2017 ANNUAL REPORT

ST. LUCIE COUNTY
FETAL & INFANT MORTALITY REVIEW

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The Fetal Infant Mortality Review (FIMR) Program is a communty-based, action-oriented program designed to enhance the health and well being of women, infants, and families through the review of individual cases of fetal and infant death.

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REDUCING INFANT MORTALITY **STARTS HERE**

DEDICATION

This first annual St. Lucie County (SLC) Fetal and Infant Mortality Review (FIMR) report is dedicated to those who have suffered the loss of their baby. And to the brave parents who have shared their painful experiences in the hopes that other families may avoid such a loss.

ACKNOWLEDGEMENTS

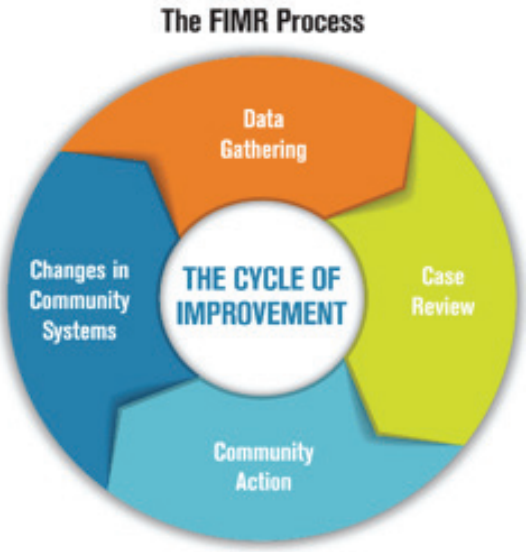
The Florida Department of Health in St. Lucie County (FDOH-St. Lucie) thanks Allegany Franciscan Ministries for their generous grant to initiate a Fetal and Infant Mortality Review program (FIMR). We also wish to extend expressions of gratitude and special thanks to the many agencies and organizations, represented by a group of very dedicated professionals, community leaders and concerned citizens who comprise the Case Review Team (CRT). We recognize the FIMR process is arduous requiring time and effort to review difficult cases.
Through these efforts, we hope to decrease infant mortality rates and the racial disparities within.

The Origins of FIMR Nationally and in St. Lucie County

FIMR is a national model that was first introduced in 1990 as a collaborative effort between the American College of Obstetricians and Gynecologists (ACOG) and the Federal Maternal & Child Bureau (MCHB). FIMR is a community-based and action-oriented process to improve service systems and resources for women, infants and families. This evidence-based process examines fetal and infant deaths, determines preventability and engages communities to take action. FIMR also provides bereavement support to those who have experienced a pregnancy loss or death of an infant (www.nfimr.org).

The operating principles of Fetal & Infant Mortality Review per the National Center for Fatality Review and Prevention (NCFRP) include the following:

- Infant mortality is the most sensitive index we possess of social welfare (Julia Lathrop, Children's Bureau, 1912 – 1920).
- The death of an infant is a community problem, and is too multidimensional for responsibility to rest in any one place.
- Fetal and infant deaths are sentinel events that illustrate system and resource issues.
- FIMR's two-tiered process enhances program effectiveness.
- The Maternal interview includes the voices of others who have lost an infant and offers information not available through routine quantitative methods.
- Reviews lead to identification of factors contributing to fetal and infant mortality.
- Review should focus on prevention and should lead to effective recommendations that improve the systems of care and resources for women, infants, and families. (www.ncfrp.org)



