doctor
   8. Dai

c. Where were you lying when you delivered your baby?
   1. Bed
      1. Were there clean sheets on the bed? (Yes/No)
   2. Floor
      1. Did you put a blanket, towel, or mat under you? (Yes/No)
   3. Other _____________

d. Were there any complications with the birth?

e. Was the baby washed after birth?
f. Who washed the baby?
   1. Husband
   2. Sister, female friend, or other female relative other than mother-in-law
   3. ASHA worker
   4. Anganwadi Worker
   5. Dai
   6. ANM (Auxiliary Nurse Midwife)
   7. Doctor
   8. Dai

2. Who cut the umbilical cord?
   1. Husband
   2. Other family member
   3. ASHA worker
   4. Anganwadi Worker
   5. Dai
   6. ANM (Auxiliary Nurse Midwife)
   7. Doctor
   8. Dai

g. What was used to cut the umbilical cord?
   1. Scissors
   2. Knife
   3. Other:___________
h. Was the umbilical cord rubbed or coated with anything?
   1. What was the umbilical cord rubbed or coated with?

i. What did you do with the afterbirth?

Did you breastfeed your child immediately after birth?

   . If Yes

      1. Why did you make this choice? (check all that apply)
         1. I felt it was good for the child
         2. I was advised to do so by ASHA worker
         3. I was advised to do so by Anganwadi worker
         4. I was advised to do so by Doctor
         5. I was advised to do so by ANM
         6. I was advised to do so by husband or other family member
         7. I was advised to do so by traditional birth attendant
         8. I was advised to do so by friend

   a. If No

      1. Why did you make this choice?
         1. I felt it was not good for the child
         2. I was advised not to do so by ASHA worker
         3. I was advised not to do so by Anganwadi worker
         4. I was advised not to do so by Doctor
         5. I was advised not to do so by ANM
6. I was advised not to do so by husband or other family member

7. I was advised not to do so by traditional birth attendant

8. I was advised not to do so by friend

b. How long did you wait to breastfeed? ----- in days

c. What did you feed the baby before you started breastfeeding?
   For how many months did you breastfeed your child?
   Did you give your baby any food other than breast milk? (Yes/No)
   Did your baby sleep in your bed? (Yes/No)
   Did you clean the baby's belly button? (Yes/No)
   What did you use to clean the belly button? (Multiple Choice?)
   Did you continue to take prenatal vitamins while breastfeeding your baby? (Yes/No)
      At what age did your baby start eating solid food?
      Did your baby get sick during its first 48 days?
      What illness did your baby have? (MC? Diarrhea, Colic, Latching Problems, Malnutrition)

a. Did you know how to treat the illness? (Yes/No)

b. Did you ask for help to treat the illness? (Yes/No)

c. Did you have to go to the PHC/CHC/Hospital? (Yes/No)

d. What treatment was given to your baby?
   Did you interact with the Anganwadi worker?
. Did she advise you on nutrition? (Yes/No)

a. Did she advise you on feeding? (Yes/No)

b. Did she advise you on how to hold your baby? (Yes/No)

c. Who do you ask for advice about your baby? (check all that apply)
   1. Husband
   2. Mother
   3. Mother-in-law
   4. Sister, female friend, or other female relative other than mother-in-law
   5. ASHA Worker
   6. Anganwadi Worker
   7. Other: ____________

Did you ever seek out the Anganwadi worker for additional advice or information? (Yes/No)

. Yes—For what?
   1. Did you follow her advice? (Yes/No)
   2. Was it helpful? (Yes/No)

a. No—Why not?
   
   Did you take your baby to receive immunizations? (Yes/No)

   Where did the baby receive the immunizations?
   
   PHC/CHC

a. Hospital

b. ARM Immunization Camp
c. Other:____________

If you went to the PHC for immunizations, did you use the blue card and complete all the checkups? (Yes/No)

What area did you deliver your babies?

. Bhubaneswar, Cuttack, Balasore, Baliapal, my married home, my mother’s home, other

Where did your mother deliver her babies?

. At PHC or CHC or Sub-divisional hospital or District Level Hospital or Private Hospital, married home, mother’s home, other

Has someone you know ever died in childbirth within the past five years? (Y/N)

Where did they deliver? (PHC/CHC/Sub-divisional hospital/District level Hospital/Private hospital/ married home/mother’s home)

How much money (if any) did you receive from Janani Suraksha Yojana the last time you gave birth?

Did you get this money on time?

Was JSY a consideration in the decision you and your family made to seek care?

Did JSY cover your transportation fees?

Have you participated in the Janani-Shisu Suraksha Karyakram program?

Do you know anyone who has delivered their baby at home but they went to the hospital afterward to be compensated as per JSY?

(The following questions (1-6) will help us assess whether the husband is a normal part of the birth process and whether that changes in the case of institutional delivery.)

1. Was your husband involved in planning for your birth?
2. Was your husband present at your birth?

3. Would you like for your husband to be or have been present at your birth?

4. Did your husband provide emotional support during your birth?

5. Would your husband have to come with you during birth in a government or private facility?

6. Do you travel to your maiden (pre-marriage, mother and father’s) home for birth?

7. Do you practice purdah or ghunghat?

8. Which aspects of purdah or ghunghat do you practice?
   1. Seclusion in the house
   2. Not going outside the village
   3. Covering up to neck
   4. Covering up to mouth
   5. Covering up to eyes
   6. Covering up to forehead
   7. Covering just the hair
   8. Not covering head at all.

**Theory of Planned Behavior**

**Behavioral Beliefs:**

1. I believe that giving birth is dangerous.

   true :__1__ :__2__ :__3__ :__4__ :__5__ :__6__ :__7__ : false

   OR

   I don’t know
2. I believe that someone is more likely to die at a PHC, CHC, or other government hospital than at a private hospital.
   true: ___1___: ___2___: ___3___: ___4___: ___5___: ___6___: ___7___: false
   OR
   I don’t know

3. I believe that someone is more likely to die giving birth at a PHC, CHC, or other government hospital than at home.
   true: ___1___: ___2___: ___3___: ___4___: ___5___: ___6___: ___7___: false
   OR
   I don’t know

4. I believe that going to a government hospital or clinic is safer than a home delivery.
   true: ___1___: ___2___: ___3___: ___4___: ___5___: ___6___: ___7___: false
   OR
   I don’t know

5. I feel that I am knowledgeable about what I will experience if I give birth in government and private facilities.
   true: ___1___: ___2___: ___3___: ___4___: ___5___: ___6___: ___7___: false
   OR
   I don’t know

6. I feel that I am knowledgeable about what I will experience if I give birth at home.
   true: ___1___: ___2___: ___3___: ___4___: ___5___: ___6___: ___7___: false
   OR
I don’t know

7. I feel that I am knowledgeable about how much it will cost if I give birth in government and private facilities.
   true :___1__:___2__:___3__:___4__:___5__:___6__:___7___: false
   OR
   I don’t know

8. I feel shame and disrespect at the way my family and I are treated at a government hospital or clinic.
   true :___1__:___2__:___3__:___4__:___5__:___6__:___7___: false
   OR
   I don’t know

9. I feel that the government and government agencies and workers are here to help me.
   true :___1__:___2__:___3__:___4__:___5__:___6__:___7___: false
   OR
   I don’t know

10. I feel that doctors are trustworthy and are here to help me.
    true :___1__:___2__:___3__:___4__:___5__:___6__:___7___: false
    OR
    I don’t know

11. I feel that ASHA workers are trustworthy and are here to help me.
    true :___1__:___2__:___3__:___4__:___5__:___6__:___7___: false
    OR
I don’t know
12. I feel that Anganwadi workers are trustworthy and are here to help me.
   true: ___1:___2:___3:___4:___5:___6:___7: false
   OR
   I don’t know
13. I feel that ANM are trustworthy and are here to help me.
   true: ___1:___2:___3:___4:___5:___6:___7: false
   OR
   I don’t know
14. If I go to government facility to deliver, I feel I will have to bribe the staff.
   true: ___1:___2:___3:___4:___5:___6:___7: false
   OR
   I don’t know
15. If I go to the government facility to deliver, I feel that they may take away my baby if I do not have the money to pay.
   true: ___1:___2:___3:___4:___5:___6:___7: false
   OR
   I don’t know
16. If I go to the government facility to deliver, I feel that they will not pay me the 1400 rs I am due per Janani Suraksha Yojana.
   true: ___1:___2:___3:___4:___5:___6:___7: false
   OR
   I don’t know
17. If I go to a government facility or private facility to deliver, I feel that I will miss out on celebrations and ceremonies around my time of birth.

true:___1__:___2__:___3__:___4__:___5__:___6__:___7__: false

OR

I don't know

18. If I go to a government facility or private facility to deliver, I feel that I will miss out on the social support that family and friends can provide to me.

true:___1__:___2__:___3__:___4__:___5__:___6__:___7__: false

OR

I don't know

19. If I go to a government facility or private facility to deliver, I feel scared by the thought of delivering without my family around me.

