Knowledge & Beliefs about Reproductive Anatomy and Physiology among Mexican-Origin Women in the U.S.: Implications for Effective Oral Contraceptive Use

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Abstract

Inherent in many reproductive health and family planning programs is the problematic assumption that the body, its processes, and modifications to it are universally experienced in the same way. This paper addresses contraceptive knowledge and beliefs among Mexican-origin women, based upon data gathered by the qualitative component of the Border Contraceptive Access Study. Open-ended interviews explored the mechanism of action of the pill, side effects, non-contraceptive benefits, and general knowledge of contraception. Nearly one-third stated they did not understand how the pill works. Findings revealed complex connections between accurate and inaccurate information. Use of scientific terms ("hormone") illustrated attempts to integrate new information with existing knowledge and belief systems. Conclusions address concerns that existing information and services may not be sufficient if population-specific knowledge and beliefs are not assessed and addressed. Findings can contribute to the development of effective education, screening, and reproductive health services.

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Introduction

Inherent in many family planning and women's health programs is the problematic assumption that the body, its processes, and modifications to it (such as those caused by disease or side effects of contraceptive methods) are universally experienced in the same way. These assumptions have contributed to the underutilization and lessened impact of health care programs in general, and specifically to the rejection or incorrect use of contraception. Worldwide statistics on non-adherence/use-effectiveness and discontinuation of OCs increasingly emphasize the need to understand women's perceptions of health and contraceptive needs. While these perceptions are based in a personal evaluation of well-being, they also are influenced by information a woman receives from medical providers as well as friends, relatives and the media. Even in the US where family planning information is readily available from many sources, sufficient information about reproductive health and fertility regulation options have not been accessed by many sectors of the population. Notably, many immigrant groups with limited access to "the system" retain interpretations of the body and body processes that are based on folk beliefs and/or incomplete information from peers, family and the media. These beliefs and misinformation often contain distorted and fallacious ideas about anatomy and physiology that prevent individuals from developing an accurate comprehension of their bodies and thus correct knowledge about contraception. Understanding these beliefs and ideas can be important for health care personnel to provide appropriate and meaningful information and education about contraceptives, their effects on the body, and their correct use.

This paper addresses these issues of knowledge and beliefs among a Mexican origin population on the US-Mexico border, and suggests that not only are traditional beliefs retained over time in spite of new technology and information resources, but that access to family planning information and services may not be sufficient if existing knowledge and beliefs are not assessed and addressed.

The Border Contraceptive Access Study

The Border Contraceptive Access Study was conducted in El Paso, Texas from 2006 through 2008. El Paso, Texas with a population of 800,000 people is located on the US-Mexico border directly across from Ciudad Juarez, Mexico. The majority of the El Paso population is Hispanic/Latino and many residents regularly cross the border into Mexico for health services because of lower costs and convenience as well as social ties, cultural familiarity, and perceived quality of care.

The study recruited current oral contraceptive users aged 18 to 44 stratified into two groups: 1) El Paso residents who use OCs obtained at family planning clinics in El Paso (target n=500); and 2) El Paso residents who use OCs obtained over-the-counter at pharmacies in Mexico (target n=500). Using convenience sampling, many of the clinic users were recruited from the major family planning providers in El Paso. Cross-border pharmacy users, as well as a considerable proportion of El Paso clinic users, were recruited using announcements, flyers, presentations at local community centers, and referrals from participants. Study participants resided in over 30 zip code areas in the El Paso metropolitan area, the majority of whom lived in areas where the average household income was below the median for the city.

El Paso, Texas is among the poorest communities in the country. According to the 2004 American Community Survey, El Paso's median household income of $31,764 ranked it 61st among the 70 cities with populations greater than 250,000. Educational attainment is also low

with just 20% of El Paso's residents holding a bachelor's degree or higher, while 18% of El Paso residents have less than a ninth grade education. Some 37% of El Pasoans between the ages of 18 and 64 lack health insurance (while the Texas average is 25%). Compared to the 14% immigrant population throughout the state of Texas, approximately 28% of El Pasoans are foreign born, of whom 86% entered the US before 2000. The border is quite porous; four bridges link the two cities, and thousands cross frequently in both directions for commerce, family, recreation, education and services, such as health. Family planning services for low-income women in El Paso have historically been provided by a limited number of health care facilities, such as Thomason General Hospital Family Planning Clinic and Planned Parenthood, with funding provided by a variety of state-administered federally-funded programs.

