Healthy mothers, healthy infants

Dr Audra Gollenberg tells International Innovation about her pioneering efforts to establish a highly collaborative, community-based coalition aimed at reducing infant mortality rates in Virginia’s most vulnerable populations.

Why did you decide to collaborate with Drs Kim Fendley and Charles Devine on the establishment of the Coalition to Curb Infant Mortality (CCIM)?

My training is in maternal and perinatal health in minority populations, while Fendley’s work is in community development and Devine has a longstanding interest in infant mortality. The combination of our training and experiences led us to set up CCIM, the overarching goals of which are to better understand and reduce disparities in infant mortalities, as these deaths disproportionately affect certain minority groups, lower socioeconomic groups and geographic areas.

What are the leading causes of infant deaths in the US?

The Centers for Disease Control and Prevention (CDC) reports that the leading causes of infant death in 2013 were congenital malformations or deformations and chromosomal abnormalities (birth defects); disorders related to short gestation and low birthweight; and sudden infant death syndrome (SIDS). These conditions have, however, all been important causes of death for decades.

Could you describe the benefits of CCIM’s community-based approach, which brings together community members, academia, local health departments and organisations?

It is becoming increasingly recognised that collaborative, community-based approaches are critical to the success of addressing health disparities at the community level. Collaborative partnerships that equitably involve community-based agencies and community members work to create sustainable change and better understand the root causes of disparities in health outcomes.

CCIM provides the foundation for bridging the gap between community stakeholders and researchers who currently share common goals for addressing disparities in infant mortality, but who may not have the opportunity to meet and share ideas and resources on a regular basis. The researchers, health and human service agencies, and community members all bring expertise to the table and work collaboratively to address shared concerns. Unlike investigator-driven projects which often finish when the funding ends, leaving the community with little and reducing trust of researchers, this type of project is designed to be sustainable and equitably involve the community in every stage.

What did you find to be the advantages of using interviews, forums and workshops to gauge community perceptions of infant mortality and guide the provision of health education programmes?

Community members interested in maternal and infant health were found and interviewed using snowball sampling methods. This enabled us to gauge understanding and perceptions of community members who were known to work with, or have an interest in, maternal and infant health. This informed us about the current state of high-risk situations, structures, behaviours and needs while also giving the desired state. It also allowed us to invite each person interviewed to join the Coalition to address maternal and infant health.

The community members said that education was the preferred solution to poor maternal and infant health. In response to the community voice, we developed workshops for professionals, workshops for high-risk populations, community forums, curricula on pertinent topics [eg. stress and self-confidence] written for youth, and conducted research on the health communication preferences of mothers with children under the age of five.

Can you elaborate on some of the biggest challenges you have faced in this investigation?

As with any community-based initiative with a true diversity of members, the strongest challenge is to develop and maintain communal goals for the Coalition that outweigh personal and professional agendas.

How is your campaign aiming to reduce maternal and infant mortality in high-risk communities progressing?

The current phase of CCIM is focused on community mobilisation and assessment. While it does involve some information dissemination and community education on topics related to infant mortality, the next phase of the project will address a specific intervention to reduce it.

Our next phase is still under development but is greatly influenced by the results generated from this current phase of work. It is clear that the community wants some form of education and social support to sustain healthy pregnancies, births and infant development. Combining this finding with empirical evidence from other studies, this suggests that we may further develop partnerships to carry out an infant mortality reduction campaign that is community-informed. Depending on what additional data we collect, the campaign may involve social support circles or brief counselling sessions to encourage healthy behaviours prior to and between pregnancies.
Although infant mortality is in decline in the US, it is declining slowly; between 2001 and 2011, the number of infant deaths per 1,000 live births dropped a mere 0.7, from 6.8 to 6.1 nationally. In addition, significant health disparities remain in terms of infant mortality rates across different socioeconomic, minority and geographic groups. If effective infant mortality reduction programmes are to be designed, a more thorough understanding of the perceptions and needs of these high-risk communities is required.

This situation is especially true in Virginia, where there are substantial infant mortality disparities between racial and ethnic groups and across socioeconomic and rural-urban gradients. As recently as 2011, for example, infant mortality among Virginia’s black population was more than twice the national average. The leading causes of infant death in the state include disorders related to short gestation and low birthweight, birth defects and sudden infant death syndrome (SIDS). Although a plethora of evidence-based guidelines and interventions exist aimed at preventing such deaths, effective education and outreach is required if these are to be effectively implemented within vulnerable communities.

