



Research Article

Lessons from a Community Health Worker Home-visiting Program to Reduce Infant Mortality Among Black Mothers in Ohio

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Abstract

The Ohio Infant Mortality Reduction Initiative (OIMRI) aims to reduce infant mortality rates among black infants in Ohio by employing community health workers (CHWs) to conduct home visits. At these home visits, CHW activities include: referring mothers to health and social services, educating mothers, giving mothers needed supplies, and providing social support. This study uses participant self-report data collected by CHWs from 2010 to 2015 and interviews with county-level program managers from 14 counties in Ohio. Program data and interviews were used to describe ways clients were recruited, client gestational age at enrollment and start of prenatal care, number of prenatal care visits, ways that OIMRI helps facilitate prenatal care, and barriers to staying in the program. Findings indicate that the earlier participants were recruited into OIMRI, the more prenatal care visits they attended, which may relate to whether barriers like transportation and poor/inconsistent housing were addressed. Programs like OIMRI may help reduce risk factors for infant mortality by improving the uptake of prenatal care.

Keywords: Community Health Workers; Home Visiting; Infant Mortality; Maternal-Child Health Services; Prenatal Care

Introduction

Infant mortality rates in many areas of the United States are higher than rates in other high-income countries [1]. There is currently a national effort to reduce the Infant Mortality Rate (IMR) with a specific focus on the IMR disparity that exists between black and white babies [2]. Across the U.S., the main causes of infant death include congenital malformations, extremely preterm birth, maternal and birth complications, Sudden Infant Death Syndrome (SIDS), and accidents [3]. Risk factors for infant death include late or inadequate prenatal care, low income, stress, inadequate housing, and many chronic conditions, but black mothers disproportionately experience many of these risk factors [4-7]. Moreover, several of these risk factors compound, as poverty, unemployment, unreliable transportation, and low socio-economic status are also barriers to prenatal care [6,8].

Ohio, in particular, has fared poorly in birth outcomes, ranking 40 out of 50 states in overall IMR in 2017 [9]. Importantly,

while the birth rate in Ohio has remained stable since 2010 [10], the IMR has increased for black infants each year from 2012-2016 [11]. In addition, the 2016 IMR for black babies neared three times that of white babies with rates of 15.2 and 5.8 per thousand, respectively (Ohio Department of Health, 2017a). Given the disparity in birth outcomes and the known risk factors, the Ohio Department of Health (ODH) created the Ohio Infant Mortality Reduction Initiative (OIMRI) in 1994, a program that provides support to high-risk pregnant black women in 14 Ohio counties with high IMRs. With OIMRI, a trained and certified Community Health Worker (CHW) who is “a frontline public health worker who is a trusted member of and/or has an unusually close understanding of the community served,” [12]. Conducts home visits to expectant mothers to provide education, support, and referrals to services and healthcare [13]. Recruitment in the home setting allows the program to target at-risk mothers (e.g., those with health problems, poverty, lack of resources), in addition to enabling identification of environmental risk factors that may otherwise be overlooked [14].

Outside Ohio, other programs have provided home visits

conducted by CHWs to provide more convenient care to expectant mothers [15]. Yet despite the evidence that CHW-led interventions are effective at addressing infant mortality risk factors, there is a lack of research about the tactics that CHWs can use to recruit and retain participants in these programs, as well as scant information about the perceived benefits and barriers to program participation and continuance. Such efforts are essential to the success of home visit programs aimed at intervening on infant mortality related risk factors as it is imperative to identify and enroll women early in their pregnancy as well as to provide support throughout pregnancy and the first year of the child's life [16,17].

Given the uncertainty around best practices relating to recruitment by CHWs, this study aims to provide insight into the tactics and processes used by CHWs to promote recruitment. This case study details the efforts of the CHWs in the OIMRI program to recruit and retain clients and enroll them in prenatal care, as well as describing benefits of and barriers to program retention. We present data on program enrollment, methods of client recruitment and retention, timing of client recruitment, prenatal care initiation and adequacy, and barriers to program retention to evaluate the effectiveness of the OIMRI program. Results of this research detailing the lessons learned from the OIMRI program can inform other CHW-led infant mortality reduction efforts and increase the likelihood of success for such programs.

