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"It's not something you talk about really": Information barriers encountered by women who travel long distances for abortion care

Megan L. Kavanaugh^{1,*}, Jenna Jerman², and Lori Frohwirth¹

¹Megan L. Kavanaugh is a Principal Research Scientist and Lori Frohwirth is a Senior Research Associate, both with the Guttmacher Institute in New York.

²Jenna Jerman was a Senior Research Associate at the Guttmacher Institute at the time of the study. She is now the Director of Abortion Access Strategy with CAPS at Planned Parenthood Federation of America in New York.

Abstract

Objective: For individuals traveling significant distances for time-sensitive abortion care, accurate information about service options and locations is critical, but little is known regarding information barriers that individuals may encounter and strategies for circumventing these barriers.

Study Design: In early 2015, we conducted in-depth interviews with 29 patients who had traveled for abortion care at six facilities in Michigan and New Mexico. We identified information-related barriers that respondents encountered in understanding their pregnancy options and/or where to obtain an abortion between the time of pregnancy discovery, including any contact with a crisis pregnancy center, to the day of the abortion procedure through inductive and deductive analysis.

Results: We identified two logistical information-related barriers—a general lack of reproductive-related knowledge and unhelpfulness on the part of perceived members of the healthcare community—and one broader barrier of perceived stigma within respondents' narratives. Of the seven respondents who did not encounter a logistical information-related barrier, having previous personal or close experience with abortion and internet savviness were both identified as strategies enabling them to circumvent the barriers.

Conclusion: Lack of clear, easy-to-find and accurate information about abortion services and availability represents a key barrier to obtaining an abortion; health care providers play a crucial role in ensuring pregnant patients' right to informed consent within reproductive health care delivery.

^{*}Corresponding author, Megan L. Kavanaugh, DrPH, Principal Research Scientist, Guttmacher Institute, 125 Maiden Lane, 7th Floor, New York, NY 10038, 646-438-8725 (phone), 212-248-1951 (fax), mkavanaugh@guttmacher.org.

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Keywords

abortion; barriers to care; crisis pregnancy centers; nondirective pregnancy options counseling; United States; qualitative

1. INTRODUCTION

Individuals faced with an unwanted pregnancy need complete and unbiased information regarding all of their pregnancy options and about locating and securing additional healthcare. Medically accurate information about what options are available to them is a key first step towards making an informed decision about how to resolve that pregnancy. Health care providers play an essential role in ensuring pregnant patients' right to informed consent within reproductive health care delivery, especially by making sure that patients are given factual, unbiased information on all their options, including parenting, adoption and abortion, as well as referrals to pursue whichever option is best for them – collectively referred to as "nondirective pregnancy options counseling and referral."[1] This is the standard of care endorsed by national medical organizations as well as by the Title X national family planning program[2,3].

Many individuals discover a pregnancy outside of a healthcare setting. In order to pursue the subsequent desired health care service (e.g. pregnancy confirmation, nondirective pregnancy options counseling, abortion care, prenatal care), pregnant individuals must first gather information regarding their options, and they often must do so under time pressure if they think they may want to obtain an abortion. This pursuit of information is one factor that influences the course of a pregnant individual's trajectory of seeking, and ultimately getting into, abortion care [4] but little is known about how individuals gather the information they need. For example, out of a total of 365 women obtaining abortions at one of three sites in Nebraska, 45% had located the site through the internet, while only 6% had been referred there through a health care provider. [5] Complicating individuals' access to direct and accurate information about abortion is that abortion itself is a highly stigmatized health care option. [6] For example, fear of being stigmatized personally may lead those who have had abortions to remain silent about their experience, which may contribute to the promulgation of misinformation about abortion. Stigma also permeates the relationship between a patient and their doctor; in a small study of two abortion clinics in Chicago and New York, only a quarter of abortion patients had seen their primary care provider regarding pregnancy options prior to the abortion due in part to fears of not being supported and concerns about judgment [7].