true:___1__:___2__:___3__:___4__:___5__:___6__:___7__: false

OR

I don’t know

20. If I go to a government or private facility to deliver, I will feel embarrassed at the thought of my husband coming with me to my birth

true:___1__:___2__:___3__:___4__:___5__:___6__:___7__: false

OR

I don’t know

21. I would prefer to deliver with close female relatives than with my husband.

true:___1__:___2__:___3__:___4__:___5__:___6__:___7__: false

OR
I don't know

22. I believe that cutting of the umbilical cord, cleaning the baby, disposing of the placenta and bathing the woman after birth is polluted work.

true :___1___:___2___:___3___:___4___:___5___:___6___:___7___: false

OR

I don't know

23. I believe that a dai is necessary to handle the pollution of birth.

true :___1___:___2___:___3___:___4___:___5___:___6___:___7___: false

OR

I don't know

24. I believe that doctors and ANM do not handle the pollution of cutting the cord, cleaning the baby, disposing of the placenta, and bathing the woman after birth.

true :___1___:___2___:___3___:___4___:___5___:___6___:___7___: false

OR

I don't know

25. If I deliver at home, I believe that during and after birth, the dai will do what I and my family decide and take orders from us.

true :___1___:___2___:___3___:___4___:___5___:___6___:___7___: false

OR

I don't know

26. If I deliver in a government facility I believe that during and after birth, the doctor or ANM will do what I and my family decide and take orders from us.

true :___1___:___2___:___3___:___4___:___5___:___6___:___7___: false
I don’t know

27. If I deliver at home, I believe that during and after birth, the dai will make her own decisions as to what to do.

true :___1__:___2__:___3__:___4__:___5__:___6__:___7__: false

OR

I don’t know

28. If I deliver at a government facility, during and after birth, the doctor or ANM will make their own decisions as to what to do.

true :___1__:___2__:___3__:___4__:___5__:___6__:___7__: false

OR

I don’t know

Normative Beliefs

1. I feel that if I go to a government facility to deliver, my mother-in-law will approve.

true :___1__:___2__:___3__:___4__:___5__:___6__:___7__: false

OR

I don’t know

2. I feel that if I go to a government facility to deliver, my husband will approve.

true :___1__:___2__:___3__:___4__:___5__:___6__:___7__: false

OR

I don’t know

3. I feel that if I go to a government facility to deliver, my parents will approve.
true :___1__:___2__:___3__:___4__:___5__:___6__:___7___: false
OR
I don’t know

4. If I go to a government facility to deliver, I feel that the village will approve.
true :___1__:___2__:___3__:___4__:___5__:___6__:___7___: false
OR
I don’t know

5. I feel that if I go to a private facility to deliver, my mother-in-law will approve.
true :___1__:___2__:___3__:___4__:___5__:___6__:___7___: false
OR
I don’t know

6. I feel that if I go to a private facility to deliver, my husband will approve.
true :___1__:___2__:___3__:___4__:___5__:___6__:___7___: false
OR
I don’t know

7. I feel that if I go to a private facility to deliver, my parents will approve.
true :___1__:___2__:___3__:___4__:___5__:___6__:___7___: false
OR
I don’t know

8. If I go to a private facility to deliver, I feel that the village will approve.
true :___1__:___2__:___3__:___4__:___5__:___6__:___7___: false
OR
I don’t know
9. If I go to a government facility or private facility to deliver, I feel that I am not doing my duty as a daughter, daughter-in-law, mother, wife, or friend.

   true :___1__:___2__:___3__:___4__:___5__:___6__:___7__: false
   OR
   I don’t know

10. If I go to a government facility or private facility to deliver, I feel that the self help group will approve.

   true :___1__:___2__:___3__:___4__:___5__:___6__:___7__: false
   OR
   I don’t know

11. If I go to a government facility to deliver, I feel that I will be a burden on others.

   true :___1__:___2__:___3__:___4__:___5__:___6__:___7__: false
   OR
   I don’t know

12. If I go to a government facility to deliver, I feel that I will break the practice of purdah or ghunghat (seclusion).

   true :___1__:___2__:___3__:___4__:___5__:___6__:___7__: false
   OR
   I don’t know

13. If I go to a government facility to deliver, I feel that I will compromise the honor of the family (izzat).

   true :___1__:___2__:___3__:___4__:___5__:___6__:___7__: false
OR

I don’t know

14. If I go to a government facility to deliver, I feel that the self help group will approve.


   OR

   I don’t know

15. If I go to a private facility to deliver, I feel that I will be a burden on others.


   OR

   I don’t know

16. If I go to a private facility to deliver, I feel that I will break the practice of purdah or ghythat (seclusion).


   OR

   I don’t know

17. If I go to a private facility to deliver, I feel that I will compromise the honor of the family (izzat).


   OR

   I don’t know

In order to address the collective nature of rural Indian villagers, we can use the following survey:
Statement (1) Extremely Uncharacteristic of Me ... (7) Extremely Characteristic of Me

1. It bothers me when other people neglect my needs.
   OR
   I don’t know

2. When making a decision, I take other people's needs and feelings into account.
   OR
   I don’t know

3. I'm not especially sensitive to other people's feelings.
   OR
   I don’t know

4. I don't consider myself to be a particularly helpful person."
   OR
   I don’t know

5. I believe people should go out of their way to be helpful.
   OR
I don’t know

6. I don’t especially enjoy giving others aid.
   true: ___1___2___3___4___5___6___7___: false
   OR
   I don’t know

7. I expect people I know to be responsive to my needs and feelings.
   true: ___1___2___3___4___5___6___7___: false
   OR
   I don’t know

8. I often go out of my way to help another person.
   true: ___1___2___3___4___5___6___7___: false
   OR
   I don’t know

9. I believe it’s best not to get involved taking care of other people’s personal needs.
   true: ___1___2___3___4___5___6___7___: false
   OR
   I don’t know

10. I’m not the sort of person who often comes to the aid of others.
    true: ___1___2___3___4___5___6___7___: false
    OR
I don't know

11. When I have a need, I turn to others I know for help.
   true :___1___:___2___:___3___:___4___:___5___:___6___:___7___: false
   OR
   I don’t know

12. When people get emotionally upset, I tend to avoid them.
   true :___1___:___2___:___3___:___4___:___5___:___6___:___7___: false
   OR
   I don’t know

13. People should keep their troubles to themselves.
   true :___1___:___2___:___3___:___4___:___5___:___6___:___7___: false
   OR
   I don’t know

14. When I have a need that others ignore, I feel hurt.
   true :___1___:___2___:___3___:___4___:___5___:___6___:___7___: false
   OR
   I don’t know

Control Beliefs

Government and Household Power:

1. The *gram panchayat* listens to women in our village and takes their opinions into consideration.
   
   true :___1__:___2__:___3__:___4__:___5__:___6__:___7__: false
   
   OR
   
   I don’t know

2. I believe the seats reserved in the *gram panchayat* are just for show. The women do not have an actual power or say.
   
   true :___1__:___2__:___3__:___4__:___5__:___6__:___7__: false
   
   OR
   
   I don’t know

3. I believe that women can make a change in the village.
   
   true :___1__:___2__:___3__:___4__:___5__:___6__:___7__: false
   
   OR
   
   I don’t know

4. I believe that women can make a change in the district.
   
   true :___1__:___2__:___3__:___4__:___5__:___6__:___7__: false
   
   OR
   
   I don’t know

5. I believe that men can make a change in the village.
   
   true :___1__:___2__:___3__:___4__:___5__:___6__:___7__: false
6. I believe that men can make a change in the district.

   true :___1__:___2__:___3__:___4__:___5__:___6__:___7___: false
   OR
   I don't know

7. The *gram sabha* is held every six months.

   true :___1__:___2__:___3__:___4__:___5__:___6__:___7___: false
   OR
   I don't know

8. My involvement in the SHG has helped me participate in gram panchayat and gram sabha

   true :___1__:___2__:___3__:___4__:___5__:___6__:___7___: false
   OR
   I don't know

9. Women in SHG participate more in gram panchayat and gram sabha.

   true :___1__:___2__:___3__:___4__:___5__:___6__:___7___: false
   OR
   I don't know

10. I feel that I have a say in household decisions about how to spend money.

    true :___1__:___2__:___3__:___4__:___5__:___6__:___7___: false
    OR
    I don't know
11. I feel that I have a say in household decisions about health care
   
   true :___1__:___2__:___3__:___4__:___5__:___6__:___7___: false
   OR
   I don’t know

12. I feel that I can decide in my household whether I want to deliver at home or in a government or private clinic.
   
   true :___1__:___2__:___3__:___4__:___5__:___6__:___7___: false
   OR
   I don’t know

13. I feel that my husband is knowledgeable about giving birth in government and private facilities.
   
   true :___1__:___2__:___3__:___4__:___5__:___6__:___7___: false
   OR
   I don’t know

14. I feel that going to a government or private facility to deliver is expensive.
   
   true :___1__:___2__:___3__:___4__:___5__:___6__:___7___: false
   OR
   I don’t know