Methods

The Ohio Infant Mortality Reduction Initiative (OIMRI)

The OIMRI program was originally established in 1994 to address poor birth outcomes among black mothers and infants in Ohio. OIMRI utilizes CHWs that perform home visits to high-risk pregnant black women in 14 Ohio counties starting at program enrollment and continuing through the first year of their child's life. Visits occur on a weekly to monthly basis, depending on the needs of the mother, and are conducted at either the mother's home or another agreed-upon location. At the first home visit, the CHW assesses risk factors, tries to meet the most immediate needs of the pregnant woman, and collects intake data. The CHWs also collect data at the first home visit after the birth of the child, and at program exit. Data from these data collection forms are combined with a caseload analysis report completed by program supervisors regarding the caseload of each CHW to form a complete OIMRI dataset.

Data Sources

Data from two sources were used in this study: the OIMRI program dataset and interviews with OIMRI county-level program managers. The OIMRI program dataset was provided by the Ohio Department of Health (ODH) and had data through the middle

of 2016; only full years were used and the sampling frame was limited to 2010-2015. Data for this study was taken from reports completed at program intake (intake report) and at the first home visit after the birth of the infant (birth outcome report). The intake report includes the intake date, demographic information, estimated weeks of gestation at OIMRI intake, and recruitment method; the birth outcome report includes data on weeks of gestation at the start of prenatal care and number of prenatal care visits.

Telephone interviews were held with 13 program managers at each county site, in addition to one interview with a program administrator at the Ohio Department of Health (ODH). We used a semi-structured interview guide to conduct interviews. In total, we conducted 14 interviews with program managers and ODH employees, lasting 45-60 minutes each. All interviews were audio recorded and transcribed to permit rigorous qualitative analysis.

Data on race/ethnicity, estimated gestational age at enrollment in OIMRI and gestational age at initiation of prenatal care, number of prenatal visits, and recruitment source was extracted from the OIMRI dataset. We chose the gestational age at initiation and number of prenatal visits as the primary indicators of adequacy of prenatal care due to the relevance to the population of interest. Standard measures of prenatal care adequacy, such as the Kotelchuck index, are problematic in populations that have high rates of preterm birth and prenatal care inadequacy [18]. Separating the measures of prenatal care provides a more detailed description of the care received. Clients estimated their gestational week as part of program intake. As a measure of the timeliness of prenatal care, clients were asked to estimate their gestational age when prenatal care started based on their circumstances or on information provided by a clinician. Additionally, CHWs recorded the method of recruitment for each client at intake based on self-report of how the client learned about the program. The total number of prenatal care visits can differ appropriately based on the needs of the mother and baby, but the standard prenatal care schedule in the United States is 11-15 visits, with more for high-risk pregnancies [19]. Using this threshold to guide our analysis, the total number of prenatal care visits that OIMRI mothers attended was categorized as 0 visits, 1-4 visits, 5-8 visits, 9-12 visits, and 13 visits or more using the OIMRI dataset. Interview data added context to this study about the methods of program recruitment as well as insight about the benefits of and barriers to OIMRI participation.

Analysis

For the quantitative analysis, a pairwise deletion approach was used; all available data was analyzed. Chi-square tests were used to assess differences in the number of prenatal care visits by trimester of program enrollment. Values are considered statistically significant at the $p < 0.05$ level. All quantitative analyses were performed using Stata version 14 (2015, Stata Corp LP, College

Station, TX). Where appropriate we also include interviewee comments to provide context for the quantitative findings.

Analyses of qualitative data used constant comparative and thematic analysis [7]. First, a preliminary coding dictionary was created based on the topics addressed in the interview guide, and then new codes were added to the dictionary as concepts and themes emerged from the analysis. Our iterative approach to analysis involved reviewing interview transcripts and discussing findings among five evaluators as the evaluation progressed. This method thus enabled exploration of emergent themes among the data and ensured that data saturation was reached. The thematic analysis was considered complete when no additional codes or sub-codes could be defined. Our analysis was supported by use of the Atlas.ti qualitative analysis software 8 (2017, Scientific Software Development GmbH, Berlin, Germany).

Results

OIMRI Enrollment

Over 4,000 women enrolled in OIMRI between 2010-2015. Women most frequently enrolled during their second trimester of pregnancy, and the earlier in pregnancy they enrolled, the more likely they were to have more than 13 prenatal visits.