Many pregnant individuals seek information on pregnancy options from their regular OB/GYN providers, who are often their first point of entry into health care[8]. However, since most OB/GYN providers do not offer abortion care, and many do not provide referrals, [9,10] patients who want more information regarding the option of abortion may be at a disadvantage in this setting. This disadvantage may also affect pregnant individuals who seek care from their primary care providers [11]. In addition, pregnant patients who obtain pregnancy testing or pregnancy options counseling at crisis pregnancy centers (CPCs)—

organizations that provide reproductive-related resources, typically from a religious and antiabortion perspective—may be misled regarding abortion, abortion risks, and the availability of medical services on site [5,12]. Likewise, misinformation about abortion can even occur at the point of abortion care itself, as some pregnant individuals who present to an abortion provider in one of the 18 states that currently mandate counseling including inaccurate or false information for some patients prior to their procedure may be receiving biased pregnancy options counseling [13].

The inability to obtain accurate information about abortion has been documented as a barrier to abortion access [14,15]. However, this barrier has not been explored in depth. Furthermore, this barrier may be exacerbated among those who do not live close to facilities that offer abortion services, because these locations could themselves potentially serve as sources of information for pregnant people seeking abortion-related resources. The objectives of this study were therefore to identify barriers to accessing information about abortion among individuals who traveled out of state or substantial distances and presented for care at an abortion facility, and to identify shared characteristics and/or experiences among abortion patients who did not encounter these barriers.

2. METHODS

2.1 Sample and Data Collection

We conducted in-depth interviews (IDIs) with 29 women seeking abortion services across six facility sites in Michigan and New Mexico. Eligible participants were 18 or older and had travelled from outside of the interview state for abortion services, or from over 100 miles within the interview state. We selected the two study states because of their proximity to one or more states (including Ohio and Texas) that had several restrictive abortion laws in place and because they had relatively fewer abortion restrictions in place than these nearby states, as determined by the 2014 Guttmacher State Policies in Brief [16].

We collected data for approximately five days in each site in January (Michigan) and February (New Mexico) of 2015. Our purposeful sample includes individuals who met the eligibility criteria described above, who presented to the study sites during these data collection timeframes, and who agreed to participate in the study. Clinic staff identified eligible patients and referred patients interested in learning more about the study to the research team. The four-person interview team, three of whom are authors, conducted the approximately hour-long interviews in English in private rooms at the facilities. We obtained verbal and written consent from all study participants. At the end of the interview, participants filled out a short questionnaire on sociodemographic characteristics. Participants received \$50 cash as compensation. Our organization's federally registered Institutional Review Board approved all study protocols and IDI guides.

2.2 Instrument

We developed an IDI guide, which we piloted with six women seeking abortion services in a New York City facility. In order to broadly understand women's experiences with seeking abortion care, we began each interview by asking each woman to describe in detail the time

from when they first found out about the pregnancy through when they walked in the door on the day of the abortion procedure. We then asked how they found information about their pregnancy options, how they chose the particular clinic and sources of information throughout the process of discovering the pregnancy through getting to the clinic for abortion care.

2.3 Data Management and Analysis

We digitally recorded and transcribed all of the IDIs verbatim. We stripped identifying information during the cleaning phase. We developed an initial coding scheme based on the interview guides and existing literature, which we subsequently updated throughout the coding process. Four members of the research team independently double-coded several transcripts and then met to resolve differences through discussion and development of new codes. After this step, at least one researcher coded all remaining transcripts. We used NVivo 10 to organize the data, code transcripts, and generate code reports.

For this analysis, we focused on information-related barriers that respondents encountered in trying to find out about their pregnancy options and/or where they could get an abortion. We consider these information-related barriers to be broadly conceptualized as a "system navigation issue" that impedes an individual's ability to obtain the type of abortion that they desire in a timely manner [14]. After reading all of the transcripts, team members identified preliminary themes related to information barriers and then counted the number of transcripts in which each of these appeared [17]. We created a matrix to track respondents whose narratives included mention of any of the themes. We also created a matrix to track respondents whose narratives *did not* include mention of the two logistical information-related barriers, and we included respondent characteristics in this second matrix to determine whether there were common characteristics shared among respondents who *did not* encounter these barriers.