15. I feel that finding transportation to a government or private facility is too difficult.
   
   true :___1__:___2__:___3__:___4__:___5__:___6__:___7___: false
   OR
   I don’t know

16. I feel that going to a government or private facility to deliver is too far to travel.
17. I feel that going to a government or private facility to deliver is too much hassle.
   true :___1__:___2__:___3__:___4__:___5__:___6__:___7___: false
   OR
   I don’t know

18. I feel that I can not predict if I will need to go to a government or private facility.
   true :___1__:___2__:___3__:___4__:___5__:___6__:___7___: false
   OR
   I don’t know

19. If I go to a government or private facility, I feel I will have to sell my possessions or borrow from a neighbor.
   true :___1__:___2__:___3__:___4__:___5__:___6__:___7___: false
   OR
   I don’t know

20. My husband or other family members do not have time to take me to the clinic.
   true :___1__:___2__:___3__:___4__:___5__:___6__:___7___: false
   OR
   I don’t know
Training Manual

By Sarah Law

GlobeMed, ARM & SHG Training Manual

It is important to note that this Training Manual (TM) is a work in progress. It is meant to be used in the initial focus groups with ARM and the SHG women in May 2014. Certain points need to be discussed, and some information needs to be filled in or changed in order to produce the final TM which will be used to train the SHG women in disseminating the surveys. In writing this preliminary TM, I have used a TM designed for the Consumer Operated Services Project (COSP) which was coordinated by the Missouri Institute of Mental Health. In a few places you will see a comment where I said <insert project title>. Our thesis has its own long title, but I think that the SHG women and ARM should come up with a unique name for the project they are about to begin so that the SHG women in particular get a sense of ownership by naming their own project.

Here as a key to help guide you in navigating the edits I made to this TM:

• Anything in plain text is from the original training manual.

• Anything in black plain text that is highlighted is from the TM, but may need to be edited because the language is rather technical or unsuitable for some reason. You should discuss these parts in the focus groups.

• Anything in red plain text is where I re-worded what the TM said, keeping the original meaning of the sentence or word(s) the same.

• Anything written in red italics is where I deleted something from the original TM and added words of my own.
1. Description of the Project

The <insert project title> is an international, multi-site study of maternal health care seeking behavior amongst women in Odisha, India (Are the SHG women happy with this phrasing?) The study is sponsored and funded by the Magellan Scholar Undergraduate Research Grant from the University of South Carolina (USC) and is coordinated by Alternative for Rural Movement and student researchers from GlobeMed at USC. The purpose of the project is to examine the factors that go into a woman’s decision making process regarding where and when she will seek care during her pregnancy and delivery. The following outcomes will be examined: [Revise, add to, and define these outcomes in the focus groups].

1. Empowerment
2. Access
3. Cultural Competence
4. Satisfaction With Services
5. Costs (Individual, System, & Society)

Participants will be [...] selected from among <fill in specific information>. The Principle Investigator of the project is <Fill in specific information here; would this be the
Rajendra Rana, the founder and current chair of ARM, asked Runjhun Bhatia and Sarah Law, the first two student researchers to work on this project, to help ARM conduct a survey to find out why many women in Odisha are not inclined to seek out skilled birth attendance or go to the health clinic for delivery, despite the incentives provided by the Indian Government. Unsafe birth is the cause of high maternal and neonatal morbidity and mortality rates in India, and skilled birth attendance is often a much safer option. This study seeks to understand what factors go into a woman’s choices about her birth plan so that ARM can provide improved services to increase the desirability and use of skilled birth attendance.

As an interviewer, you will be conducting [...] face to face interviews with local women. The survey will be administered to a total of <insert sample size number> women who will be [...] selected from <fill in specific information>. This study is unique in its design because it is based on a research philosophy called Community Based Participatory Research (CBPR). Within this research philosophy, the traditional roles between the researcher and the subjects are broken down. You, and the women you interview, will be co-researchers in this process, and you will be encouraged to participate in many different ways. You will have the opportunity to shape this TM to make sure it suits your needs and prepares you for the kind of interview you think will be most beneficial. You will also have the opportunity to share your thoughts and opinions regarding the research questions, the survey instrument, the overall design of the study, the interpretation of the data, and more. The purpose behind this
collaborative approach to research is to create mass decision making to empower all who are involved. The results of the study are meant to help your community; therefore, the study needs to be designed to fit your unique needs.

In the following sections of this manual, you will be given instructions or guidelines for interviewing, and administration, as well as definitions and explanations of the survey instrument. Each section will also be thoroughly reviewed during the interviewer training sessions, during which you will be able to practice conducting interviews and can ask for further information or explanations. During the training and at the conclusion of training, you will be asked to give feedback to the trainers to adjust and improve the clarity and delivery style of the training. We appreciate your being a vital part of this innovative project.

II. The Survey Process

In a typical survey procedure there are a number of important steps that must be completed, including the construction of the survey instrument or questionnaire, the testing and re-testing of the instrument, the collection of the data, the coding of the collected data, the analysis of the data, and preparation of the final report. In this study we are focusing on all of these steps. As an interviewer you will be involved in collecting data from <insert specific information>. The data are the answers given by the participants to the questions on the survey […], and we must interview each participant to obtain the answers. Interviewing skills are therefore a very important part of the process. The interviewer must understand the purpose of the survey, know how to create a comfortable interview environment, how to ask the questions, how to record the
answers, how to communicate with the <Who at ARM will be the main contact for the SHG women?>, and how to keep track of the process from beginning to end.

The answers obtained from all of the participants will be grouped together for analysis so that the information reported in the results is about the group of answers, not about an individual. Because it is the group of answers that will be analyzed, it is important that the questions be asked of each person in the same way. This allows for the standardization of the instrument, and thus assures that each participant is asked the same question. <For example, if you were to ask a sample of people how long they had been attending a specific peer-support program, you would have to ask each person the same question. If you suddenly begin asking people how long they had been attending peer-support programs in general, you would no longer be able to compare the answers. This is the example provided by the original TM. Is there a better example the SHG women can come up with?>

We are concerned with maintaining the validity and reliability of the survey. Validity is whether the questions being asked are really measures of what the researchers want to know. Reliability refers to the consistency of the responses received, or whether the answers would be the same if the question were asked at a future time. If you change the meaning or the wording of the questions, the validity and reliability of the responses would also be affected thus making it very difficult to compare the responses. It is also important that the survey is completed as much as possible. Finally, you must maintain a neutral position while being able to clarify questions for a participant and probe for a response when information is unclear or incomplete. As an interviewer, your role is one of the most critical in the survey
process. The quality of the data depends on you. *Here are five ways to avoid introducing errors to the data:*

1. Read questions as written
2. Avoid probing for a certain answer
3. Maintain a neutral disposition so as to not bias the participant’s answers
4. Make sure to record answers accurately
5. Make sure the *participant* answers each question rather than assuming you know her answer.

**III. Interviewer’s Responsibilities in Administering The Survey**

*NOTE:* There are some questions you will need to answer in the focus groups before you can edit this section. Some questions to consider before writing this section include:

- *From which villages will women be invited to participate in this study?*
- *How will local women be alerted about the study and the opportunity to be participants?*
- *Who will women be told to approach to find out more information about the study before they commit to completing an interview?*
- *How or to whom will women express their interest to be a participant?*
- *How will participants be chosen from those that volunteer? What will be the selection criteria?*
- *What characteristics (if any) will prevent a woman from being included as a participant?*
- *What precautions will be taken to ensure privacy and confidentiality for women who come to hear about the study? What steps, if any, should be taken to*
prevent an interested woman's husband from prohibiting her from participating in the study?

- What will be the protocol for approaching women for an interview?

**A. Contacting Participants**

In *this study* there are <insert number> steps involved in contacting possible participants and conducting interviews. First, eligible women (Do they like referring to the prospective participants as “women” or would they prefer a different term? Which term would they prefer? How can we make this more specific to the women we are actually interviewing?) are told of the study by <fill in specific information about how and by whom women will be made aware of this study and the possibility of participating>. Women who wish to find out more about the study <fill in specific information about what a woman should do if she wants to find out more about the study>. Second, consenting women are referred to <fill in specific information about who women should contact at ARM if they wish to participate in the study>. Project staff explain the study to them in greater detail, including the responsibilities of the participant, the responsibilities of the project staff, and the rights of the participant. Third, participants are referred to interviewers for an [...] interview. At the conclusion of the [...] interview, <fill in specific information about what happens once an interview is completed>. Are there any other steps that need to be added?

**Instructions for Contacting Participants**

**NOTE:** This section will certainly need to be edited, but figuring out the sample population is the first step. If SHG leaders are interviewing other women they know, they will not need such a formal introduction.
Your introduction is crucial when trying to obtain participants in a project. It is therefore important that you prepare the introduction in advance and practice it several times before contacting people. It is important to remember that successful introductions take planning and practice. Although the introductions may seem difficult at first, they will become easier with time. The following points should be observed with each introduction:

1. Immediately give your name and the title of the project/organization with which you are affiliated.
2. Provide a brief summary of the project.
3. Do not ask questions that may elicit an undesired response. (For example: Are you too busy to answer some questions?)
4. Assume that the participant is willing to do the interview and you are trying to find a convenient time.
5. Remind the participants about confidentiality and informed consent procedure.
6. Respect the participant’s right to say "No."