It was this state of affairs that prompted Shenandoah University researchers Drs Audra Gollenberg and Kim Fendley to team up with Dr Charles Devine, Health Director of the Lord Fairfax Health District (LFHD), to launch the Coalition to Curb Infant Mortality (CCIM). The Coalition is a community-based participatory research programme aimed at increasing community partnership, awareness and education to decrease disparities in infant mortality. Its members include individuals from the community, peer leaders from traditionally underrepresented populations, Shenandoah University researchers, and various community-based organisations dedicated to improving child and maternal health. These include the LFHD, social services, law enforcement, faith-based organisations, non-profits and healthcare providers. By bringing together these many stakeholders, CCIM fills a previously unmet need, as prior to its creation there were no collaborative community partnerships in the region. The Coalition is active within three distinct geographic regions within LFHD: Winchester City (a diverse socioeconomic urban setting), Page County (a medically underserved rural setting) and Frederick County (a partially rural, medically underserved setting).

Working with the Community
CCIM has now been active for two years, during which time there have been 19 Coalition meetings and two large community education workshops designed to meet points of local concern, the first highlighting the importance of safe infant sleep in the prevention of sudden unexplained infant death (SUID) and the second exploring the importance of maternal health prior to pregnancy in improving outcomes. A number of other education workshops have been held during coalition meetings.

In addition, 74 semi-structured interviews have been conducted with community members and representatives of community-based organisations from across the three focus regions, with the goal of better understanding community-level priorities, resource needs and perceptions of health disparities. For the large part, there was little regional difference in how respondents perceived resource needs, with the majority of interviewees highlighting the need for health and parenting education for those living in poverty, improved access to medical care for the uninsured; and more support for adolescent mothers, single mothers and substance users. A large proportion of interviewees in Winchester City also mentioned the language and cultural barriers often faced by Hispanic immigrants. “One particularly notable finding was that, when asked: ‘Which groups are at highest risk of infant mortality?’, over 50 per cent of the sample responded ‘I don’t know’,“ Gollenberg comments. “We interpret this finding as an opportunity to spread awareness of the risk factors for infant mortality among the general community.”

Furthermore, numerous open community forums and group interviews have taken place across LFHD aimed at establishing a dialogue within communities around infant mortality reduction. As a result of these events, a number
of areas of community concern relating to infant mortality were identified, and appropriate health education provided. For example, in response to concerns regarding unhealthy behaviours in youth approaching reproductive age, Shenandoah University sociology students led by Fendley developed an active-learning curriculum for adolescents covering areas such as stress reduction, self-esteem and communication with parents. The students hope to implement these curricula within agencies like the Boys and Girls Club of the Northern Shenandoah Valley later this year.

Finally, last year, the Coalition also administered a short survey (available in both English and Spanish) to approximately 300 pregnant women and mothers with children under five, with the goal of determining their preferred health outreach and communication methods. The insights gained through this activity will be used to guide future engagement campaigns with high-risk families.

A Healthier Horizon

CCIM partners are now preparing the next phase of the project, which will be aimed at developing and implementing infant mortality reduction campaigns that, being heavily informed by CCIM’s assessment work to date, will be targeted to specific vulnerable communities. Potential future activities range from the provision of safe sleep blankets, swaddlers and preconception health information for mothers to the expansion of support services for high-risk women.

It is clear that the Coalition is making significant headway; the results of an evaluation survey sent to CCIM members last year were overwhelmingly positive in terms of Coalition productivity, progress towards goals and, most importantly, community benefits. If things continue with the same momentum and enthusiasm, it seems likely that this highly collaborative, community-based Coalition will make a significant and sustainable impact on reducing infant mortality in some of Virginia’s most vulnerable populations.

Risk Factors for Infant Mortality

Demographics and factors often associated with pregnancy complications and infant death include:

- Single mothers
- Adolescent pregnancies
- Mothers with low levels of education
- Lack of or late entry to prenatal care
- Poverty
- Maternal obesity before/during pregnancy
- Folic acid deficiency during early pregnancy
- Smoking, alcohol and drug use

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