Title: Developing a scale to measure abortion stigma and evaluate community-based stigma reduction interventions

Introduction: Abortion stigma is a complex issue, and understanding its manifestation and perpetuation is challenging. Stigma was once conceptualized as a process of what some individuals do to other individuals (Parker and Aggleton 2003). Stigma theory has progressed from an individualistic focus towards recognition of stigma as a socially constructed process — one that occurs within a broad social, cultural and political framework (Parker and Aggleton 2003; Corrigan et al. 2004; Yang et al. 2007). The social construction of stigma, as conceptualized by Link and Phelan (2001) and Link et al.(2004) is easily applied to the issue of abortion and can serve as a framework for furthering our understanding of abortion-related stigma.

First, people distinguish and *label* human differences – abortion is portrayed in a community as an abnormal event and women who have them as deviant. Second, dominant cultural beliefs link labeled persons to undesirable characteristics or negative *stereotypes* – communities link women who have abortions to traits such as promiscuity, carelessness, selfishness and lack of compassion for human life. Third, labeled persons are put in distinct categories as to establish a *degree of separation* between "us" and "them" – anti-abortion forces present inaccurate information about risks of abortion and women who have them. Fourth, emotional reactions occur in the stigmatizer and the stigmatized – anti-abortion individuals may feel anger, disgust or fear, and women who have abortions may feel embarrassment, shame, guilt and fear of disclosure. Lastly, labeled or stigmatized persons experience *status loss and discrimination* as a result of the issue being disclosed or discovered - a woman who's had an abortion may experience rejection, exclusion or discrimination as a result of the abortion being voluntarily or involuntarily revealed to her community (Shellenberg et al. 2011; Kumar et al. 2009).

Using this framework of interrelated components (i.e. labeling, stereotyping, separating/excluding and discriminating), we set out to further our understanding of abortion stigma at the community level, and to develop a scale to measure abortion stigma that can also be used in the design and evaluation of community-based stigma reduction interventions. Specifically we aimed to: a) generate an item pool for stigma scales through focus group discussions (FGDs) with women and men about abortion in their community; b) use these data to develop a set of test items for an abortion stigma scale; c) identify scale items that have a consistent factor structure to measure abortion stigma; and d) examine the relationships between levels of stigma and age, gender, marital status, educational attainment and religious affiliation.

Methods: The research comprised a sequential mixed-methods design in which we explored the context of abortion stigma through qualitative research and then used the findings to develop items for a scale to measure abortion stigma at the individual and community levels (Tashakkori and Teddlie 1998). This design follows a standard procedure for new scale development (DeVellis 2012). Each step in the scale development process is described in detail below.

<u>Sites</u>: The research was conducted in four communities, two communities in Zambia and two communities in Ghana. These research sites were chosen because Ipas is currently working in both of these countries, which provides the study team with knowledge of the local situations, pre-established relationships critical to gaining access to local communities, an infrastructure that facilitates the logistical aspects of the project, and opportunities for integrating the research with our other work. This research was approved by the University of Zambia Biomedical Ethics Committee and the Ghana Health Service Ethical Review Board.

<u>Focus group discussions</u>: Focus group data was collected during March and April, 2011. A total of 8 FGDs were conducted in Zambia, two for each of the following categories: married women, unmarried women, married men, and unmarried men. A total of 15 FGDs were conducted in Ghana; the groups were divided into categories based on sex, marital status and age (15-24 and 25-54). A common interview guide was developed based on an interview guide previously developed by Billings, Hessini and Anderson (2009) and the work of Link and Phelan which focuses on four key interrelated components that produce and sustain stigma: labeling, stereotyping, separation/exclusion, and discrimination.

All FGDs were digitally recorded and transcribed by moderators and note-takers within 24 hours of the session, following a prescribed transcription protocol. Once the recordings were transcribed, moderators or note-takers translated the FGD transcripts into English (when necessary). Each site maintained participant confidentiality by keeping all informed consent documents, audio recordings and transcripts under lock and key.

Once transcription and translation was complete, core study team members read and analyzed the transcripts by identifying passages that illuminated some aspect of abortion-related stigma and then categorizing those passages or quotes into one (or more) our four key areas of inquiry about stigma: labeling, stereotyping, separation, and discrimination.