Keeping Track of Contacts

<You will need to develop a method for keeping track of who has volunteered to participate in the interviews so that the SHG women can know who to contact to set up interviews.>

Contact Script

Note: This is the contact script that was in the original TM for setting up an interview time. I have left it in this TM as an example. Use the focus groups to write a new, culturally appropriate script. During the focus groups, you will have to decide how
the women will be contacted to set up the interviews. The Contact Script in the original TM mentions calling the participants, which may not be an option for many (or any) of our participants. For the purposes of this TM, I changed the word “calling” to “contacting.” However, this will likely need to be changed in order to be more specific.

**Interviewer:** Hello, my name is __________. I am an interviewer with the <title of the project>, a study about women’s health care seeking behavior that is sponsored by Alternative for Rural Movement and GlobeMed at the University of South Carolina. You recently spoke with our staff about the project and indicated that you wanted to participate. I am contacting you to set up a date and time for an interview with you. Is this a good time to talk?

**If the participant says “yes,” continue with next section…**

**Interviewer:** Thank you. Your participation is very important for the success of this project. Let me remind you that you will receive a small gift for participating <ONLY KEEP THIS STATEMENT ABOUT A GIFT IN IF IT IS GOING TO BE TRUE. Providing incentives requires funding. If you do decide to provide a gift, ask ARM and the SHG women what will be appropriate. ARM often gives out cookies or small snacks.>. Now, we need to set a date and a time. I have the following dates and times open (read your list of dates and times). Which of these times work for you? (Decide on a date and time). We appreciate your cooperation and I look forward to meeting you on (date and time) at [site].

**If the participant says “no”:** What would be a more convenient time to contact you in the next day or two? Let me remind you that you will receive a small gift in
gratitude for the time you spend being interviewed. (Decide on date and time to contact the participant again).

Once the appointment date and time have been decided, record this information on your contact sheet.

Go to Exercise #1

B. Handling Refusals

If the person does not seem willing to meet with you to do the interview, never pressure the person. In some cases, however, the person may hesitate or decline when more information or reassurance from you is needed. You may then use one of the following possible responses in asking for their participation:

• **Too busy:** We appreciate your time and will provide a small gift to thank you. Sorry to have caught you at a bad time. I would be happy to come back. When would be a good time to come back in the next day or two?

• **Feel inadequate:** The questions are not at all difficult. There are no right or wrong answers. We are concerned about how you feel rather than how much you know about certain things. These are questions about your health care seeking behavior. (Is there a better way to words this?)

• **Not interested:** It’s very important that we get the opinions of everyone. Otherwise, the results won’t be very useful. So, I’d really like to talk with you. Your input is valuable to us and we need your help.

• **No one’s business:** I can certainly understand. That’s why all of our interviews are confidential. Protecting people’s privacy is one of our major concerns, so we
do not put people’s names on the interview forms. All the results are reported in such a way that no individual can be linked with any answer.

C. Following the Confidentiality Procedures

Confidentiality means that the participant’s name and identifying information (such as phone number or address—how can we change this language from the original TM to be more culturally appropriate?), as well as the information supplied by the participant during the interview, are to be kept private. Therefore, you must never share names or information with anyone else, discuss individual responses, or show the questionnaire results to another person. During debriefing meetings, you need to discuss the interview process and any problems you may have experienced; however, you may not refer to a participant by name or use other identifying information.

Although you will use the person’s name and telephone number (change “telephone number” to whatever method of contact is decided upon during the focus groups) to make the contact and set up the appointment, these will not appear on the questionnaire. Instead, an identification number will be used. The completed questionnaires will be kept <insert: in a box, cabinet, desk, etc,>, marked with the interviewer’s name, at Alternative for Rural Movement until the end of the <specify length of time: example = 2 month> data collection period. The information will also be sent to the University of South Carolina in the United States. Once the data collection has been completed, the finished materials will remain at ARM for data analysis. It will be your responsibility to reassure the participant that their identity and answers to the questions will be kept confidential, and grouped with other responses for analysis.

D. Informed Consent
A standard request for informed consent will be conducted prior to each interview. An example of the form is in the Appendix of this TM. At the beginning of each interview, you will also review the purpose of this study, tell them why you are asking them to answer questions, and remind them that they are free to withdraw their consent and participation at any time. Then you will ask the participant to read the brief informed consent statement included in the introduction and sign it. (Note: Ask the women here to brainstorm on how to proceed if the woman they are interviewing can not read or write. How will they avoid offending someone who cannot read? What will they do if someone says she can read and then is clearly struggling? What will they do if someone does not know how to write her signature?) You cannot begin an interview until this form has been signed. Instruct the participant that this form will be kept confidential and in a locked file. You will turn in the forms to <someone at ARM>. Some women may decline to sign the consent form. If this could occur, use the responses to refusals (see above). If the participant refuses to sign the consent form, do not conduct the interview and notify <name of person at ARM to contact>.

E. Using Standardized Responses

To prevent bias, there are some explanations that must be stated in the same way for each participant, and there will be questions from participants that must be answered in the same way. The following list of standardized responses has been prepared for your use in such situations:

- **What is the purpose of this project?** We are trying to figure out why women are not seeking skilled birth attendance and perinatal care.
• **What agencies are doing the research?** This study is being conducted by Alternative for Rural Movement and students from GlobeMed at the University of South Carolina in the United States. ARM asked the students to help them conduct this study. As an SHG leader, I am also included as a participant researcher in this study. I have helped created this survey and will be helping to interpret this data.

• **Why is this research important/needed?** ARM has recognized that care-seeking behavior is a problem in this village. By discovering the factors that are preventing women like yourself from seeking skilled birth attendance, ARM will be able to help us figure out ways to combat problems related to unsafe birth practices. It is very important that we get the opinions of everyone in order to get useful results. Your input is valuable to us and we need your help.

• **How did you get my name?** <The section that would answer this question (above) still needs to be written.>

• **How will the results be used?** The results of this study will be used to help policy makers decide how to improve women’s health services.

**Go to Exercise #2**

**IV. Preparing for Interview**

A. **Understand the Purpose of the Survey**

   It is important that you understand the purpose of the project and the survey process so that you can explain them to the participant as needed. Use the standardized explanations.

B. **Practice**
You will participate in practice interviews during the training period. Continue to practice reading the questions on your own, paying close attention to order. This will help you to ask questions smoothly and without hesitation during the interview. Practice also assures that questions are asked the same way for each participant. It will also be helpful to practice recording answers and making interviewer comment notes during the practice sessions.

C. Reserve Interview Location

Make sure ahead of time that a room or private space is available on the day and time of the interview. Because of the length of the questionnaire, it is important to be sure of a quiet, private, comfortable place. <Make plans for what the interviewer should do if a woman has decided to be a participant even though her husband or mother/father-in-law did not want her to>.

D. Take Required Forms

Before each interview, prepare the questionnaire with the person’s identification code number. Also have available all required documents, including the informed consent form, the survey, and <insert any other materials>. Additional copies of these materials can be obtained from <insert specific person or place>. See Checklist in Section XII.

E. Take Supplies

Prepare and take with you sharpened pencils, an eraser, […], the participant’s gift, […] an envelope for the completed questionnaire, and <insert any other necessary supplies>. See Checklist in Section XII.

F. Create a Favorable Environment
When the participant arrives (or when you arrive, if you are conducting the interview at the participant’s home), introduce yourself (if you do not already know each other well) and show (or ask, if you are the guest in their home) the participant where to sit. You should be in a seating arrangement where you are facing one another (or you could sit side by side if they are able to read and want to follow along with the survey). This position allows each of you to see the other’s facial expression and maximizes the ability to hear both questions and answers. You will need to arrange beforehand for a table or hard surface upon which you will place the questionnaire, forms, [...] and any other supplies [...] that you will use with the questionnaire. After you have both been seated, take a few minutes to get comfortable. Thank them for volunteering to be a participant and spend a few minutes in small talk until you both feel comfortable with starting the interview.

Have a discussion with the SHG women about timeliness. Will either party (the interviewer or participant) be troubled by not meeting at the exact scheduled time? What will they do if one person is late. Discuss how to reschedule in the event of last minute conflicts.

It is possible that the participant may bring a friend or guest to the interview. Our confidentiality procedure strictly prohibits the interview being conducted with more than one participant at a time. It is also possible that the participant will not be completely honest when answering questions if a person other than the interviewer is present during the interview. You should explain to the participant that all answers must remain confidential and that their friend/guest must wait for them outside or elsewhere while the interview is being conducted, or if they choose they can reschedule the interview for
another time. If the *participant* has questions about this guideline, refer their questions to <insert name of the person at ARM who can take care of this question>.