In the section below, we first provide an overview of the three key themes that emerged related to information-related barriers to abortion care, using select quotes to provide illustrations within each theme. Because respondents described CPCs as both presenting a barrier to obtaining general information about abortion as well as being perceived health care sites where abortion misinformation was used to dissuade respondents from choosing this option, CPCs are mentioned under both of these two latter themes. Finally, we explore characteristics of respondents who did not encounter logistical information-related barriers to understand whether there are potential shared characteristics or experiences among women seeking abortion that may help in overcoming information-related barriers. We identify respondents using pseudonyms; we include age and gestational age of the pregnancy for each respondent to provide greater context to the accompanying quote.

3. RESULTS

3.1 Characteristics

Study participants varied by demographic characteristics (Table). The majority of participants were in their 20s (n=19), were poor or low-income (n=22), had at least one

previous birth (n=20), were in their first trimester (n=18) and had at least some college education (n=19). Participants were split almost evenly between the two interview states. All but one respondent had crossed state lines to reach the abortion facility where they were interviewed. The one remaining respondent had traveled 115 miles within the state to reach the site of care/interview.

We identified two logistical information-related barriers—a general lack of knowledge and information and unhelpfulness on the part of perceived members of the healthcare community—and one broader theme of perceived stigma within respondents' narratives. Of the 29 respondents in the total sample, 22 encountered one or more of the logistical information-related barriers, six encountered both logistical barriers, and seven respondents encountered neither of the barriers. Twelve described experiencing perceived stigma.

3.2 Logistical information-related barrier: General lack of knowledge and information

Overall, 15 respondents described feeling as though they had limited information regarding abortion and where to get an abortion when first confronted with this pregnancy. In some cases, respondents described being generally unaware about options that individuals have when pregnant, including having no knowledge about what an abortion entails or how to obtain one, as well as not knowing anyone in her life who had had an abortion. For some, abortion was a topic that they had never thought about because they assumed they would never need to consider it. Lily connected her general obliviousness about abortion to the relative silence from her peers and school about the topic:

I didn't know anything about abortion clinics. It's not something you talk about, really. You know, it's not something you learn about in school, and it's not something that your friends are like oh, hey, did you hear about this new clinic that opened?

- Lily, age 22, 17 weeks

Even respondents who had some general knowledge about abortion described information about obtaining one as being difficult to find, and, once found, to navigate in terms of accuracy and reliability. For these respondents, lack of access to abortion where they lived and sought other types of health care – as well as to the information that these clinics provide about pregnancy options and abortion – exacerbated their sense of not being able to find information. The following woman had grown up in a large city on the East coast, but was now living in a small city in Texas. She noted the differences between the two environments, and the impact this difference had on her ability to find abortion care:

It was hard to even find any kind of abortion clinic where I'm [living] [...]I was Googling '[national chain of reproductive health clinics],' just abortion clinics in general. Nothing really came up, and I was kind of concerned, because where I'm from, those resources are just there. [...] I didn't think trying to find an abortion clinic was going to be so hard, ever.

– Madison, age 25, 7 weeks

Not living near an abortion clinic made abortion information harder to find, as internet search results are partially based on an algorithm that takes into account a user's geographic location.

A few respondents specifically identified CPCs as perpetuating the confusion around exactly where one could obtain an abortion and what an abortion entails. Eight respondents had sought information and/or services at a CPC prior to presenting to the abortion care site where they were interviewed. CPCs were the first point of contact with the healthcare system for some respondents, and given advertising about the availability of free pregnancy testing and ultrasounds at these sites, they were the initial source of information for individuals deciding whether, and how, to end a pregnancy. However, upon contacting those CPCs, they were unable to get the full range of information they desired:

It was a clinic downtown and all their services are completely free and at that time that was a beneficial factor. So I went there and they gave me a sonogram and tried to talk to me, but I wasn't really trying to hear any of their options because they just kept trying to push for adoption more than help me figure out you know, where I could get an abortion— and then I kind of just pushed them off, I'm like "All right, it's time for me to go because that's not what I want to hear."