In total, OIMRI has reached over 15,000 mothers since 1996, enrolling 700 to 800 women a year for the past 10 years. From 2010-2015, there were 4,358 clients that provided intake data used in this study, and 95% of clients self-reported their race as “Black or African American.” The 14 OIMRI counties contain the largest cities in Ohio and participants are primarily urban, however, there are rural and suburban participants in some of the less populated counties.

OIMRI Recruitment

The recruitment strategies for the OIMRI program are summarized in (Table 1). As shown, the primary means through which clients come to OIMRI are through social service agencies (e.g., Child and Family Health Service, Job and Family Services), self-referral, or referral by a friend, relative, or neighbor.

	n	%
Social Service Agency		
Social service agency other than CFHS	1,047	24
Child and Family Health Services (CFHS)	229	5.3
Referral		
Friend, relative, or neighbor referral	754	17.3
Self-referral	752	17.3

Prenatal care provider	646	14.8
Canvassing		
Home visit	421	9.7
Neighborhood canvassing	383	8.8
Door-to-door canvassing	126	2.9

Table 1: Recruitment Methods in the OIMRI Program, 2010 to 2015.

All of the program managers described actively recruiting in-person at locations that the target population commonly utilizes; these included The Special Supplemental Nutrition Program for Women, Infants and Children (WIC) offices, physician offices, and Job and Family Services. Describing in-person recruitment efforts, one interviewee explained, “we work and partner with our local FQHC [federally qualified health center], so they have a prenatal center there. So we’re housed there several days a week where we’re meeting all the pregnant women that come in and out, making sure that they’re linked with home visiting.” Another interviewee said, “We’re going to Job and Family Services on a regular basis and WIC on a regular basis...And just kind of a permanent face there and trying to recruit families that way.” In addition, beyond the categories in the table, interviewees from a few sites discussed recruiting in-person at parenting classes, churches, homeless shelters, and even local schools.

Recruitment also reportedly occurs through word of mouth among friends and family members, as well as during home visits to other clients. One program manager explained, “word of mouth is huge here in our county. So you know, it may not be applicable to them at the time, but somebody else in their housing complex or somebody else in their family could potentially benefit. So you know, information is-information sharing is the best thing we can do to try to get the word out about our program.”

Enrollment and Prenatal Care

Women most frequently enrolled in OIMRI during their second trimester (44.9%), started prenatal care during their first trimester (72.0%), and had 9-12 (38.7%) or 13 or more (40.6) prenatal visits, as shown in (Table 2).

	n	%
Weeks’ Gestation at Enrollment in OIMRI		
<13 weeks	1,190	27.5
13-27 weeks	1,947	44.9
>27 weeks	1,198	27.6
Weeks’ Gestation at Start of Prenatal Care		
<13 weeks	1,922	72

13-27 weeks	639	23.9
>27 weeks	108	4.1
# of Prenatal Care Visits		
0 visits	30	1.1
1-4 visits	167	6.3
5-8 visits	354	13.3
9-12 visits	1,030	38.7
13 + visits	1,079	40.6

Table 2: Gestational Age at Enrollment in OIMRI and Receipt of Prenatal Visits.

For 2010-2015, there was a statistically significant difference in the number of prenatal care visits attended by women who enrolled in OIMRI in the first vs. the second vs. the third trimester ($p=0.001$) (Figure 1).

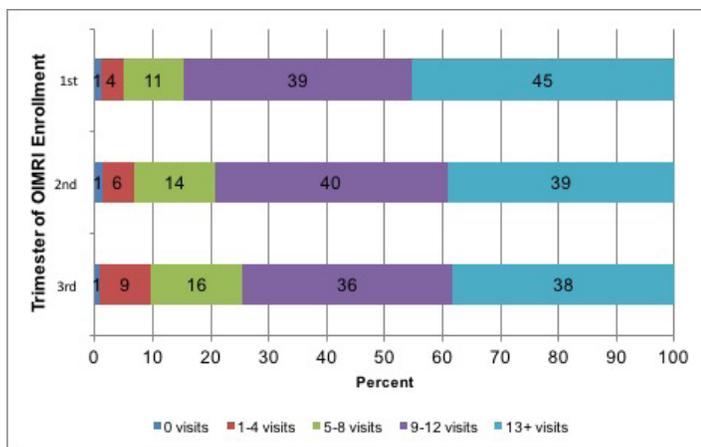


Figure 1: Trimesters of OIMRI Enrollment.