G. Review the Information for Informed Consent and Confidentiality

Before asking the interview questions, take time to explain once again the purpose of the survey and how the information will be used. Go over the standardized responses, including:

1. Who is sponsoring the survey and conducting the research
2. How you got the *participant*’s name
3. How you will use the *participant*’s answers
4. How the *participant* will receive a small gift
5. Why the *participant*’s participation is important

Go over the issue of confidentiality. Review the procedures that will be used to ensure the confidentiality of the *participant*’s identity and of the information recorded on the questionnaire (See Consent Form in Section XII). Next, verify that the *participant* has signed an informed consent form. If not, give him or her a copy of the form. Ask the *participant* to read it carefully or read it to them and then ask her to sign it if […] she understands and agrees to be interviewed […]. Remind the *participants* that they may stop participating in the survey at any time […].

H. Present the Instructions about the Interview Format

You will need to explain the format of the interview, covering the following items:

- Length of the interview

- *How some questions will have a list of possible answers that the interviewer will read and that some will be open-ended.*
• How answers will be recorded on the paper questionnaire [...]  
• <Anything else?>

You are now ready to begin asking the survey questions!

V. Asking the Questions

As an interviewer, you must be aware of everything that is going on during the question and answer process. The following information should be used as a guideline to help you to recognize potential problems during the interview.

A. Interviewer Effects

The interviewer can influence the participant's answers consciously or unconsciously through the use of verbal and non-verbal cues. You must avoid interjecting your own expectations and values that could lead the participant to provide biased answers. Respect the participant's personality, customs, and cultural background and do not impose your own beliefs, values, and interpretations on the participant. Always maintain a neutral approach and do not distort the wording of questions or instruction guidelines. If a participant tells you about a painful experience to which you relate, do not share your own experience with them. Instead, you may say, “I am sorry that happened to you,” or “That must have been a difficult time for you.”

To avoid creating interviewer effects, do not:

• Offer your own opinion during the interview

• Display approval or disapproval through your tone of voice, facial expression, or side comments

• Discuss your own experiences with the participant
• Read the questions using your own words instead of those written on the questionnaire

**Examples**

The following examples show situations in which you could influence the participant: (In focus groups with ARM, see if you can come up with better examples before presenting this to the SHG women. During focus groups with the SHG women, see if they find these examples relatable or if they have ideas for better examples.)

• **A question reads, “What is your profession?”** The Interviewer asks, “What is your current job?” A teacher by profession might be currently working in a clothing store because of a teacher’s strike and would answer the first question “teacher” and the second “clothing store clerk.” The correct response is lost, and what’s worse, those who interpret the data will never know it unless a supervisor has observed the interview.

• **A question reads “How did you find out about our program?”** with Interviewer instructions, “Do not read response options.” The Interviewer does not read the whole list of options out loud but begins offering some of them when the participant hesitates. The participant was about to say she was told about the program by a friend, but when the Interviewer suggests a health camp, she says, “Oh, maybe I did hear about this at a health camp.” She does not go on to say that her friend’s recommendation is what most motivated her to look into the program. The correct response has again been lost.

• **A question reads, “What is your opinion of how well the President is doing his job?”** Although the Interviewer’s probing instructions are to remain neutral, to
say “un-huh” (Does this sound mean the same thing to them as it does to us? Is there another sound or expression that is more appropriate than “uh-huh”?) and “please continue” to get a complete response, when the participant says she is happy with the President’s performance, the Interviewer chuckles and asks, “Well, what about that recent incident?” The chuckle tells the participant that the Interviewer disagrees with [...] her, and the question about the recent incident takes the participant in a direction he would not have chosen if left to respond on [...] her own.

(From Frey and Oishi, How to Conduct Interviews by Telephone and In Person, Sage, 1995, p. 34)

B. Listening Skills

In this context, listening involves two important aspects. First, by listening attentively to the participant you will be able to probe for more information when necessary and be sensitive to the participant’s level of comfort or discomfort with the question. Second, you must be able to hear and understand the participant’s answer to record it correctly on the questionnaire. The best conditions for active listening include a state of “relaxed concentration” during which the interviewer is listening to the participant, watching the participant’s face and body language, and trying to understand the participant’s ideas.

C. Body Language/Non-verbal Cues

As an interviewer, you must be aware of your own and the participant’s physical expressions. Non-verbal cues can be conveyed through facial expressions, posture, and hand and foot movements. Slouching in the chair, resting your head on a hand,
tapping your fingers, shaking your foot, playing with a pencil, or other object, yawning, fidgeting, or staring may all signal lack of interest in, anxiety about, or frustration with the interview process. Other body signals may indicate different emotional reactions, including sadness, anger, or confusion. Observe the participant’s body language when [...] she first enters the room and during the course of the interview. If the body language changes and there are obvious prolonged signs of distress during the interview, you may need to offer the participant a short break to get a drink, go to the restroom, or walk about. Also be tuned-in to your own body language. You may be unintentionally telling the participant you are bored, uninterested, or impatient, and this could affect [...] her attitude and answers.

D. Reading the Questions:

When beginning an interview, you should reassure the participant that there are no wrong or right answers. As an interviewer you must:

• Read questions exactly as they are worded in the questionnaire.

• Read questions in the order in which they are presented on the questionnaire

• Ask every question on the questionnaire [...].

• After reading the question, listen quietly and patiently for the response.

• Do not interrupt or make a comment before the participant has completed an answer.

• Read questions with no additions, deletions, or substitutions.

• Read each question slowly [...].

• Use a tone of voice that conveys assurance, interest, and a professional manner that is neutral and non-judgmental
• Emphasize underlined words to enhance meaning.

Do not attempt to re-word or explain a question. If the participant does not understand, repeat the question slowly. You can also use the standardized definitions presented with the questionnaire (see Section IV). If they continue to ask what it means, reply, “Whatever it means to you (MTY).”

Sometimes a participant will want to answer a question before you have finished reading it. It is crucial that the participant hear the entire question before answering. If the participant interrupts, you must continue reading the question. This allows the participant to hear the entire question and it also discourages future interruptions.

Don’t skip a question because the answer was given earlier or because you “know” the answer. In those situations in which the participant has already provided information that probably answers the next question, you may preface the question with some combination of the following phrase:

• “I know we’ve talked about this,”—or—“I know you just mentioned this, but I need to ask each question as it appears in the questionnaire.”
• “You have already touched on this, but let me ask you…”
• “You’ve told me something about this, and this next question asks…”

Do not direct the participant toward an answer or assume that an “answer” you got in passing is the correct answer to a specific question at a particular point in the interview. Do not direct the participant by mentioning an earlier answer. If an answer is different from the one you expect, do not remind the participant of an earlier remark or try to force consistency. Finally, remember that although you may have read these
questions many times, the participant is hearing them for the first time and needs time to understand the questions in order to decide on the answers.

E. Using Interview Probes

There may be situations in which the response to the question is unclear, incomplete, or not related to the question. Some participants may frequently reply that they “don’t know” the answer. In these situations, you can use an interviewing technique known as the “probe.” The probe is used to obtain more information, but please remember that probing must not bias the participant's answer. Do not supply an answer for the participant by probing them to elicit a specific answer. Here are examples of probes that are permitted in an interview:

- **Show Interest.** An expression of interest and understanding, such as "uh-huh" (Again, check to see if “uh-huh” has the same meaning for them or if another sound or phrase would fit better) , "I see", or "yes", conveys the message that the response has been heard and more is expected.

- **Pause.** Silence can tell a participant that you are waiting to hear more.

- **Repeat the question.** This can help a participant who has not understood, who has misinterpreted, or who has strayed from the question.

- **Repeat the Reply.** This can stimulate the participant to say more, or to recognize an inaccuracy.

- **Ask a Neutral question.** "Can you tell me more about that?"

- **For Clarification:** "What do you mean exactly?", or "Could you please explain?"

- **For Specificity:** "Can you be more specific about that?"
For Relevance: "I see. Well, let me ask you again." (REPEAT QUESTION AS WRITTEN)

(From Frey and Oishi, How to Conduct Interviews by Telephone and in Person, Sage, 1995, pp. 123-124) Go to Exercise #3

**Probe Abbreviations**

- Repeat question (RQ)
- Repeat Frame of Reference (RFR)
- Repeat Choices (RC)
- Whatever ______ means to you (MTY)
- Whatever you think of as __________________ (WYT)
- What do you mean? (WM)
- How do you mean? (HM)
- Would you tell me more about your thinking on that? (TM)
- Would you tell me what you have in mind? (HIM)
- What do you think? (WT)
- What do you expect? (WE)
- Which would be closer to the way you feel? (WC)
- Are there any other reasons why you feel that way? (AO)

Are there any abbreviations that were left out? Do these probes make sense to them?

What short-hand will they use with probes?

**Neutral Prefaces to Probes That Should Not be Recorded**

- Overall…
- Generally speaking…
• Well, in general…
• In the country as a whole…
• Yes, but…
• Of course no one knows for sure…
• Of course there are no right or wrong answers…
• We all hope, but…
• We’re just interested in what you think…
• Let me repeat the question…

Make sure these examples make sense to all the SHG women.

