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Women's perspectives on screening for alcohol and drug use in prenatal care

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Abstract

Background—Screening for alcohol and drug use in prenatal care is widely promoted in the United States as a public health strategy for reducing alcohol and drug use during pregnancy. However, the published literature does not consider women's perspectives or the potential negative ramifications of screening.

Methods—Twenty semi-structured interviews and two focus groups [n=38] were conducted with a racially/ethnically diverse sample of low-income pregnant and parenting women using alcohol and/or drugs in a northern California county.

Results—Most women were averse to having drug but not alcohol use identified and were mistrustful of providers' often inconspicuous efforts to discover drug use. Women expected psychological, social, and legal consequences from being identified, including feelings of maternal failure, judgment by providers, and reports to Child Protective Services. Women did not trust providers to protect them from these consequences. Rather, they took steps to protect themselves. They avoided and emotionally disengaged from prenatal care, attempted to stop using substances that could be detected by urine tests prior to prenatal care visits, and shared strategies within social networks for getting the benefits of prenatal care while avoiding its negative consequences.

Conclusions—Considerations of the public health impact of screening for drug use in prenatal care should account for the implications of women's physical avoidance of and emotional disengagement from prenatal care, specifically the direct effects of late, limited, and no prenatal care on pregnancy outcomes and missed opportunities for health promoting interventions.

Keywords

drug abuse screening; pregnant women; illicit drugs; consumer involvement; prenatal care

Introduction

Universal screening for alcohol and drug use in prenatal care is promoted as a public health approach to alcohol and drug use during pregnancy (ACOG, 2008; Chasnoff, 2008; Kennedy, Finkelstein, Hutchins, & Mahoney, 2004; Littaua, Ramstrom, & Jocson, 2006; WSDOH, 2008). Women's perspectives on screening have not been considered but are important because women who drink 7 or more drinks per week and who use drugs are overrepresented among women who deliver with late, limited, and no prenatal care (Hankin, McCaul, & Heussner,

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2000; Kelly et al., 1999; Maupin et al., 2004; Melnikow, Alemagno, Rottman, & Zyzanski, 1991; Pagnini & Reichman, 2000) and little is known about barriers to care for this population.

Research about barriers to prenatal care for women who use alcohol and drugs has been primarily conducted with low-income women and suggests that pregnant women who use drugs face difficulties with health insurance and transportation, fear being reported to Child Protective Services (CPS) and, at times, prioritize drug use over prenatal care (Klein & Zahnd, 1997; Milligan et al., 2002; Murphy & Rosenbaum, 1999). Although screening could influence decisions about prenatal care attendance, these two literatures – universal screening and barriers to prenatal care - have developed separately. At the nexus of the two is the question of screening acceptability: how does the possibility of being identified as a pregnant alcohol and/or drug user through screening in prenatal care influence prenatal care attendance and engagement?

Research has been conducted in related areas, such as acceptability of screening for alcohol misuse in dental offices and emergency departments (Miller, Ravenel, Shealy, & Thomas, 2006; Schermer, Bloomfield, Lu, & Demarest, 2003), screening for domestic violence (Ramsay, Richardson, Carter, Davidson, & Feder, 2002; Renker & Tonkin, 2006), and mandatory testing for HIV among pregnant women (Fielder & Altice, 2005). This research indicates that screening is acceptable to some, but not others; and in certain settings, not others. People not wanting to be identified have responded by avoiding care if they think they will be subject to mandatory testing (Fielder & Altice, 2005) and/or concealing problems if screening relies only on verbal disclosure (Renker & Tonkin, 2006). Importantly, the possibility of being identified as drug users by providers is a reason some people who use drugs avoid health care (Fitzgerald, McDonald, & Klugman, 2004; Murphy & Rosenbaum, 1999). These findings raise questions about the acceptability of alcohol/drug screening in prenatal care and the implications of excluding women's perspectives. No research has been published about women's perspectives on alcohol/drug screening in prenatal care or how the possibility of being identified as a pregnant *alcohol or drug user* through screening influences prenatal care attendance and engagement.