Data Collection

After obtaining signed informed consent, an hour-long face-to-face baseline interview was administered in either Spanish or English. Participants were offered a small compensation for completing the baseline interview and each of the follow-up interviews. This study was approved by the Institutional Review Boards at the University of Texas at Austin and University of Texas at El Paso.

The baseline questionnaire contained a wide range of items related to the participant's background: marital status, parity, health status, medical history, use of health services, knowledge of pill use, contraceptive history, and reproductive intentions. The second and third interviews took place approximately three and six months after the initial interview. These interviews were administered via telephone and lasted 15-20 minutes. Women were asked about changes in their contraceptive practice during the prior three months, the source and number of pill packs obtained if she resupplied since the previous interview, and, again, how she long she planned to use OCPs. The final (fourth) interview was scheduled approximately nine months after the baseline interview and was conducted in person. In total, we recruited 1046 OCP users who completed baseline interviews. Of the 941 OCP users who completed the last interview, 216 discontinued use during the approximately nine month period of observation. Among those who discontinued use, 15% did so because of method failure, 19% stopped in order to become pregnant, and *nearly 60% stopped because of side effects or other reasons*. Only 14 women reported stopping OCPs in order to switch to another method of contraception

The Qualitative Component: Open-ended questions in the last interview of the Prospective Study

In the baseline instrument, a series of closed-ended questions were included to assess women's knowledge of pill use and practice. These questions included knowledge of the mechanism of action of hormonal contraception, contraindications to the pill, and positive and negative side effects of pill use. While developing the final interview, a preliminary analysis of women's answers to these knowledge questions found that, in general, their knowledge about the pill was very low. A series of open-ended questions to the final interview was then added to explore further what women in the study believed about the pill and its effects on the body. Among a number of questions, respondents were asked to describe how the pill works in a woman's body to prevent pregnancy, and if they knew of any serious health problems that could result from taking the pill, as well what they knew or had heard of the positive and negative effects associated with the pill.

After approximately 50 final interviews had been completed, two members of the research team,

using a grounded theory approach, developed a coding scheme for each of these questions. The codes, therefore, emerged from women's responses rather than from any a priori assumptions about their answers. Interviews completed after this first round of coding were then coded in the field before being submitted for data entry. Coding descriptions were refined based responses after the first 50 responses. Finally, after completion of the last interview, a review of all the responses was made and resulting codes to ensure consistency across the data collection. New codes based on the "other" categories were created, if warranted.

Cultural Beliefs about Reproductive Anatomy and Physiology

In addition to taking into account the influence of culture on body knowledge and beliefs, any examination of adherence and continuation must consider the cultural acceptability of methods. Acceptability is not acceptance, but rather the compatibility of the method with individual and group values, norms, and beliefs. Acceptability means consonance with a sense of well-being. In 1973, the World Health Organization suggested that methods are assessed by potential adopters in terms of their qualities or attributes, which include gender of user, mechanism of action, mode of administration, route of administration, effectiveness, safety, duration of action, organs implicated, provider or self-administration, requirement of an examination, frequency of use, physical attributes; ease of use, coitus-relatedness, and side effects. The importance and meaning of each attribute varies among individuals and cultures. The ultimate acceptability of each method depends on the potential user's cost/benefit assessment of all the attributes perceived as important. In addition, health, age, parity, lifestyle, and motivation to avoid pregnancy influence how a method and its attributes are assessed (WHO, 1973; Polgar & Marshall, 1976).

If any of the important attributes of OCs are perceived negatively by a woman, this may directly affect use-effectiveness and adherence. For example, if a woman or couple are concerned that the "medicine" contained in the pill will harm future offspring, or that a pill is not as effective as an injection, or that the effect will be permanent or cause impairment of future fertility, or that the hormones contained in the pill will cause cancer, these fears and beliefs may influence her motivation or commitment to correct use.