Use of Probes

It is important to read the questions slowly, pausing when necessary to allow the participant time to provide complete and accurate responses. At first it may be difficult to know when to repeat questions or how long to pause, but this will become easier with practice. Repeat the entire question if the participant indicates that she did not understand it. In contrast to those who are not providing enough information, there may be participant’s who talk excessively or ramble in their replies. You will have to remind them that it is important to complete the interview in the given time (Is this culturally sensitive in respect to time? Do the SHG women have an opinion on how long the interview should take?). You may also have to refocus some participants by saying “Let me make sure I have this down right” and repeating the answer to bring them back to the survey process.

What about the participant who gives an “I don’t know” answer? Consider what she might really mean.
• *The participant* doesn't understand the question but doesn't want to admit it.

• *The participant* is thinking about his/her answer and is filling the silence.

• *The participant* doesn't want to answer the question.

• *The participant* really doesn't know or doesn't have an opinion on the subject.

Remember: You should probe a “I don’t know” response at least once. The most effective probe for an “I don’t know” is to repeat the question (RQ) or pause.

**Exercises #4-8**

**F. Displaying the Scale Cards**

There are a number of questions on the survey form that have more than 4 or 5 responses. It would be too difficult for the *participant* to remember all of the choices. For this type of question, a scale card is supplied with the reply choices listed on it. Each of these questions will tell you which scale card to use. Before you read the question, hand the card to the *participant*. Read the question, ask the *participant* to look at the code card as you read the responses, and ask the *participant* to choose one answer from the list. You will use a code packet, so that you can flip to the appropriate card to display to the *participant*.

**G. Answering Questions From the Participant**

During the interview, the *participant* may have questions about the purpose of the survey, the meaning of the questions, or about you as the interviewer. Remember that you must try to keep the answers to the questions as standardized and unbiased as possible. For that reason, you must not engage in a general conversation or lengthy explanations. For questions regarding the survey process, use the standardized replies provided in Section XII. Do not give personal information to the *participant*, because
you will be conducting other interviews in this setting and may also be doing a re-test interview.

Other key phrases that may be used when the participant asks for more information include:

- “This is all the information available to us.
- “We would like you to answer the question in terms of the way it is stated.
- “Shall I read it again for you?”
- “I’m sorry, I don’t have that information.”
- “I will write on the questionnaire the qualifications to your answer that you have just mentioned.”

If the participant still requires more information, instruct them to contact <name of the specific person at ARM the person should contact>.

(From Frey and Oishi, How to Conduct Interviews by Telephone and in Person, Sage, 1995, p. 134)

H. Feedback

Feedback consists of statements or actions that indicate to the participant that she is successfully answering your questions, and encourages appropriate behavior and responses for future questions. Feedback should not be confused with interviewer effects. Giving the participant feedback does not lead anyone to answer in a specific way, but rather it indicates to the participant that the answers she is providing are appropriate for the questionnaire. You must decide when and how to give feedback to the participant. Participants who exhibit appropriate behavior will listen to the entire question before beginning to respond, give serious and clear answers, and stay on task
when answering a question and avoid digression to unrelated stories or topics. If a participant interrupts your questions, offers partial or unclear answers, or answers each question with a story, this is inappropriate and you should use probes or neutral non-verbal techniques to encourage more appropriate responses.

Since you are interviewing in person, you will have the opportunity to use non-verbal feedback. “Small talk” before beginning an interview may help to establish trust between you and the participant. Once the interview has begun, a smile, nod of the head, or eye contact will acknowledge the participant’s answer and encourage similar responses. However, non-verbal feedback must be used carefully in order to encourage appropriate behavior or discourage inappropriate behavior. For example, if a participant refuses to answer a question or strays from the topic, you must not smile or nod your head. If this should occur, use probing techniques or ask the participant a neutral question. However, please remember that while it is important for interviewers to be objective, it is essential that they don’t come across as cold. Interviewers should be both professional and friendly, but this balance can only be achieved through practice.
Feedback Phrases

<table>
<thead>
<tr>
<th>Long</th>
<th>Short</th>
</tr>
</thead>
<tbody>
<tr>
<td>• That’s useful/helpful information.</td>
<td>• I see...</td>
</tr>
<tr>
<td>• It’s useful to get your ideas on this.</td>
<td>• Uh-huh/Um-</td>
</tr>
<tr>
<td>• Thanks, it’s important to get your opinion on that.</td>
<td>hmm.</td>
</tr>
<tr>
<td>• I see, that’s helpful to know. It’s important to find out</td>
<td>• Uh-huh/Um-</td>
</tr>
<tr>
<td>what people think about this. That’s useful for our</td>
<td>hmm, I see.</td>
</tr>
<tr>
<td>research.</td>
<td>• Thank you.</td>
</tr>
<tr>
<td></td>
<td>• Thanks.</td>
</tr>
</tbody>
</table>

Interviewer Task-Related Comments

- "Let me get that down."
- "I need to write it all down."
- "I want to make sure I have that right (repeat answer)."
- "We have touched on this before, but I need to ask every question in the order that it appears in the questionnaire."

For further clarification on feedback, read the following examples and then examine the page of feedback responses:

**Example #1**

**Interviewer:** Do you do any volunteer work or any other kind of work for which you are not paid?
Participant: Yes, I really like to volunteer at my church, by offering to organize events.

Interviewer: Thank you. That was a very thorough answer.

Example #2

Interviewer: What is your current marital status? Married, widowed, divorced, separated, or never married?

Participant: I am married but living separately from my husband and children this year.

Interviewer: I see. Now, what is the highest level of school that you have completed?

In the examples above, “I see” and “Thank you” are feedback phrases used to indicate that the participant is providing appropriate answers. In contrast, the next example demonstrates feedback to an inappropriate answer:

Example #3

Interviewer: Have you had any problems associated with alcohol use in your lifetime?

Participant: Well, growing up, my best friend’s father had a drinking problem.

Interviewer: I see, (pause) but, ‘Have you had any problems associated with alcohol use in your lifetime?’

Participant: I guess not, no.

Remember that effective Interviewers give feedback for good performance, not “good” content. Interviewers should not use the phrases, “O.K.” or “all right” (Are there any other phrases to avoid?) when providing feedback to a participant because they indicate agreement with the response. Instead, you should always use neutral phrases that do not indicate agreement. As a general rule, you should give short feedback phrases for short answers and long feedback phrases for longer answers. You can also use a brief pause followed by a feedback phrase to make it more powerful. The pause
signals to the *participant* that you have considered […] her answer carefully. An Interviewer should determine how often to give feedback by considering the performance of the *participant*. Some *participants* may need more feedback to encourage appropriate responses while other *participants* may need less feedback.

**Go to Exercise # 8**

I. Recording the Responses:

The *participant’s* answers must be completely and properly coded on the questionnaire […], or the interview results cannot be used for analysis. Record every answer in the appropriate category. If a response has been “Don’t Know,” enter NANS for that question. If the *participant* refuses to answer the question, also enter NANS. If you must probe for a response, write P next to the question. If the *participant* has difficulty in understanding the question, make a note next to the question. You may also use the interviewer’s comment section for further explanations. Every question must have some recorded answer, or an explanatory mark, in the available space. If an item was part of a skip pattern, or if you forgot to ask it, enter NASK for that question. Common errors made by the interviewer include:

- Omitting an answer.
- Recording the wrong answer code.
- Circling more than one answer or entering more than one number.
- Writing illegibly, or in abbreviations that are not readily understandable to the people who are coding.

(From Ralph, “Research Interviewer Handbook,” p. 7)
If you accidentally mark the wrong answer, cross out your mark, write ‘error’ next to it and circle the correct answer. [...] Some participants may change their mind while giving an answer, so it is useful to wait a couple seconds between questions to be sure the participant has finished speaking before marking their final answer. If you have finished the interview, but have some concern about whether the participant answered accurately or truthfully, make a note of this or of any other concern in the section for Interviewer’s comments.

J. Taking Breaks

Half way through the interview, you should take a 10-minute break. This gives you and the participant a chance to stretch your legs and rest your minds. You will get more accurate and complete responses during the last half of the interview if the participant has had a chance to rest half-way through. Some participants may need more than one break. Be aware of fidgeting or other non-verbal behaviors that indicate that the participant is tired or restless. Be careful during the break not to talk about anything that would bias answers to any of the rest of the questions in the interview. Small talk about matters such as [...] the weather are good topics of conversation during the break.

K. Troubleshooting

It is rare but possible that a person who has agreed to be interviewed may become uncooperative during the interview causing you to feel uncomfortable about the participant’s behavior. If you feel that the person cannot actively participate in the interview because she is uncooperative, rude, threatening or hostile towards you, [...] you should end the interview immediately. Conducting interviews at a neutral site, <insert location>, can reduce these types of behaviors. Therefore, during this project, all
interviews will be conducted at the <specify location>. If an alternate interview setting is needed for a participant, notify the <name of the person at ARM> to receive approval. Although we will be using a neutral site to conduct interviews, it is still possible for people to act inappropriately. Since every person has a different comfort level, it is impossible to foresee all situations that may cause Interviewers discomfort. As a general rule, Interviewers and participants should refrain from the following: (Are these examples relevant to our SHG women? Are there any others they would add to this list?)