Methods

This paper is based on analysis of data collected as part of a larger qualitative study on barriers to prenatal care among pregnant women who use alcohol/drugs in which concern about being identified as a *drug user* by prenatal providers emerged as a key finding. Human Subjects approval was obtained from the University of California, Berkeley and written informed consent was obtained from all study participants.

This study took place in a California county where all public and some private prenatal providers conduct universal alcohol/drug screening using a combination of paper screening and supplementary urine testing. A purposive sampling strategy was employed with the intention of selecting women who were currently using alcohol/drugs and women with a history of alcohol/drug use during pregnancy who could speak to challenges pregnant women who use alcohol/drugs face in relation to entering and continuing prenatal care. We recruited 38 women who were either pregnant or new mothers (youngest child less than two years) with current alcohol/drug use or history of substance abuse. Participants were recruited from programs serving low-income women, including substance abuse treatment, the Women, Infants, and Children (WIC) Program, and a home visiting program for pregnant women. Staff at participating sites recruited women through posted flyers and a standardized script.

Twenty semi-structured interviews (Bernard, 1995) and two focus groups, with 8 and 10 women each, were conducted between September and December 2006. Interview and focus

group guides addressed similar topics: thoughts about and experiences with prenatal care; barriers and facilitators to prenatal care for women who use alcohol/drugs; and how the health department and providers could motivate women who use alcohol/drugs to enter prenatal care earlier, including ideas for a media campaign promoting prenatal care. Women were treated as study participants, key informants, and collaborators in creating the media campaign. Women were also asked close-ended questions about their demographic characteristics, timing of prenatal care entry, and substances (alcohol and type of drug) used.

Interviews lasted approximately sixty minutes and were conducted at participating agencies and nearby sites women identified as safe places to talk. Focus groups lasted approximately ninety minutes and were conducted at treatment agencies. Focus groups were facilitated by the lead investigator and supported by a note-taker. Interviews and focus groups were recorded. Participants received $30 and $20 Target gift cards for interviews and focus groups, respectively.

Data were transcribed verbatim. Coding was completed in a multiphase, iterative process beginning while data collection was ongoing, generally following procedures outlined by Miles and Huberman (Miles & Huberman, 1994). Analysis focused on women's thoughts about, experiences with, and actions taken in relation to the possibility and actuality of being identified as an *alcohol* or *drug user* by prenatal providers. Codes were developed by the lead investigator in an inductive process where themes emerged from the data (Miles & Huberman, 1994). Further refinement of codes and fitting of codes with the data was completed in consultation with the co-investigator. Disagreements about theme designation were resolved via consensus discussions between the two investigators. Case studies, cross-case studies, and typologies (Patton, 2002) were used to explore the themes in more detail and identify variation in women's responses to similar concerns. Memos were used to group themes into larger categories and determine how component parts of categories fit together.

Validity checks included time spent in the study setting, respondent validation, triangulation, and a check for researcher reactivity (Maxwell, 2005; Miles & Huberman, 1994). Respondent validation included multiple rounds of feedback on study findings from key stakeholders in the county, including additional women who used alcohol/drugs during pregnancy, health care providers, treatment providers, and CPS. Triangulation included use of both interviews and focus groups as well as comparison of qualitative findings to county administrative data about screening and CPS reporting. Additional analysis of a key finding relating to fear of CPS was conducted to check for researcher reactivity (Maxwell, 2005). No question in interviews or focus groups asked about CPS. To ensure that findings related to CPS did not come from a single inadvertent leading question or from a single interview in which this emerged as a dominant theme, we counted the number of open-ended questions in the interview guide in which fear of CPS was mentioned (17/24) and the number of interviews and focus groups (18/20 and 2/2 respectively) in which fear of CPS was mentioned.

Sample Characteristics

Participants included 38 English-speaking women [See Table 1], primarily methamphetamine users [See Table 2]. The sample was racially and ethnically diverse, with low-levels of education. Most had more than one child, although few lived with all children. Most received some prenatal care.