While 45% of those who enrolled in OIMRI in their first trimester had 13+ prenatal visits, 4% had 1-4, and 11% had 5-8 visits; those who enrolled in OIMRI in their third trimester more frequently had 1-4 visits (9%) or 5-8 visits (16%), and fewer had 13+ visits (38%).

Client Retention and Support

We identified three main themes in our interviews with program managers related to the ways in which the OIMRI program assists its clients: 1) addressing social determinants of health; 2) providing resources; and 3) providing social support. These three themes are described in further detail below.

Addressing Social Determinants of Health: Many program managers emphasized the importance of referrals to community resources. As one commented, “If you ask the community health

worker, they would say that their primary thing is relationship building, and secondly it’s referrals to community, linkages to community resources.” During home visits, the CHWs regularly ask their clients for updates about appointment attendance and whether they obtained referred services. In addition, each CHW keeps information about which referrals were successful so that they can continue to encourage clients that have yet to access referred services.

The CHWs also frequently support their clients in ways beyond these referrals. Specifically, they play the role of service coordinator by contacting care or service providers for a client or by working directly with providers. One program manager highlighted the advocacy role played by the CHWs:

For the client, the social determinants of health play so many factors in the disparities. So it may be that the community health worker may be spending some time trying to get the client housing, or making phone calls because there may be some domestic violence. Bed bugs are an issue, so sometimes our clients may be in less than desirable living conditions. So the community health care worker plays a vital role in trying to lessen the stressors around the mom and the family, as well as educate them on how to have a healthy pregnancy.

Providing Resources: Another benefit of the OIMRI program is directly providing resources that may help with appointment attendance or infant care after the birth. OIMRI supports clients by giving them incentives for prenatal care and to stay in OIMRI, including bus passes or gas cards, coupons, gift cards for supplies, or physical supplies such as diapers, wipes, or bottles. As one manager explained, “One thing that I’ve learned is that incentives go a long way. And that has been something that our agency has not been big on even though the grant, you know, loves for you to incentivize different things. If you go for your postpartum checkup, what’s wrong with giving them a gift card?” Another interviewee discussed how these resources facilitate the CHWs’ connections with clients: “the program has afforded us to give the clients incentives and it kind of makes it easier when you have something to bring to the home other than just data collection and getting information. If you have a gift or just something to say ‘hey, we appreciate you, you know, taking part in this, allowing us to intrude into your life and giving me this information.’” One county specifically detailed their incentive structure: “You know; we do have incentives in our program too. If they go to all their prenatal appointments, we give them a \$20 Walmart card. If they go to their postpartum visit we give them \$20 card, and then when they complete the program. And it used to be immunizations sometimes they would get a \$20 gift card.”

Social Support: All program managers were asked what they thought the OIMRI program did exceptionally well and the most common theme mentioned involved communication and

support for the clients. One program manager noted that the CHWs often become the client's "best friend." A manager reflected, "I think [the CHWs are] there for a support system which a lot of our women do not have...I think [that] has really impacted [the clients/mothers] in their lives to make some changes." As another interviewee said, "for many of our clients...they don't have anyone other than the community health worker. That is like their lifeline." Program managers linked this social support role to program success, saying:

You know, we're certainly impacting, making sure that [clients] get to the doctor and, you know, that they're having a healthy baby. It's helping them identify areas that are causing them stress or...helping give them the skills and the resources that enable them to address those and move forward and be in a better place than when we first came into their lives, and whatever that means for them, whatever their goals are.

Barriers to OIMRI Participation and Prenatal Care Retention

We also found that potential clients face many barriers to participation in both OIMRI and prenatal care, contributing to high rates of loss to follow-up and non-compliance with recommendations. As a result of mothers dropping out of the OIMRI program prior to birth, only 61.2% of participants with an intake report have birth outcome data completed in the dataset used for the 2010-2015 analyses. We found three major themes around barriers to participation: 1) housing insecurity; 2) lack of transportation; and 3) issues with mental health and substance abuse. Each of these barriers is described in more detail below.