- Touching other than to shake hands.
- Using profanity.
- Acting out (yelling, slamming furniture).

You should also be aware of other behaviors signifying that the participant is not able to complete the interview, including <what cues would make an SHG woman feel like a participant is not capable of completing an interview at this time?> If at any time you experience discomfort due to the behavior of the participant, you should end the interview immediately. Tell the participant that you have finished your questions, that you appreciate her time, and that if the participant has any questions she should be referred to <name of the person at ARM to contact. Then promptly leave the interview site. Make written notes in the post-interview Observation Section, and then report your experience to <name of person at ARM> immediately, before you conduct another interview. If this kind of problem should occur, please stay calm, and know that their behavior is not related to you or this project. Always remember that your safety and
comfort comes first and that if you have to end an interview, this will not be held against you.

**L. Ending the Interview**

Once the interview is completed, thank the *participant* for [...] her time and effort. Let the *participants* know that their participation was very important for the success of the project. At this time, they may express some concern about the content of the survey questions, and you may need to spend a short time reviewing the purpose of the survey and use of the information. If necessary, give the *participant* the `<contact information for the person at ARM who will answer questions during this study>` and reassure the *participant* that [...] she may contact the them at any time regarding the survey content or process. *Give the participants their small gift.*

**M. Post Interview Observations**

Once you have finished the interview and left the interviewing site, take a couple minutes to make some written notes about the interview and the *participant*. Record any problems you may have had during questioning, whether the *participant* seemed attentive and responsive, and whether the *participant* understood the questions. It may be useful to record specific behaviors, statements and impressions that occurred during the interview. In addition, you should record any errors or mistakes that were made during the interview. These notes will help you with future interviews and will also help ARM and the USC student researchers ensure the validity of the project by noting *participants* who may have been giving false or biased answers. This process can also help other interviewers because you can later draw upon these notes to share your experiences with each other.
VI. Editing the Interview

After you have completed each interview, you will edit the questionnaire. Editing consists of re-reading the questions and answers making sure that every question has been answered, to correct errors you may have made in coding, and to make sure that notations such as NANS for “I don’t know,” or if the participant refused to answer, P for “used probing”, or any other note or explanation is clearly written in the proper place on the form. The site coordinator will also review the interview form a second time. If errors or incomplete sections are found, the site coordinator will ask you to make the corrections and if necessary, contact the participant for the missing information.

To each completed questionnaire, attach a control sheet with the following information [...]:

**Control Sheet**

Project ID______________

<table>
<thead>
<tr>
<th>Status</th>
<th>Date</th>
<th>Signature</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interview Completed</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Edit Completed</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Corrections Completed</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Data Entry Completed</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*(From Frey and Oishi, p. 132)*

VII. Keeping Track of Contracts & Completed Interviews

You are responsible for scheduling all of your interviews and follow-up interviews over a <insert number of weeks or months> period. You will contact the participants twice: first to schedule a meeting time and second to conduct the interview itself. A
special box for collection of these forms will be kept in the <insert place at ARM where completed questionnaires will be kept>. <Insert name of person at ARM> will review the forms and completed questionnaires at the beginning of each week […].

The field contact record will list all of the participants being interviewed on one sheet. There is a separate field contact record for each follow-up interview with each participant.

Field Contact Record - First Interview

Interviewer:_________________

<table>
<thead>
<tr>
<th>Project ID:</th>
<th>Location</th>
<th>Interview Date</th>
<th>Interview Time Start</th>
<th>Interview Time End</th>
<th>Outcome Code</th>
</tr>
</thead>
<tbody>
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</table>

Outcome Codes

CI=Completed Interview  IT=Interviewer Terminated Interview
RF=Refused Interview   RT=Participant Terminated Interview

Submit copy of field contact record to <person at ARM> every week for signature:

Date:_____________  [Site] Coordinator:_________________
VIII. Providing the Small Gift

To say “thank you” to each participant, we would like to give them a small treat. In the Focus Groups decided on what that small treat should be and how each SHG woman will obtain that treat before each of her interviews.

IX. Attending Debriefing Meetings

After the training has been completed, <name of person at ARM> will maintain in regular contact with you by <insert method of contact>. In addition, there will be a <specify frequency, example: bi-weekly> meeting of the ARM coordinator and all interviewers. At this meeting, you will be encouraged to discuss any questions that may come up or any difficulties you may be encountering during the interview process. Of course, you may also contact the site coordinator or lead interviewer <insert specific names of people at ARM to contact> for your region at any other time.

X. Providing Feedback to the Trainers and Project Coordinators

Because we are in the developmental stages of this project, it is important that we understand any difficulties that may be occurring for you or the participant in the interview process, including setting up and keeping appointments and asking and answering the questions.

As previously indicated, you should make a note next to any question that seems to be confusing or difficult to answer, and provide further explanation if necessary in the interviewer’s comments section.

In addition to your feedback on the survey process and instrument, we would like your evaluation of the training process. Please feel free to give us feedback on the various steps in the training itself. You do not have to write your name on your comments, but
please, when you have constructive comments or suggestions and leave them in the questionnaire box in the project office.

You are also encouraged to speak to the trainers about these issues whenever you feel comfortable in doing so. Some of the topics identified by the interviewers may be brought up for discussion during the debriefing meetings or staff meetings. In addition, it is important to provide regular feedback to the Site Coordinator. We need your input to make sure that we are providing the best possible training to meet the needs of both interviewers and the project.

XI. Other Important Components

A. Supply Checklist

- Participant contact sheet
- Directions to interview location (if needed)
- Paper questionnaire
- Consent form
- Sharpened pencils
  - Eraser
  - Envelope
  - Participant gift
  - Other ___________________________

B. Exercise #1: Exercise in Contacting Participant

For each pair of statements below, circle the letter of the one you might use during an introduction.

1. a. Since this week is busy, when would be a better time?
b. Since this week is busy, I can *come* back next Monday, between 10:00 AM and noon to see if you would have time next week.

2. a. Good morning. I’m Sally Doe (substitute a common Odishan name for ‘Sally Doe) calling you in regard to the Consumer Operated Services Project being conducted at the [Site] by the [site].

b. Good morning. I’m an Interviewer calling from a large social research center.

3. a. The interview will consist of answering a set of questions about your health, your *daily* living situation, and your *choices about perinatal health care*.

b. The interview will ask you a bunch of questions about your life.

4. Now, compose your own introduction:

______________________________________________________________________

______________________________________________________________________

______________________________________________________________________

C. Exercise #2: Exercise in Standard Responses

Below are some commonly asked questions. Think about how you would answer each question and then write your response.

1. What is the survey about?

______________________________________________________________________

______________________________________________________________________

______________________________________________________________________

______________________________________________________________________
2. How did you get my name?

______________________________________________________________________
______________________________________________________________________
______________________________________________________________________

3. What will you do with my answers and who will see this information?

______________________________________________________________________
______________________________________________________________________
______________________________________________________________________
______________________________________________________________________

4. Who is conducting this project?

______________________________________________________________________
______________________________________________________________________
______________________________________________________________________
______________________________________________________________________

5. Why do you need me to participate?

______________________________________________________________________
______________________________________________________________________
______________________________________________________________________
______________________________________________________________________

6. It is really important for me to participate?

______________________________________________________________________
D. Exercise #3: Exercise in Probes

In each example below, decide whether the participant has answered the question and indicate Yes or No in the blank.

1. Interviewer: “How much choice do you have about how you will spend your free time?”

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>No choice</td>
<td>Not too much Choice</td>
<td>Some Choice</td>
<td>A Lot of Choice</td>
</tr>
</tbody>
</table>

Participant: “I don’t have any free time.”

   YES    NO (Circle One)

2. Interviewer: How do you feel about the way things are between you and your family?

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
<tbody>
<tr>
<td>Terrible</td>
<td>Unhappy</td>
<td>Dissatisfied</td>
<td>Mixed</td>
<td>Mostly Satisfied</td>
<td>Pleased</td>
<td>Delighted</td>
</tr>
</tbody>
</table>

Participant: I haven’t seen my family in a long time.

   YES    NO (Circle One)

3. Interviewer: Overall, how do you feel about the amount of friendship in your life?
1. Study the following interview situation.

*The question on the survey reads as:* Which member of your family is the primary decision maker for health care choices?

*Participant:* “Let me think...that is a difficult question.”

Interviewer: [Pause]

*Participant:* “I’m trying to think...my father-in-law.”
In this example, how did the pause help to get the answer?

What does a pause by the interviewer indicate to the participant?

2. Interviewer: **During the past week**, how often did you spend time with friends or family in recreational activities?