Results

Thematic Findings

The process of being identified—Women worried that if they attended prenatal care, providers would identify their drug use. Some expected that providers would "find out" or somehow just "know" they were using. Women described the strategies providers used to identify them such as asking questions about drug use and testing their urine samples for drugs. When providers asked questions about drug use, women not wanting to be identified tended to deny use. Even when women chose to not disclose use, most feared and many experienced providers testing their urine for drugs, often without their knowledge or consent. They did not report worrying that providers tested for alcohol. Women reported often learning that their urine was tested only when confronted with positive results.

> Every time I went, they did a pee-test on me and never told me. Like the county… they don't tell you that when you go sign up for Healthy Start and all that stuff that they're testing you for everything you can think of…, cocaine, barbiturates, meth, all that. They don't tell you that. They test you, and tell you you're pregnant and then, oh, by the way, did you know your test was dirty for cocaine?

Additionally, women indicated that when they informed providers that they had either stopped or were not currently using drugs, providers sometimes tested their urine anyway, seemingly to confirm reports of cessation.

Expected consequences of identification—Women expected that having drug use identified by providers would expose them to adverse psychological, social, and legal consequences. These concerns related primarily to drug and not alcohol use.

Generally, women did not want others to know they were using drugs during pregnancy. They were concerned with how they would feel about themselves if others learned of their use. They consistently used words such as "guilt", "shame," and "embarrassment" to describe feelings related to being identified. Feelings included "guilt," a fear of confirmation that they had harmed their fetus through drug use, and "shame", a concern about violating expectations about motherhood by using drugs while pregnant. These feelings connected to women's senses of whether they deserved to mother their children.

> In your heart you know you don't deserve that baby…because look at what you've done to this baby.

Attending prenatal care while using drugs also raised the possibility of "embarrassment," of having violations of expectations of maternal behavior, specifically unmanaged drug use, made public.

> You're pregnant, how embarrassing to get busted for bein' high.

Among women for whom drug use was made public, this occured when providers confronted them with positive urine test results in front of family or partners.

> Then the doctor came in and my grandma was in the room with me and the doctor goes, are you still usin' drugs?… My grandmother was all, ohh, god. She was disappointed. He didn't even tell my grandma to leave the room or nothing.

Many women expected providers to judge or look down on them for having used drugs and for their inability to immediately cease all drug use. However, regardless of how providers actually responded, women feared being identified because they were unsure how providers might respond.

> It's not something you want people to know. Any woman, or man who has never used, or didn't use during pregnancy is judgmental. Doctors look down on you.

While women feared and took steps to avoid experiencing judgment, some were greeted with "understanding." "Understanding" included providers giving them credit for progress in reducing use rather than expecting immediate cessation.

> They were really understanding…They impressed upon me not so much I was perfect or that I did everything perfect, but that I attempted to, it was progress rather than perfection.

The social and legal consequences women worried about included being: arrested, forced to have an abortion, terminated from a prenatal care program, and reported to CPS. Women viewed providers identifying drug use as putting them on a path to these consequences. Rather than viewing providers as sources of protection, many women considered providers sources of punishment. A few reported receiving information and tangible support from providers that seemed to increase their chances of keeping their babies or reuniting with previously removed children. However, most did not expect providers to be on their side. Instead, women expressed concern about provider trustworthiness.

> With me being pregnant, obviously, you can't trust, you don't know who you can trust, you've heard other people going through their pregnancy and hearing horrible stories about the doctors turning on them and then you hear, I've had people in my life who've been to the doctor while they were using and they've had…experiences, where the doctors have helped them, but us, as users, don't know who we can trust, and we're not willing to take that chance.

Most importantly, women did not trust providers to keep information about their drug use confidential, specifically from CPS. Women's overwhelming concern was that if identified, providers would report them to CPS. This concern stemmed from past experiences of being reported after disclosing drug use, having use discovered by providers, from other women's experiences, and from providers' stories about other women getting arrested or losing children for using drugs during pregnancy and telling them they would be reported if they did not enter treatment or had additional positive urine tests.