<u>Translating FGD data into questionnaire items</u>: Study team members developed potential scale items based on the FGD transcripts. Team members were instructed to formulate the items in the form of declarative statements that would represent a respondent's personal beliefs or attitudes about abortion. An example of this translation process is as follows: First, a FGD participant's statement would be identified as relevant to abortion stigma, such as this quote from a young woman in Zambia when talking about how abortion affects women marriage prospects:

"There could be that a man wants to marry [one] of us, and as he moves [around the community] and hears that one of us has had an abortion, the preference would be [to marry] the one who has not aborted before so the treatment differs between different women." Second, this passage would be categorized as "exclusion" or "discrimination" and possible scale items might include: A man should not marry a woman who has had an abortion or I would advise a friend not to marry a woman who has had an abortion. Using this approach, each member of the core study team generated as many scale items as necessary to fully address the perceived and enacted abortion stigma described in the FGDs. After all items had been created by individual team members, the study team came together to discuss the developed items, remove any redundancies and finalize the list of items.

<u>Scale items and the structured questionnaire</u>: Using the final list of items, a structured questionnaire was developed, including questions on a respondent's age, sex, level of education attainment, marital status and religious affiliation. The response categories for the stigma items are based on a 5-point Likert scale ranging from "strongly agree" to "strongly disagree." The questionnaire was pre-tested (interviewer administered) with 6 men and 6 women from each country to ensure comprehension of the items. Modifications were made to the questionnaire based on the pre-testing activities.

The finalized stigma scale is currently being fielded in both Zambia and Ghana. Data collection will be completed by October 15, 2011. Both countries are administering the questionnaire to a purposive sample of approximately 250 individuals (500 total). The sample should include men and women, ages 18-49, and married and unmarried individuals. Although there are variations in the suggested sample

size needed for scale development, our intended sample of approximately 500 surpasses the suggested minimum of five respondents per scale item (DeVellis 2012). The questionnaire takes about 25 minutes to complete and respondents in both countries will receive a cell phone card worth US\$2.50 for their participation.

<u>Analysis</u>: Once data collection is completed and the data is entered and cleaned, exploratory factor analysis will be used to identify items that cluster together in meaningful ways for the study participants. Factor analysis is a statistical technique used to validate unidimensional and multidimensional scales by analyzing the pattern of correlations among the item pool and grouping these related items together with those that received similar responses from the study participants (DeVellis 2012). In factor analysis, items that are highly correlated are considered to be measuring the same underlying concepts.

Initially, we will use a principal components analysis to extract factors from our data and an oblique rotational method to arrive at a terminal factor solution. We will focus on factors with eigenvalues greater than 1.0. Only those items with a factor loading of .40 or higher will be included on any scale or subscale. These empirically derived factors will still need to be considered in terms of the items that are actually included. The research team will determine whether they are conceptually meaningful and useful in the context of intervention design and evaluation. Final item selection for each subscale will be determined by reliability calculations.

Additionally, bivariate and multivariate relationships between measures of abortion stigma and personal characteristics of interest will be explored.

Results: The FGDs generated a wealth of information about participants' attitudes and beliefs, as well as community norms surrounding the issue of abortion, women who have them, men who are involved in an abortion decision, traditional providers who help women terminate pregnancies and trained medical professionals (i.e. physicians and midwives) who perform abortions in a clinical setting. A woman who needs an abortion is often labeled as a bad person (or bad mother if she has living children), who cannot be trusted and may bring illness upon the community if people come in close contact to her postabortion. Not surprisingly, women who choose to voluntarily terminate a pregnancy are perceived to bring shame to their family and their community. In Zambia, women who have abortions are often isolated from other people for at least 1 month post-abortion to prevent the spread of "illness," and in both countries some people expressed the belief that women should keep their abortions a secret or be sent away for having an abortion. Individuals who perform abortions (both traditional healers and medically trained professionals) were also perceived by some FGD respondents to be bad people who don't care about women or their health and safety, and are just performing abortions for the money. Interestingly, participants did qualify their negative attitudes towards abortion providers, indicating that traditional healers are directly hurting women by providing unsafe abortions while trained professionals are sometimes "simply doing their job."