Side effects have been shown to be the most salient attributes in OC acceptance and continuation. Side effects and how they are perceived, experienced, and interpreted are also important factors in use effectiveness/adherence. This, in turn, depends to a large extent on the previously mentioned issue of beliefs and knowledge of reproductive anatomy and physiology. Such knowledge and beliefs may combine correct and erroneous assumptions and may cause a woman to fear alterations in her body, such as changes in bleeding patterns. In other cases, these beliefs may be responsible for a misinterpretation of the mechanism of action of OCs. Both of these possibilities can negatively affect use because women' concerns and understanding of the method serve as barriers to appropriate action/correct use.

An interesting example of how body knowledge can influence contraceptive initiation and adherence was illustrated by Shedlin and Hollerbach (1981). Research on traditional fertility regulation in Central Mexico in the 1970's documented the belief that conception occurs when the "blood" of the man joins with the "blood" of the woman in the "stomach" (or uterus). The pill was believed to weaken the woman's blood so that it could not join with that of the man. Pills were thus "missed" periodically to permit the woman's blood to "get stronger" because, in most traditional cultures, weak blood is believed to cause susceptibility to illness. Cancer, and problems caused by the accumulation of pills in the body were also cited as concerns with the

"medicine" in the pill (as well as in injectables). In this case it was particularly clear that incorrect knowledge and traditional beliefs interfered with women's adoption of, and adherence to, their OC regimen. Although instructions for use were understood, those instructions did not take into account the womens' lack of knowledge of the internal map of their bodies, their beliefs about blood, or how conception occurred. There was little provider awareness of how women (and their partners) understood the mechanism of action of the method or their concerns about specific side effects such as cancer and even future fertility. The way side effects and therefore the personal assessment of a risk/benefit ratio of OC use was perceived, represented an important factor in determining decisions to begin use of a method and adherence to recommended regimens.

What makes this early study especially interesting is the comparison of these findings from Mexican women living in Central Mexico in the 1970's with few informational options, to findings from our study in 2006-8 among Mexican origin women living on the Border with numerous sources of information (and misinformation) easily accessible. The following discussion raises numerous issues about both structural and cultural factors influencing women's understanding of oral contraception.

The open-ended questions in the final round of the Contraceptive Access Survey yielded a wealth of information regarding the womens' range of knowledge and understanding about their bodies and the mechanism of action of OCs. Not surprisingly, rather than the almost homogeneous responses of the Mexican women in the 1970's who also had access to OCs through a community-based family planning program in their town, the women in El Paso demonstrated a far more detailed knowledge of their bodies, a wider vocabulary for anatomy and physiology, and more, but decidedly uneven, information about hormonal contraception. They also demonstrated a wider range of misunderstandings and erroneous assumptions about the mechanism of action of OCs.

Assessing (and distinguishing) "knowledge" and the role of traditional beliefs in interpretation and integration of new information is inherently difficult. It is all the more so in the context of different cultural frames of reference. In this study, we dealt with (theoretically) different cultural frames with considerable overlap, reflected in the language used to probe and respond in the interviews. While the interview matched local Spanish equivalents to English, we acknowledge that all vocabulary reflects context, and that the same word, even matched by careful translation (blood = *sangre*) may not occupy exactly the same space in a semantic field. This is equally true of close cognates (medicine = *medicina*). Technical terms in either language may have been acquired informally, or formally with little explanation resulting in little understanding of their meaning within the context of medical science. Use of a technical term (hormones/*hormonas*, for example) does not guarantee underlying knowledge of all that the term implies scientifically. Moreover, in a context of bi-lingual influence and language mixing, a complex dynamic is created where cross-border service access, media, informal information channels and cultural factors all shape vocabulary and meaning.

An additional aspect of this systemic approach to understanding knowledge about the body and the mechanism of action of hormonal contraception through language use is to acknowledge the difference between denotative and metaphorical meaning. Modern science of course aspires to the exclusive use of the former, while Hispanic cultures employ metaphor to a greater degree (Zúñiga, 1982, Berdes and Eckert, 2007). Beyond the scope of this paper is the question of how knowledge changes, and how language is both an indicator of change as well as a screen for the lack of it. For example, the acquisition of new words may imply a new concept, or matching to an existing, erroneous concept.

We note, therefore, the importance of viewing comments reflecting knowledge and belief as elements of a system, which must be treated as such. The methodological questions raised by these language considerations are acute, but not intractable. It is in part the goal of this paper to demonstrate that comprehensive analysis can be achieved and that attention to a range of beliefs may bring an underlying system into focus.