> [When] I was almost five months pregnant and they were already telling me, you know, you've been testing positive for meth and marijuana and so, if this happens in your next trimester, then you're gonna be CPS involved.

Some saw urine tests as something providers did to check the baby's health. For others, however, mistrust extended beyond what providers were required to do if they identified drug use during medical care. They saw providers' efforts to identify drug use as connected to CPS reporting rather than treatment.

> They never once referred me to a drug program, not once gave me any kind of information, didn't even attempt to, but she gave me a referral to quit smoking, twice, as a matter of fact. Then, once I…had my baby, they wanted to take her from me. Right then and there….If you guys are so concerned with my child, with keep[ing] me away… and so worried about my child's well-being, why didn't you do anything while I was pregnant, why didn't you refer me to some kind of program?

Balancing prenatal care attendance with risk of being identified—Women individually and collectively sought to take back control over interactions with prenatal providers. They sought to get what they wanted from pregnancy - a healthy baby – while avoiding the negative consequences of being identified - CPS reporting and child removal – and shared strategies within social networks for accomplishing these goals.

To avoid having drug use identified through urine tests, some delayed entry into prenatal care and skipped appointments. Women shared the belief that it was necessary to stop using drugs before attending prenatal care. Therefore, many delayed entry to care. Many women, especially women with previous CPS involvement, stopped or tried to stop drug use before entering prenatal care to avoid being identified and thereby avoid being reported to CPS.

> 'Cause I was using, [I] d[id]n't want to go because [I] hear[d] all this stuff about how they automatically take your kids and stuff…I waited till all my bloodwork stacked up together and went, went in at once. Made sure I was clean before I went in and it took me days and days to go in.

A few planned to stop using before entering care, but had not successfully done so by their third trimester. These women either entered prenatal care during their third trimester or delivered without prenatal care. Other women entered care and then skipped appointments after having used drugs and at which they had to give urine or blood.

> I didn't go to every appointment, I went to at least three and, none of the appointments where they had me urinate or take my blood.

Some women used drugs throughout pregnancy and attended all appointments, even though they feared CPS reports. A primary motivator was their baby's health. These women sought to avoid consequences by testing providers, navigating and negotiating urine tests, and using prenatal care to build track records. Some "tested" providers to see how they might respond to drug use.

> I mentioned the drug use and everything to see what they'd say…She didn't bat an eye or anything, she was just totally like, ok, and that's good and I'm glad you came in, and she was really respectful.

When providers appeared to "understand" and supported women for progress in reducing use, it was easier for women to attend and engage in subsequent prenatal care, even if they continued drug use.

> You're wanting the drugs, but I was going to all my prenatals because my doctor was really cool, she said, if you can't stop this cold turkey, try and taper off.

Although "understanding" encouraged prenatal care attendance and temporary reductions of drug use, it did not always lead to sustained reduction or complete cessation.

Others assessed how providers responded to general health concerns to predict how providers might respond to drug use. When providers did not listen or take time to answer questions, women protected themselves by emotionally disengaging.

> I went usually to all my appointments…one of the reasons I was using drugs…I feel lonely, like nobody is for me. I'm out there by myself, had to take care of me, had to do everything by myself…to feel that someone else has genuine concern for your health, your safety or something like that, I think that will make a person, even if it's once a month, go to that. And, you go to the doctor, and they just throw you some pills, and tell you come back in a month. It makes you feel like, go sell the pills. Or give them away, or leave them sittin' somewhere.

Women also navigated and negotiated urine tests while attending appointments. They managed drug use around appointments by counting days; used alcohol while stopping drugs; told providers about use to prevent urine testing; and used other women's urine.

After previous child removal, some women were determined to do everything correctly and therefore attended prenatal care. They sought to use prenatal care attendance to build track

records of prenatal care attendance and clean urine tests to keep the baby with which they were currently pregnant and help them reunite with previously removed children.