- Lucy, age 21, 25 weeks

CPCs effectively served as dead ends for information on abortion for Lucy and other respondents like her who sought to identify where to go to obtain an abortion. Although some respondents were aware that they would not be able to obtain abortion information from CPCs and had opted to visit solely for the free pregnancy test, they were also aware that these sites represented a limited first point of entry for obtaining the health services they needed.

3.3 Logistical information-related barrier: Healthcare community (perceived and actual) unhelpful in linking to abortion information

Thirteen respondents traveling for abortion care in our study described seeking information from the healthcare community but encountering staff who were unhelpful or resistant to linking them to resources, effectively playing the role of gatekeeper to abortion-related information. Respondents described seeking care from their regular OB/GYN provider in private settings or from unfamiliar providers in hospital settings during which assumptions were made about the pregnancy outcome; providers either could not or would not offer information about abortion as an option. The following woman described how her doctor would only see her if she was continuing her pregnancy, referring to a timetable of care more aligned with prenatal care than with options counseling and abortion:

¹We operationalize "healthcare community" in this analysis to include both actual and perceived members of the health care field. Since respondents in our study overwhelmingly described seeking medical resources and information at CPCs in the same manner in which they sought this information in actual health care settings, we group them together in this section to reflect the respondent perspective.

I called my gynecologist's office and they were kind of not really receptive to the fact that I wanted to have an abortion. They said, "Well, you can only come in if you are only eight weeks or further on."

– Jennifer, age 26, 6 weeks

Some providers were described as explicitly steering their patients away from abortion and towards continuing the pregnancy, either with the goal of parenting or adoption. This steering happened across healthcare settings, with a range of providers where women sought care:

The only one I talked to was my gynecologist and she gave me a list of psychologists to go to, but she told me maybe they could help me change my mind, but I don't think so. I don't want to change my mind.

- Jade, age 21, 12 weeks

As expected, this directing away from abortion by a (perceived) member of the healthcare field occurred frequently in the CPC setting. Vanessa, who had visited the same CPC during her prior pregnancies with her two children, described seeking information about all of her options and being clearly guided away from abortion at this particular CPC:

They help teenagers and young adults out, like it's a free pregnancy test. If it comes out pregnant they pray with you and counseling and stuff I wasn't about to tell them I was considering abortion but right away, they kind of throw stuff down your throat they actually even took me to go hear the heartbeat just in case I was thinking of abortion, that's how serious they are and they gave me all these pamphlets about adoption.

-Vanessa, age 24, 5 weeks

Still other providers at CPCs were described as not just steering individuals away from abortion but explicitly providing inaccurate and misleading information about abortion, "*like what could happen if having one or the side effects or the emotional distress from it*" (*Abigail, age 20, 16 weeks*) with the goal of convincing people not to have an abortion.

3.4 Perceived stigma

In the narratives of this sample of respondents who were all traveling to obtain an abortion, several (12) described the process of seeking information about abortion as one in which they continuously encountered general and broad negativity towards abortion. The lack of abortion services close-to-home (real for some respondents, perceived for others) often contributed to their sense that their community did not approve of abortion as an option. The presence of protesters at a few of the interview sites where they ended up obtaining abortion care also added to their impression that the people around them disapproved of abortion.

The absence of easily accessible abortion information and care led some to question the safety of abortion, and whether the abortion facilities that they could find were legitimate. The secrecy surrounding abortion in general, coupled with the inaccessibility of clear information and resources about where to obtain one, created an atmosphere of doubt around abortion:

We just didn't know exactly how any of this worked, what kind of place we were going to be coming to. Is it like a dungeon-like place or what the hell is this place? [...] We were both worried about it being done in a clean place, that wasn't like some place that they were just going to have some barbaric way of doing something.