The following categories and quotes (translated) are illustrative of this range of language, interpretation and understanding of what the women were told in clinics, pharmacies; from providers, TV, friends and family on both sides of the Border (as El Paso and Juarez have been one metro area comprised of these sister cities).

Beliefs About the Mechanism of Action of OCs

Nearly three in ten of the women (n=268/940) who answered the open-ended question about how the pill works stated that they did not know. For those who answered this question, a frequently cited explanation of the mechanism of action of the pill was that it "tricked the body into believing it is pregnant". This clearly repeated phrase seems an easy way for providers to "educate" their clients, but is obviously not sufficient to prepare women to make informed decisions about their contraception, to evaluate side effects or to assess the validity of what they hear from the media, friends, and other non-medical sources. "(The hormone) tricks the egg into thinking it is pregnant and does not pick up the sperm", explained one woman.

Women were generally familiar with the term "hormones", and many knew that somehow the hormones affected ovulation, eggs, and sperm, but many said they did not know what hormones were or where the hormones worked in the body to prevent pregnancy. Some women stated simply that hormones were "cells in the body". "The contraceptive pill has hormones but I don't know what they are", explained a respondent. Hormones were said to "stay in the vagina for when the sperm enters to eliminate it". Many of the women simply stated that they affected "all the body".

The most frequently cited incorrect explanations for mechanism of action of the pill was that the hormones or "medicine" killed or incapacitated the eggs as well as the sperm, ("…when the sperm of the man enters the vagina, the contents of the pill kills the sperm."), blocked the sperm, blocked the uterus. One woman offered that the pill "forms a little fabric between what is the uterus and the ovaries so that the sperm cannot pass...". Another stated, "the pill gets into the egg to freeze it and you don't get pregnant". One woman stated that the pill is made up of "curative herbs"," it affects the strength of the sperm of the man to be able to cause pregnancy…". An acid in the pill was also said to kill sperm as well as a "toxic substance to kill what we have", and "a chemical" that destroys the egg. Another said that the medicine in the pill covers the eggs so that the sperm cannot enter. One woman, however said, "kills the egg?, no…I don't believe that...it kills the desire to have relations!"

While many women believed that the pill does not affect the blood, as in the 70's, others stated, for example, "It affects the blood because it enters the blood". One respondent offered, "it affects the blood by maybe thinning it out because of the blood clots". Another explained that she heard that "from taking so many pills the blood carries cancer to the breasts". Some said simply, "all pills affect the blood".

Again, we hear that the pill is medicine "because it comes from laboratories and it's for your well being"; "Medicine is anything that helps the body to function better; the pill is a medicine because it is prescribed to regulate the period or for cysts on the ovaries and in menopause

when hormones are missing". Another woman stated, "The pill is made of one part herbs and another of experiments that they've made…". One woman stated, however, that the pill was not medicine because she was not using it to improve her health: "…all to the contrary, I'm contaminating myself, but what else can I do?"

The relationship of length of use to problems, namely cancers, was salient throughout the interviews. The uterus, kidneys, liver, stomach and other organs were listed as at risk from long term use, specifically gall stones, headaches, blood clots, and vaginal infections.

An interesting quote from one of the current OC users also echoed another concern described by Shedlin and Hollerbach in Central Mexico and elsewhere in Central America (Shedlin, personal communication, 2010) decades ago, that by taking pills for any length of time, they would accumulate or "fall into the same place and cause a wound/sore, like accumulating in the uterus".

Beliefs About Non-Contraceptive Benefits of OCs

The most frequently noted benefit of the pill was the effect on the menstrual cycle, including regulating, shortening, decreasing severity, cramping and bleeding. Effects on the skin were also salient in their lists, e.g. "It helps my skin; it's no longer so dry". Effects on weight, hair, sexual desire, headaches, breast development, mood, hormone balance and effects on symptoms of menopause were listed. Some women noted protection against vaginal infections, breast cysts, ovarian inflammation and cyst prevention or reduction. Protection from some cancers was also listed but by less than 7% of the sample. Many of the responses listed multiple benefits:

> "They say it stops hair from falling out; if you put it in shampoo, the hair will shine more"
>
> "Yes there are times when the pill makes you thinner; you get less sick because I figure they contain something of vitamins or something like that; I even believe it takes away headaches…there are less possibilities of uterine cancer...they also help to prevent inflammation of the ovaries, breasts develop more and they are good for your health"
>
> "…it regulated the period, increases sexual desire, hair becomes very pretty"
>
> "…one feels more secure on the pill to have sexual relations without protection"
>
> "avoids uterine cancer, not that it can't happen but it is less likely. You have less cramps, the period is more exact, it takes away pains around the waist, and the menstrual period is shorter and less heavy"
>
> "..hormones help us in the body with the state of mind ("*estado de animo*")

Almost 14% of the respondents stated that they did not know of any benefits or that there were no benefits: "positive things? I don't think there are any"; "…never heard anything positive about the pill, only negative things but not many."

Negative Side Effects Either Heard About or Experienced

Not surprisingly, the most frequently cited negative side effect of the pill was weight gain and the associated increase in appetite. Conversely, other women said weight loss and a decrease in

appetite was the problem, but far fewer. Migraines and headaches were the other most cited negative effects. While some women noted improvements in their skin and hair, others complained of skin problems ("acne emerges") and hair loss. Hormone regulation was given as a positive effect but also listed here as hormone imbalances. The pill was also said to decrease libido, cause vision blurring, tenderness in breasts, itching, abdominal pains, increases in blood pressure, insomnia, spotting and bleeding, thinning of the blood, fainting spells, nausea, depletion of vitamins and minerals, decrease energy, and cause reproductive cancers as well as heart attacks, strokes, palpitations, and blood clots. Aches, pains, cramps, numbness and swelling of hands, feet, legs, and uterus were mentioned. Impaired future fertility was also mentioned ("they battle more to get pregnant"), as were effects on the "nervous system" including mood swings, depression, anxiety and stress. Symptoms of pregnancy and "morning sickness" were also attributed to the pill. Less than 4% stated that there were no negative effects of OCs.

Some of the comments included:

> "I believe it is like anything, it has to cause damage in something but I don't know in what…"
>
> "..to smoke and take the pill…more likelihood of cancer; more risk if you smoke although there are also risks if you don't smoke. Everything that enters the body (medicines, chemicals) that isn't natural has some effect. Heredity has much to do with this…"
>
> "…causes problems in the reproductive apparatus…"
>
> "…they lower self esteem…one feels little, it causes depression"
>
> "First of all, what I feel when I take it, I don't have any desire to have relations…the hair begins to lose brilliance…varicose veins come out and itch…"
>
> "…legs hurt a lot, they cause nausea, headaches, women get fat, sometimes they lose vision; they say they bring cancer in the breasts and the uterus if one takes them for many years. They can damage the blood from so much hormone in the pill, making it more red and even getting the nerves sick"
>
> "damage the kidneys"
>
> "it doesn't have an effect in some women and they get pregnant anyway"

Vocabulary vs Understanding

A paradigm case of the role of language in this process, both for respondents and investigators, is hormone/*hormona*. Unlike blood/*sangre* or even medicine/*medicamento* it is a new term. Respondents use it freely. But their extended comments reveal a dense cognitive web that mixes isolated scientific terms and facts with traditional and individual understandings. Most agree that COCs contain hormones, which are medicines, because they improve health, and doctors prescribe them. This is consistent with the wide-spread belief that the hormones in the pill are essentially spermicides. Many respondents also combine this "medicine" view with the "residual accumulation" idea, which then requires that the body rest and recover. As to where in the body the hormones act, respondents tend to agree that the hormones are somehow present in all of the body (otherwise how would they have other effects, both positive and negative, such as stimulating/impeding hair growth, acne, or general skin texture?). Opinion seems divided on

the effects of hormones on other organs. Some respondents believe that the pill can cause cancer, typically of organs associated with reproduction (uterus and breasts are most often mentioned, with kidneys and liver getting an occasional mention). Yet at the same time other respondents observe that COCs apparently have no effect on other organs (stomach, lungs, heart, etc). The relationship between hormones and blood is interesting. Hormones are carried by the blood, but do not affect it directly.