Housing Insecurity: One of the most common barriers mentioned was housing insecurity, as many women that might participate in OIMRI are homeless or live in poor conditions. An interviewee explained, "We have homeless clients, we have clients living in cars, we have clients living with extended family in crowded conditions, we have clients that move a lot. So you know, people who are lost to follow up are common, or people who can't keep up with the visits because their lives are too chaotic." For other clients, their housing is not adequate, and this leads to CHWs playing a housing advocacy role. A program manager commented, "Some of our families have housing, but it's not what I would call adequate housing. So we're doing a lot with landlords. Teaching them their rights, the tenants' rights, linking them with agencies that can help with those issues, trying to help them find other housing." This housing insecurity leads to a lot of stress among clients who do participate, as one interviewee explained:

I mean the main thing that's happening with our moms...is the stress, because maybe their water is getting shut off or they're getting evicted. I wish that we had a pot of money that would be

available for those types of emergencies. Like they were going to get their water shut off and they needed the \$50 to keep it on and we could [pay] that. And you know, food allowance. Sometimes, these pantries, they run out. Or they've been there in the last 30 days."

Transportation: Lack of transportation to referred services was also a barrier to participation, notably because it can cause clients to appear non-compliant with the CHW's referrals. Further, transportation barriers were reported to be a more pervasive problem in rural counties. As one interviewee explained, "Usually transportation is an issue in [counties where] there is no public transportation... It's a problem because they don't go to appointments because of that." After identifying this barrier, one program manager detailed how an OIMRI CHW would strive to help the client overcome this barrier: So it may be that she's in the 6th month of the pregnancy, all may be going well, however transportation may be an issue. She doesn't have transportation to get back and forth to the doctor's office or what have you. And we come in and educate her on that stage of the pregnancy, assess the home environment so that it'll be a safe environment for the baby.... And then we'll provide her with bus tokens for transportation to the doctor's office. And then we'll work to see how she can get assistance so that this is not a recurring theme for her. Lack of transportation.

Another program manager mentioned the opportunity to address this barrier by trying to help clients ahead of time: "You know, I'll call a day or two before the appointment to just to make sure, you know, if there are transportation issues or childcare issues, try to get that all handled before the appointment to assure that that client will keep the appointment."

Mental Health and Substance Abuse: Mental health and substance abuse were frequently mentioned together as barriers to program participation as well as notable challenges faced by CHWs serving clients. When asked about concerns, one interviewee noted, "I definitely think the mental health and substance abuse we're facing - how to keep those clients involved, how to keep them involved long-term, how to keep them involved to completion." Interestingly, substance abuse was often mentioned in the context of the growing heroin epidemic: "we're seeing a lot of drug use-more drug use, specifically heroin ... There's a big waiting list for any kind of drug facility so by the time they're at the top of the list, they're strung out or overdosed." These issues appear to be increasing in prevalence in some counties. As one manager commented, "mental health is a big issue right now that we're facing with probably over 50% of our caseload. We have a lot of extensive mental health issues, far beyond anxiety and depression. You know, we're into schizophrenia, bipolar, substance abuse--all of those things have increased over the past four or five years."

Discussion

While CHWs have been found to be effective in increasing participation in infant mortality reduction efforts, the impacts of such programs with respect to outcomes and addressing barriers to program participation have been unclear. In particular, it has remained unclear how these front line public health workers can best recruit and retain program clients. Our case study of the OIMRI program enabled us to improve our understanding of these issues in the context of a program designed to target high-risk black mothers in Ohio.

Across the OIMRI program, we identified several approaches that CHWs use to recruit pregnant women and reduce the barriers they face to receiving prenatal care. We found that the most frequent sources of recruitment into OIMRI included via social service agencies; friends, family, and neighbors; and self-referrals. Further, we found an association between early enrollment in OIMRI and the client attending at least 13 prenatal care visits. This finding suggests that a CHW-led program can facilitate women's access to adequate prenatal care if initiated early, satisfying recommendations for the number of prenatal care visits by the American College of Obstetricians and Gynecologists (i.e., 11-15 visits for a full-term infant) (American Academy of Pediatrics & American College of Obstetricians and Gynecologists, 2017). This finding aligns with prior research showing, for example, that among WIC recipients, those enrolled in community programs are more likely to initiate prenatal care early in their pregnancies [20]. Similarly, other home-visiting programs and CHW-led programs have been previously found to improve utilization of healthcare among underserved populations [21].