– Jennifer, age 26, 6 weeks

The barriers of a lack of information, a lack of help from the healthcare community and the perceived stigma of abortion care are, of course, related. Taylor from a small city in Texas related her search for a clinic, highlighting all three obstacles:

Well I called my regular OB/GYN [...] I am pretty sure I want to terminate [...] Of course, they were like, "We don't offer those services." Okay, well can you refer me? My doctor was not able to. My next stop was [national chain of reproductive healthcare providers] [...] They really could not direct me to anybody in the state of Texas. They said that the closest thing that they could recommend would be in Dallas or Fort Worth, and I know that that would probably involve, like I said, a lot of protestors and a lot of judgment that I didn't really want to deal with [...] so that was when I got on Google.

- Taylor, age 27, 6 weeks

3.5 Characteristics of respondents who did not encounter information-related barriers

We examined the narratives of the seven women who did not encounter either of the two logistical barriers to identify shared characteristics or experiences that may have enabled them to circumvent or avoid these barriers. Four of these women described having had a previous abortion, either at the same or different clinic, which provided them with a foundation of knowledge about abortion that many of the other women in the sample did not have. The remaining three women described using, and being comfortable with, the internet to find health information and, specifically, where to go to obtain an abortion. Having some technical savvy with navigating online searches may also be related to the age of these women, as two of the three were in their early twenties.

Three of the seven women also described having had a close friend or family member who had had an abortion, which both helped to provide them with additional knowledge about abortion and abortion care as well as helped to combat the perceived stigma around abortion as a relatively rare and illegitimate healthcare service. However, of note, although all seven of these women did not report either of the logistical information-related barriers, they did not necessarily circumvent the perceived stigma of abortion. Five of them described encountering perceived stigma, often in the form of protesters obstructing their access to the abortion clinic.

4. DISCUSSION

Existing evidence indicates that not knowing where to find abortion care is a common barrier resulting in delays in accessing services; findings from this study provide a fuller understanding of how this barrier is experienced. For individuals with prior first or second-

hand exposure to abortion and individuals who can successfully navigate online information about abortion, overcoming the black hole of information about abortion is manageable. However, for those who do not have this contextual background, the pursuit of information about abortion following discovery of an unintended pregnancy can present a stymying barrier, as many people are not familiar with abortion information and options until they need one. This may be especially true for those who, like our respondents, live in areas where abortion providers have closed or don't exist in the first place [18], as Internet search results—referenced by most study respondents as a major resource for finding information—are influenced by algorithms that account for geographic location, and may include inaccurate or unreliable information about abortion and abortion clinics [19].

Although abortion is a common experience among reproductive-aged women in the United States [20], abortion stigma perpetuates an environment in which accurate information and clear linkages to care are obfuscated. Continued silence around this experience allows many to believe that it is a relatively rare occurrence. This "prevalence paradox"[21] impairs women's ability to access information about abortion from a range of resources, including friends, family, and healthcare providers. Thus, women faced with an unintended pregnancy may not necessarily turn to their social networks for guidance regarding how to obtain an abortion, a strategy commonly employed when individuals are faced with other healthcare-related concerns and decisions [22]. Additionally, findings from this study suggest that even when individuals seek out abortion information and referrals from their initial points of entry within the healthcare community, those individuals and institutions often act as gatekeepers, discouraging or refusing attempts at obtaining knowledge and linkages to care.

Given the vacuum of information about, and the stigmatized nature of abortion, health care providers can play a key role in combating these barriers by linking women to resources. Indeed, nondirective pregnancy options counseling and referrals should be available to all pregnant individuals seeking pregnancy-related resources in health care settings [2,3]. OB/GYNs especially, whom many women perceive to be a key source of information on reproductive-related health issues, are uniquely well-positioned to provide unbiased and accurate resources and referrals for abortion care. However, referrals from staff at publicly funded family planning clinics are an important complement to physician referrals, especially in rural areas [23]. Referrals can fall along a spectrum from taking on a passive role to an active, caring one, but a key tenet undergirding best practices in referral behavior is the provision of information in a unbiased manner [24]. Findings from our study and others' [25] indicate that some health care providers are not currently meeting the needs of women who seek abortion-related information.