> Having clean urine tests helps me to get them back…This benefits me when I go to court…How am I going to get my other kids back if I can't take care of my baby?

Reflections about and suggestions for screening—A few women mentioned that it might have been helpful if providers had identified them during pregnancy.

> If my doctor had been able to tell that I was [using drugs] and talked to me about it, it would have been easier to admit to my doctor than my family and get the help from him.

While women feared urine tests while pregnant, once they stopped using drugs, some described urine tests as motivating them to stay clean. Upon reflection, some thought urine tests in prenatal care could be helpful. Women suggested that providers should let women know in advance about urine testing, offer help right away in response to positive tests, demonstrate "understanding," and allow more than one positive test before reporting to CPS.

> I think that the doctors should be a little bit more open to listenin' to somebody instead of more open to tryin' to write a CPS report right away, that maybe they should offer the woman help before they report them to CPS. If the woman doesn't want the help, then report them to CPS, but I think that the doctors should be more open to women. We just need somebody to tell, to vent to, I'm, I was a drug addict, I'm pregnant, I want to get high still, help me. I think they should make it more like that, not like its ok to use drugs, but it's ok to talk to somebody about it, and that they could help you find help.

Discussion

Three main findings emerged. First, many women were averse to having drug use identified by prenatal providers – especially through urine tests and especially when not informed of testing in advance. Second, women's concerns with having drug use identified centered around expectations that identification would lead to adverse psychological, social, and legal consequences. Overall, women did not trust providers to help or protect them from these consequences, especially CPS involvement. Women's concerns about identification leading to CPS reporting, especially for drugs and not alcohol, may be warranted. Federal policy requires providers caring for infants affected by prenatal exposure to illicit drugs (and not alcohol) to notify CPS ("42 U.S.C.A. Section 5106a," 2007).

Third, women took steps to avoid being identified and thereby avoid adverse consequences. Women concealed use and avoided prenatal care based on fear of CPS. Avoidance and concealment are not specific to pregnant women who do not want their drug use identified by providers (Fielder & Altice, 2005; Renker & Tonkin, 2006). These are strategies people use in a range of contexts to avoid surveillance of health status and health behaviors (Abel, 1998; Bloor & McIntosh, 1990). These, along with information sharing in situations of limited power, are signs of resistance (Bloor & McIntosh, 1990). That pregnant women who use alcohol and drugs engage in these behaviors indicates that some pregnant women are averse to having drug use identified by prenatal providers and that screening, especially when it includes urine testing, may not be acceptable among this population.

Concealment and avoidance have wider implications. For example, attempts to stop drug use before entering prenatal care may influence the timing of entry and thereby influence pregnancy outcomes (Berenson, Wilkinson, & Lopez, 1996; Broekhuizen, Utrie, & Van Mullem, 1992; Burkett, Gomez-Marin, Yasin, & Martinez, 1998; Chazotte, Youchah, & Freda, 1995; El-

Mohandes et al., 2003; Faden, Hanna, & Graubard, 1997; Green, Silverman, Suffet, Taleporos, & Turkel, 1979; MacGregor, Keith, Bachicha, & Chasnoff, 1989; Racine, Joyce, & Anderson, 1993; Richardson, Hamel, Goldschmidt, & Day, 1999) and lead to missed opportunities for health promoting interventions. Unless women attend prenatal care, screening is unlikely to help women reduce or stop their alcohol or drug use.

These findings should be considered in light of study limitations. First, we used a small sample that is not generalizable to the larger population of pregnant women who use alcohol and drugs. However, it may be similar to the larger population of low-income pregnant women who have alcohol and drug use identified by prenatal care providers in the county as demographics of the sample are similar in terms of race/ethnicity, partner status, education status, and timing of prenatal care entry to a sample of low-income women identified as using alcohol and/or drugs through universal screening in the county between 2001–2003 (S. C. Roberts, 2009). Further research with larger and more representative samples is needed to confirm these findings and determine whether they are generalizable to women in other geographic contexts. Notwithstanding, this study documents a range of women's thoughts about and experiences with having drug use identified by prenatal providers and has important implications for understanding the impact of universal screening.