The study team's original plan was to categorize qualitative passages or quotes into four different groupings for item development: labeling, stereotyping, separation/exclusion and discrimination. During our qualitative analysis phase, we collapsed the 4 groups down to 2, and developed items that could fall into labeling/stereotyping or exclusion/discrimination categories. Table 1 provides examples of quotes from each of those categories and the corresponding scale item.

Table 1. Illustrative quotes and corresponding scale items

Quote and Category	Corresponding Scale Item(s)
Labeling / Stereotyping	
"A woman who has an abortion probably had sex with	A woman who has an abortion probably has sex with
lots of men. She doesn't even know who the father is."	lots of different men.
	A woman who has an abortion probably does not know
	who is responsible for the pregnancy.
"[Abortion providers] are sinners. I see them as	Doctors and midwives who perform abortions in a clinic
murders."	are committing a sin.
	Doctors and midwives who perform abortions are
	murderers.
Exclusion / Discrimination	
"We will laugh at her and also be pointing fingers at	I would point my fingers at a woman who had an
her. This will make her unhappy and it will force her to	abortion so that other people knew what she had done.
even leave the town."	I would tease a woman who has had an abortion so that
	she will be ashamed about her decision.
"In my church, a woman who has aborted is not	A woman who has had an abortion should be
allowed to stand in church or give a health talk or do	prohibited from going to religious services.
other things."	
"I think doctors [who perform abortions] should be	Traditional healers who help women terminate a
arrested."	pregnancy should go to jail.
	Doctors and midwives who perform abortions in a clinic
	should go to jail.

While a majority of our developed items focus on women and providers, we made an effort to include a few items that reflect the type/level of stigma directed at men who are involved in an abortion decision. Additionally, we separated items about traditional healers and trained medical professionals because our pre-testing respondents indicated that they think of these two groups as different types of "providers" and we wanted to be able to distinguish between stigmatization of trained providers vs. more traditional healers. The final version of the tested scale included 52 items and we expect that the factor analysis will assist us in further reducing the number of items in the scale.

Discussion: A statistically validated scale to measure community level stigma will provide an invaluable tool for measuring abortion stigma, and for informing the design and evaluation of interventions that can mitigate stigma at the community level. We expect that our stigma scale will be used to help Ipas and partner organizations design, implement, and evaluate a range of programs and projects. Additionally, this research represents an important contribution to the field of reproductive health. To date, research on abortion stigma has been limited; therefore, this represents an important contribution to a new area of research and will help form a foundation on which a future body of work can be built.

References

- Corrigan, P. W., F. E. Markowitz, and A. C. Watson. 2004. "Structural levels of mental illness stigma and discrimination." *Schizophrenia bulletin* 30 (3):481-491.
- DeVellis, Robert F. 2012. Scale development: theory and applications. Thousand Oaks, Calif.: SAGE.
- Kumar, A., L. Hessini, and E. M. Mitchell. 2009. "Conceptualising abortion stigma." *Culture, health & sexuality* 11 (6):625-639.
- Link, B. G., and J. C. Phelan. 2001. "Conceptualizing Stigma." *Annual Review of Sociology* (27):363-385.
- Link, B. G., L. H. Yang, J. C. Phelan, and P. Y. Collins. 2004. "Measuring mental illness stigma." *Schizophrenia bulletin* 30 (3):511-541.
- Parker, R., and P. Aggleton. 2003. "HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action." *Social science & medicine* 57 (1):13-24.
- Shellenberg, K. M., et al. 2011. "Social stigma and disclosure about induced abortion: results from an exploratory study." *Global public health* 6 Suppl 1:S111-125.
- Tashakkori, Abbas, and Charles Teddlie. 1998. *Mixed methodology : combining qualitative and quantitative approaches*. Thousand Oaks, Calif.: Sage.
- Yang, L. H., A. Kleinman, B. G. Link, J. C. Phelan, S. Lee, and B. Good. 2007. "Culture and stigma: adding moral experience to stigma theory." *Social science & medicine* 64 (7):1524-1535.