CPCs capitalize on both the lack of available information and women's general lack of exposure to abortion and present themselves as legitimate health care providers that offer care to pregnant women. In some instances, CPCs represent a dead end for information about where and how to obtain an abortion; in others, they represent a source of misleading or inaccurate information. Although some respondents appreciated obtaining free pregnancy tests at these sites, many described feeling pressured to give birth, including being provided with misinformation about abortion risks. With CPCs being much more widespread than abortion services [26], there is a greater chance that a woman will encounter these

potentially misleading resources rather than ones that provide accurate information; even for those opting to continue a pregnancy, there is no evidence to suggest that CPCs provide accurate information about pregnancy, informed consent, or acceptable care for pregnant individuals. One recent study in Louisiana, which included respondents from both abortion and prenatal care sites, found that few pregnant women reported visiting a CPC for their pregnancy, indicating that these sites played a negligible role in their pregnancy decision-making [27]. However, CPCs have the potential to cause delays in obtaining abortion care, interfere with the desired type of care, and mislead individuals regarding pregnancy outcome options [26].

One limitation of our study is that the findings represent the perspectives of abortion patients who were able to overcome information-related barriers in order to access abortion care in a clinic setting; we can therefore not generalize these findings to the experiences of women who are unable to surmount these barriers. In addition, our sample intentionally includes abortion patients who had to travel for care, often due to clinic closures in their home areas, and may predispose them to experiencing difficulties finding providers and information about them, thus overemphasizing the role that clinic closures play in obstructing women's access to abortion information. Geographic and cultural differences between the two states where abortion patients were recruited may limit our ability to draw conclusions about the study sample as a group; we are unable to account for these undetectable differences in this study. Because our sample is limited to those who presented to the study sites during the data collection periods in each state, we may not have reached full saturation of themes with our final sample size of 29.

This study highlights the gap in information and care linkages between the place of pregnancy discovery and the location of abortion services among those who travel to obtain abortion care. Our findings highlight the importance of accurate and accessible information about abortion and abortion care locations in facilitating individuals' access to desired and timely care. Although high levels of decisional certainly have been documented among abortion patients [28], future research should examine the extent to which misleading or inaccurate information about abortion is associated with uncertainty about the decision. Because the majority of women do not have detailed knowledge of abortion before experiencing an unintended pregnancy, and because of the need for timely information in order to make an informed decision about pregnancy outcomes, it is imperative for health care providers to be ready, willing, and able to provide patients with the full spectrum of resources and referrals for pregnancy and abortion care. This is especially true for women's health specialists that do not currently provide abortion care, as our findings indicate that direct referrals from trusted health care providers, in the context of nondirective pregnancy options counseling, more clear and accurate information about abortion care and accessibility being made available readily online, and prior experience with abortion may facilitate quicker access to abortion care.

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IMPLICATIONS

Women's health care providers should provide their patients with the full spectrum of resources and referrals for pregnancy and abortion care; recent federal guidelines proposing to restrict abortion counseling and referral at Title X-funded facilities would only exacerbate the current challenges that pregnant patients encounter when seeking abortion-related information and further decrease linkages to timely, desired abortion care.

Table:

Characteristics of respondents who traveled across state lines or over 100 miles within the same state for abortion care

Characteristic	Experienced logistical information- related barriers (N=22)	Did not experience logistical information-related barriers (N=7)	Total N (N=29)
Age-group			
18–19	1	1	2
20–24	9	2	11
25–29	7	1	8
30–34	2	2	4
35–44	3	1	4
Race/ethnicity			
Hispanic	6	4	10
White	9	1	10
Black	5	2	7
Other	2	0	2
Family income as % of federal po	overty level		
<100%	10	4	14
100–199	6	2	8
200	6	1	7
Educational attainment			
<high school<="" td=""><td>0</td><td>1</td><td>1</td></high>	0	1	1
High school graduate/GED	7	2	9
Some college/associate degree	10	4	14
College graduate	5	0	5
Number of prior births			
0	7	2	9
1	6	0	6
2	9	5	14
Gestational age *			
0–7	8	3	11
7.5–12	6	1	7
13–19	4	1	5
20–25	4	2	6
Interview state			
Michigan	12	3	15
New Mexico	10	4	14

Gestational age was self-reported by participants