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Not at all</td>
<td>Once</td>
<td>2-3 Times</td>
<td>4-6 Times</td>
<td>Once or more/day</td>
</tr>
</tbody>
</table>

Participant: I'm not sure…

Interviewer: Let me repeat the question (RQ). **During the past week**, how often did you spend time with friends or family in recreational activities?

Participant: Oh, okay, I guess about two to three times. Was repeating the question effective in this situation? Why or why not?

Name another situation in which the Interviewer might repeat the question to the participant?
F. Exercise #5: Exercise in Probes—Repetition

Part I: Study the following example:

**Interviewer:** How do you feel *about your social relations with other* people? Terrible, unhappy, mostly dissatisfied, mostly mixed, satisfied, pleased, or delighted?

**Participant:** I feel sort of okay.

**Interviewer:** Would that be mostly mixed, satisfied, pleased, or delighted?

**Participant:** I would say satisfied.

It is important to provide repetition of the misunderstood portion of the question.

Part II: Use the Repetition Probe on the following examples.

1. **Interviewer:** How do you feel about the amount of time you spend with other people?

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
<tbody>
<tr>
<td>Terrible</td>
<td>Unhappy</td>
<td>Mostly Satisfied</td>
<td>Mostly Mixed</td>
<td>Satisfied</td>
<td>Pleased</td>
<td>Delighted</td>
</tr>
</tbody>
</table>

**Participant:** People seem to visit me often and ask me to do things and that makes me feel good.

In the above question, what is the topic?

______________________________________________________________

Did the participant answer the question?

______________________________________________________________

Put parentheses around the misunderstood portion.
Write the correct probe here: ______________________________________________

2. **Interviewer**: How do you feel about the people you see socially?

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
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<tbody>
<tr>
<td>Terrible</td>
<td>Unhappy</td>
<td>Mostly Satisfied</td>
<td>Mostly Mixed</td>
<td>Satisfied</td>
<td>Pleased</td>
<td>Delighted</td>
</tr>
</tbody>
</table>

**Participant**: I don’t get out that often.

In the above question, what is the topic?

________________________________________

Did the participant answer the question?

________________________________________

Put parentheses around the misunderstood portion.

Write the correct probe here:

________________________________________

G. Exercise #6: Exercises in Probes—What do you mean? Could you tell me what you mean by that? (WM)

Read the following situation and answer the questions below. (WM) is used if participant gives an unacceptable response to an open question.)

**Interviewer**: Do you believe you have been discriminated against?

**Participant**: Well, discrimination is a fact of life.

**Interviewer**: Could you tell me what you mean by that (WM)?

Why did the Interviewer use the probe (WM) in this situation?
Interviewer: Are you currently looking for a new or paying job?

Participant: Oh sure, I'm always looking for a quick buck.

Interviewer: What do you mean? (WM)

Why did the Interviewer use the probe (WM) in this situation?

H. Exercise #7: Exercise in Probes—Which would be closer to the way you feel? (WC)

Read the situation below and answer the questions that follow. (WC is used when the participant has narrowed the choices to two or a range between two.)

1. Interviewer: How do you feel about the things you do with other people?

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<th>2</th>
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<th>4</th>
<th>5</th>
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<td>Mostly Mixed</td>
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<td>Pleased</td>
<td>Delighted</td>
</tr>
</tbody>
</table>

Participant: Somewhere between satisfied and pleased.

Interviewer: Which would be closer to the way you feel? Would you say that you are more satisfied or more pleased?

What was wrong with the participant’s answer?

How did the WC probe help to isolate the participant answer?
What other probe could the Interviewer have used.

Interviewer: The people who work here believe I can grow, change and recover.

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<tr>
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<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
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<tbody>
<tr>
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<td>Agree</td>
<td>Neutral</td>
<td>Disagree</td>
<td>Strongly Disagree</td>
<td></td>
</tr>
</tbody>
</table>

Participant: Sometimes I would agree that is true, but other times I am not so sure.

Interviewer: Which would be closer to the way you feel most of the time?

What was wrong with the participant’s answer?

How did the WC probe help to isolate the participant’s answer?

I. Exercise #8: Exercise in Feedback

Part I: Read the example below and answer the following questions.

Interviewer: How long have you been attending this peer-support program?

If you can, please tell me the date you first started coming here.

Participant: Well, I guess it was about three months ago when I first came here.

Interviewer: I see…Now, during a typical week, how often do you attend this program?

Participant: I suppose about four times.
In the above example, the Interviewer uses the brief phrase, “I see,” as feedback. Why?
(Circle the letter of the correct response(s) below.)
a. Because it indicates to the *participant* that *she* is doing a good job.
b. Because it tells the *participant* her answers are heard and understood, and thus *she* will be more likely to give an answer to the next question as well. What other feedback phrase could the Interviewer have used? What other feedback could the Interviewer have used in combination with this response?

**Part II: List Two Short and Two Long Feedback Phrases**

1. 
2. 
3. 
4. 

**Part III: Below is a list of possible feedback phrases. Cross out phrases that should never be used because they comment on content instead of performance.**

a. This is helpful information
b. What a good idea.
c. I see.
d. That’s very interesting.
e. Okay.
f. It’s important to find out what people think about this.
g. I agree with you there.
h. Uh-huh. Thanks. It’s important to get your opinion on that.
i. All right.
Part IV: Now, get with a partner and go through the following exercise. Each partner will ask four sample questions to the other. While one partner is asking the questions, the other partner will keep score of the feedback responses (one point for each feedback response). Write down which feedback phrase is used. Also note any interviewer effects or non-verbal behavior which may be occurring. Each person should try to give feedback for every other question.

Question Set #1:

1. Have you ever been employed? _____Yes _____No
   Phrase:______________________________________________________________

2. Are you currently doing any work for pay or on a volunteer basis?
   _____Yes _____No

3. Used Feedback Phrase: Yes No (Circle One)
   Phrase:______________________________________________________________

4. Is having a paying job important for you? _____Yes _____No
   Used Feedback Phrase: Yes No (Circle One)
   Phrase:______________________________________________________________

5. Are you currently looking for a new or paying job? _____Yes _____No
   Used Feedback Phrase: Yes No (Circle One)
   Phrase:______________________________________________________________

Total Points for Question Set #1: _____________________
Question Set #2

1. Where do you currently live?

_____ an apartment  
_____ a shelter or halfway house

_____ a house  
_____ a hotel or motel

_____ transitional living center  
_____ the street

_____ group home/board and care or halfway house

_____ other: please specify ________________________

Used Feedback Phrase: Yes  No (Circle One)

Phrase: ________________________________

2. Who currently lives in your residence with you?

Interviewer: Check all that apply.

_____ parents  
_____ adult children

_____ spouse or partner  
_____ no one (participant lives alone)

_____ friends  
_____ other Please specify________________________

_____ other peers

_____ minor children

Used Feedback Phrase: Yes  No (Circle One)

Phrase: ________________________________

3. Do you receive any help in managing your money?  _____ Yes  _____ No

If yes, ask: From whom do you receive help (check all that apply)?

_____ People at this peer program.

_____ Staff from another program

_____ Family
_____ Friends
_____ Spouse or Partner
_____ Other (Please specify) __________

Used Feedback Phrase: Yes   No   (Circle One)
Phrase:______________________________________________________________

4. Do you receive any help with cooking?
   _____ Yes   _____ No

If yes, ask: From whom do you receive help (check all that apply)?
   _____ People at this peer program.
   _____ Staff from another program
   _____ Family
   _____ Friends
   _____ Spouse or Partner
   _____ Other (Please specify) __________

Used Feedback Phrase: Yes   No   (Circle One)
Phrase:______________________________________________________________

5. Do you receive any help with housekeeping?
   _____ Yes   _____ No

Used Feedback Phrase: Yes   No   (Circle One)
Phrase:______________________________________________________________

6. Are you currently working for pay?  _____ Yes   _____ No

Used Feedback Phrase: Yes   No (Circle One)
Phrase:______________________________________________________________
Total Points for Question Set #2: _________________________

J. Example: Control Sheet

Project ID__________

Status Date Signature

Interview Completed _______ _____________

Edit Completed _______ ________________

Corrections Completed _______ ______________

Data Entry Completed _______ ______________

Outcome Codes

IS=Interview Scheduled BZ=Busy Signal

RF=Refusal AM=Answering Machine

NA=No Answer DS=Disconnected

RC=Returned Call WN=Wrong Number

(Adapted from Frey and Oishi, p. 140)

Field Contact Record - Baseline Interview

Interviewer:______________

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<th>Interview Date:</th>
<th>Interview Time Start</th>
<th>Interview End</th>
<th>Outcome Code</th>
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</thead>
<tbody>
<tr>
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</tbody>
</table>

Outcome Codes:

CI = Completed Interview IT=Interviewer Terminated Interview

RF=Refused Interview PT=Participant Terminated Interview
Submit copy of field contact record to field coordinator every week for signature:

Date:___________  Field Coordinator:________________

K. INTERVIEW TRACKING

Interviewer____________

<table>
<thead>
<tr>
<th>Project ID Number</th>
<th>Date Completed</th>
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<tbody>
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