Representative comments include:

> It affects certain systems of the body, maybe the liver or kidney because of taking so many. Taking the pill for a long time affects the uterus. The uterus becomes rigid (freezes) because of the pill and it is difficult to conceive.
>
> *Afecta cierta sistemas del cuerpo al la mejor el hígado o el riñón por estar tomando tantas. Tomar la pastilla por mucho tiempo afecta la matriz. La matriz como que se congela por tanto pastilla y es difícil no embarazarse.*
>
> No, it doesn't affect anything else, I've never heard anything like that. I have heard that the pill can cause harm but it doesn't affect the blood or the organs.
>
> *No, no afecta nada (órganos/sangre), nunca he oído nada de eso, he oído que la pastilla cae mal pero, no afecta la sangre ni los órganos.*
>
> The pill goes from the stomach to the abdomen through an intestine, it stays there in the uterus, it goes on to the vagina and waits for the sperm there to kill it. The pill is a medicine because if you don't take it, you get pregnant. Hormones are what give energy to the body and it needs them to continue living because otherwise you would be weak and depressed. No, they don't affect blood or organs because if they did, they wouldn't be sold.
>
> *La pastilla se va del estomago al abdomen por una tripa, allí se queda en la matriz, se extiende a la vagina y allí se queda esperando la esperma para deshacerla. La pastilla si es un medicamento porque si no la toma, se embaraza. Hormonas, son lo que le da energía al cuerpo y las necesita uno para seguir viviendo porque si no uno estuviera todo débil y depresivo. No, no afectan la sangre ningún órgano porque si no, no las venderían.*

In this context, hormones as spermicides makes some sense as an explanation of their ability to prevent conception. Using the word, but lacking a comprehensive and accurate picture of what hormones are and how they act, the spermicide (or alternatively, barrier) explanation allows the total picture to remain basically unchanged.

DISCUSSION

It seems clear from this limited qualitative exploration within the larger Contraceptive Access survey that fertility regulating behavior in our Border sample is not solely affected by contraceptive access, family planning information or even much cited cultural constructs such as *familismo* (the importance of family) and related fertility desires and intentions. There also is no question that the Mexican-origin women living in El Paso, Texas have vastly more information about their bodies, about hormones and about contraception than the Mexican women interviewed in Mexico in the mid-70s. However, for many of these women taking OCs, the numerous sources of information and the many "facts" about contraceptive methods, hormones and their effects on the body are misinterpreted because of inadequate

understanding of the body, of reproductive physiology, and of the hormonal contraceptive mechanism of action.

While women in Mexico in the 70's had far less input (information from one family planning program and a few providers) and were much less formally educated, the bottom line is that, although less detailed and complex, and with more limited contraceptive vocabulary, their concerns were also based on erroneous assumptions about how the "medicine" prevented conception, how it affected their blood, organs, health, and future fertility. It is significant to note that the women today are citing some of the same erroneous ideas about the body as they interpret risks and benefits of OCs. It is also important to note beliefs about how hormones or "medicine" or "chemicals" in the pill, described as "toxic" by some, kill eggs and sperm as well as producing negative side effects on the body. A new element, however, is that today's pill users are also using this misinformation and lack of information to explain both non-contraceptive benefits as well as health risks. Even more interesting is that the pill, or the hormones/"medicine" in the pill, are said to cause both positive and negative effects on the same organ or body part. For example, hormones make hair strong and shiny (especially when dissolved in shampoo as well as taken orally), but hormones for others make hair dull and fall out; hormones protect against reproductive cancers but cause them as well; hormones affect the libido both positively and negatively; and hormones cause weight gain and weight loss while making the skin dry and less dry.

This contradiction should not be lost on providers and educators, signaling that the words are out there, but the physiology is not understood nor communicated by providers, media or friends (the grapevine). Aside from this lack of basic body knowledge, it is also obvious that concerns about such issues as duration of effect, consequences of long term use, and future fertility must still be addressed with potential adopters and users if we are to support use effectiveness, adherence and continuation of oral contraception.

The analysis of respondents' wider picture of how OCs work, and the examination of change (or lack) in this picture over a period of 40+ years in which new facts and new language have been introduced, are interesting and significant in themselves. They also may allow insight into ongoing discussions concerning some concrete questions of OC use and effect. These include possible explanations of (non-)continuation patterns, often argued to be due to either "cultural" or "structural" factors, how best to communicate "new information" to users (without recognizing that "input" is not necessarily "intake"), and policies regarding OCs (prescription vs. OTC). Both the explanation of observed patterns of use and policy recommendations will be enriched through more exhaustive understanding of the information available.

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