Our findings also offer insight into why the CHWs are able to improve healthcare utilization among high-risk pregnant women. For example, some of the incentives offered by the OIMRI program (e.g., bus passes and gas cards) directly affected mothers' ability to attend appointments, while other incentives were given as a response to prenatal care attendance. These tactics help address common barriers, including transportation, logistical challenges, and low support [22,23]. Additionally, the CHWs' efforts to support the women they serve may contribute to clients' empowerment and sense of self-efficacy in managing their health, which in turn may positively affect maternal health behavior [24].

Nonetheless, we also found that the majority of OIMRI clients did not begin the program during their first trimester, raising concerns about the adequacy of program recruitment methods. It is possible that women are unlikely to self-enroll if they do not see information in the neighborhood or hear about the program, nor will they be referred until others know about their pregnancy. Notably, the pathways to recruitment identified suggest several opportunities to improve CHW-led infant mortality reduction efforts, such as partnering with social service agencies. OIMRI

CHWs should focus on raising awareness about the program among women likely to be eligible through as wide a variety of methods as possible to encourage early program initiation and self-enrollment.

In addition, while OIMRI CHWs were effective in circumventing barriers to prenatal care for a number of their clients, additional factors noted (e.g., housing insecurity, mental health or substance abuse issues) likely affected the ability of clients to stay engaged in OIMRI and obtain adequate prenatal care. Prior research reports that mothers who do not seek prenatal care note substance abuse, denying that they are pregnant, financial problems, hiding their pregnancy, and feeling they know enough from previous pregnancies as reasons, many of which are risk factors for infant mortality [25]. Adding to these issues, previous studies have shown that black women who receive no prenatal care tend also to have many behavioral risk factors for infant mortality, and experience poor birth outcomes at higher rates than white or Hispanic women who do not receive prenatal care [26]. As OIMRI targets high-risk black women, their program clients may be more likely to experience these known risk factors and barriers to care.

For the OIMRI program to improve its impact, obtaining additional resources for incentives and raising awareness of the program may both be needed. Additionally, OIMRI funding may be subject to ODH budget limitations, potentially creating staff turnover and limiting both the sustainability and impact of the program. Further, as timing of recruitment is important to receipt of adequate prenatal care, focusing recruitment efforts to increase early enrollment, in particular, may be critical. Increased canvassing and advertising for the program within communities with high concentrations of black women could help by raising awareness and increasing self-referrals. With the continued high rate of infant mortality among black Ohioans, increasing recruitment and retention in programs such as OIMRI is essential to affect change.

Limitations

Our study findings should be interpreted in light of several limitations. The quantitative data reported in this study relies on self-reported program data, as clients were the source of most outcome data. Self-reported data can result in inaccuracies due to mothers being unaware of gestational week or misreporting the number of prenatal visits, potentially due to a desire to increase social desirability. Second, this study was limited by incomplete data, as many clients dropped out of the program and were unreachable after program intake, or did not answer certain questions. Third, the kinds of prenatal care received were not recorded, only the number of visits. Fourth, since infant mortality is a rare event, our study cannot evaluate the impact of CHW efforts on this birth outcome. Instead, this study focuses on operational measures of program success. Finally, the program managers

could have introduced bias themselves in their interviews if they were unwilling to report negative aspects of the program. Future analyses could further specify what kinds of prenatal care were received rather than just the number of visits and start date. In addition, while we had qualitative data detailing benefits and barriers, future data collection efforts could quantify the number and types of barriers to care among high-risk mothers to improve upon existing interventions.

Conclusion

The OIMRI program targets risk factors for poor birth outcomes and infant mortality by recruiting high-risk black women to receive home visits from CHWs. We found that early enrollment in OIMRI was associated with attending more prenatal care appointments. Further, OIMRI CHWs helped women overcome barriers to care by providing referrals to prenatal care and social services, incentives helping with transportation and childcare, and social support. Yet the women participating in OIMRI often encountered difficulties with housing, transportation, mental health, and substance abuse that the program had to address to improve care adherence. CHW-led programs like OIMRI may reduce infant mortality risk by helping women receive adequate prenatal care. However, future work is needed to explore ways to overcome these barriers to program participation among high-risk populations in order to ensure success in efforts to reduce infant mortality.

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