Second, the small numbers of Black and Asian/Pacific Islander women in the sample precluded comparisons of attitudes and experiences by race/ethnicity and may have excluded some attitudes and experiences unique to these groups. This is significant because previous research had documented racial/ethnic differences in experiences with health care (IOM, 2002) and drug use during pregnancy (D. E. Roberts, 1999). Third, all participants were receiving formal substance abuse services and most had ceased drug use. Thus, reports of thoughts and experiences with decision-making about prenatal care and concerns about being identified were filtered through later experiences, including CPS involvement, which may have influenced the level of emphasis placed on certain concerns and experiences. Finally, there was an absence of women who used alcohol only. Therefore, assessing acceptability of screening among women who use alcohol only was not possible.

This study also has a number of strengths. First, it reports on the emergent theme of "being identified" that has short-term policy relevance. The finding that women's concern with having drug use identified by providers influences their decisions about prenatal care attendance connects two literatures - universal screening and barriers to prenatal care - that have not been previously connected. Findings suggest that screening for drugs may influence decisions about prenatal care attendance and engagement. That the phenomenon of women avoiding prenatal care out of fear of being identified emerged from study participants, gives it significant weight. While findings need confirmation, the range of responses to the possibility of having drug use identified by prenatal providers offers a solid beginning for understanding the larger public health impact of universal screening in prenatal care, including health tradeoffs and missed opportunities that may arise from physical avoidance of and emotional disengagement from prenatal care.

Second, this research brings women's voices and perspectives into a conversation that has previously excluded them. Attention to women's perspectives makes it clear that without attention to the context in which providers screen, screening for drug use in prenatal care may have unintended and negative consequences. Importantly, including women's perspectives also helps identify changes that could make screening more acceptable, including: 1) training for providers on non-judgmental responses, 2) clear policies and communication about urine testing, and 3) clear policies and communication about confidentiality of alcohol and drug use information obtained through screening in prenatal care.

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Table 1

Demographics of interview and focus group participants (n=38)

		N (%)
Age	Mean	30
	Range	20–47
Ethnicity	White	16 (42%)
	Hispanic/Latina	10 (26%)
	Black	7 (18%)
	Asian/Pacific Islander	1 (3%)
	Mixed	4 (11%)
Highest level of education	8th grade or less	3 (8%)
	Some high school	14 (37%)
	GED	2 (5%)
	Graduated high school	13 (34%)
	Some college	5 (13%)
	Graduated college	1 (3%)
Partner status (current) **	Single	6 (30%)
	Living with partner	7 (35%)
	Married	4 (20%)
	Divorced	2 (10%)
	Other	1 (5%)
# of children	1	11 (29%)
	2	9 (24%)
	3	5 (13%)
	4	7 (18%)
	5	1 (3%)
	6+	5 (13%)
% currently pregnant		9 (24%)
# children living with mother*†	All	14 (38%)
	Some	11 (30%)
	None	12 (32%)

* missing data

† many women were in residential treatment and did not have all of their children with them.

** based only on individual interview participants

Table 2

Prenatal Care and Alcohol and Drug Use (n=38)

Trimester started Prenatal Care this pregnancy*	
1st	50% (n=10)
2nd	25% (n=5)
3rd	20% (n=4)
None	5% (n=1)
Substance used most often	
Meth primary	61% (n=23)
Crack/cocaine primary	16% (n=6)
Heroin primary	3% (n=1)
PCP primary	3% (n=1)
Poly-drug	5% (n=2)
Marijuana and alcohol	8% (n=3)
Unknown**	5% (n=2)
Percentage of women who reported using alcohol	
Prior to or during current pregnancy	42% (n=16)
In the distant past	8% (n=3)

*based only on individual interview participants

**were in treatment; participated in focus group and did not disclose which substance they used on exit interview