FIMR PROCESS

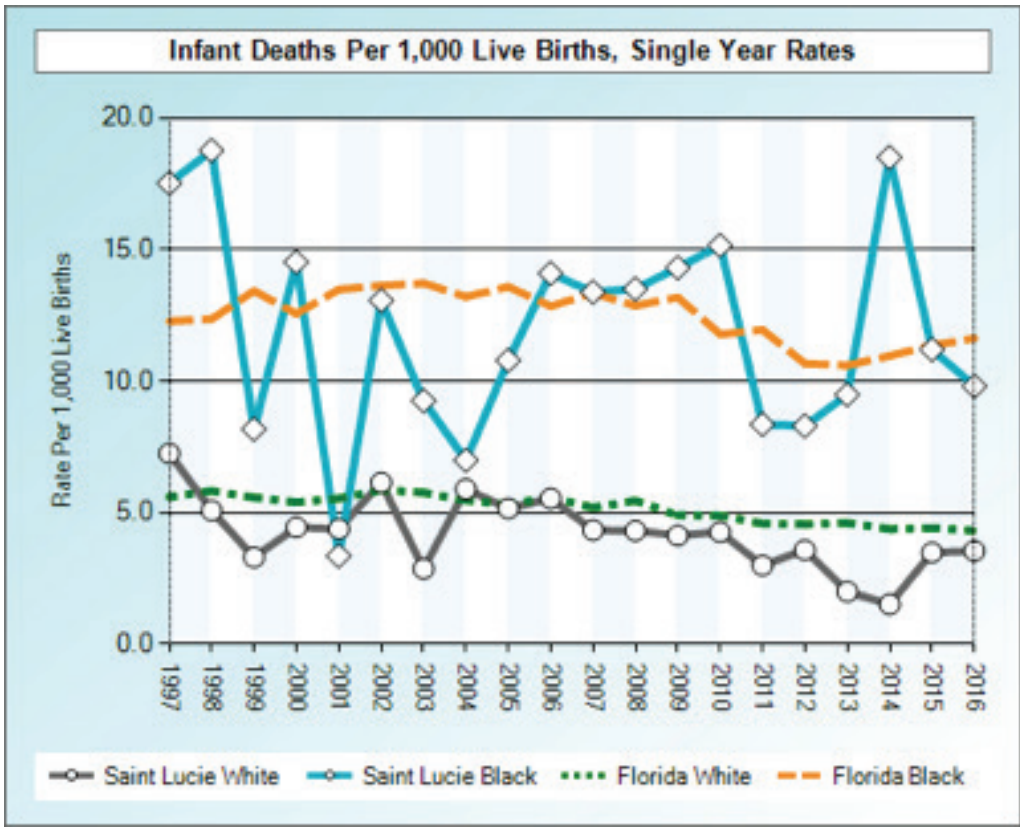
Data Gathering – Nurse abstraction service gathers information from multiple sources, including interviewing parents and family members who have experienced a loss. The interview is an important component of the FIMR data gathering process.

Case Review – The Case Review Team (CRT) is made up of clinical and non-clinical professionals, encompassing a broad spectrum of providers serving the diverse population. The CRT reviews fetal and infant cases prepared by the nurse abstractor. Confidentiality is strictly maintained. All cases brought before the review team are de-identified of patient, provider and institutional information. The data collected and reviewed are used to identify causal or contributing factors, trends and preventability, as well as help the community implement changes for preventing future losses.

Community Action – The Community Action Team (CAT) will be established and will consist of a team of elected officials, professionals, representatives and members from various community agencies in St. Lucie County. The CAT is the body with the responsibility of implementing the recommendations made by the CRT.

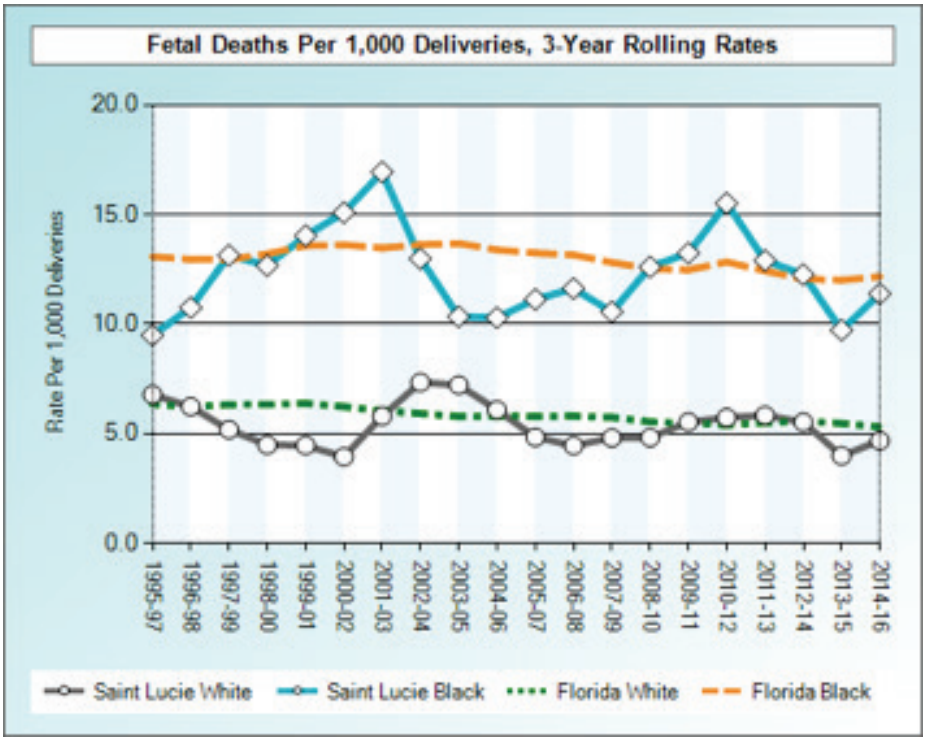
THE FIMR PROCESS BEGINS IN ST. LUCIE COUNTY

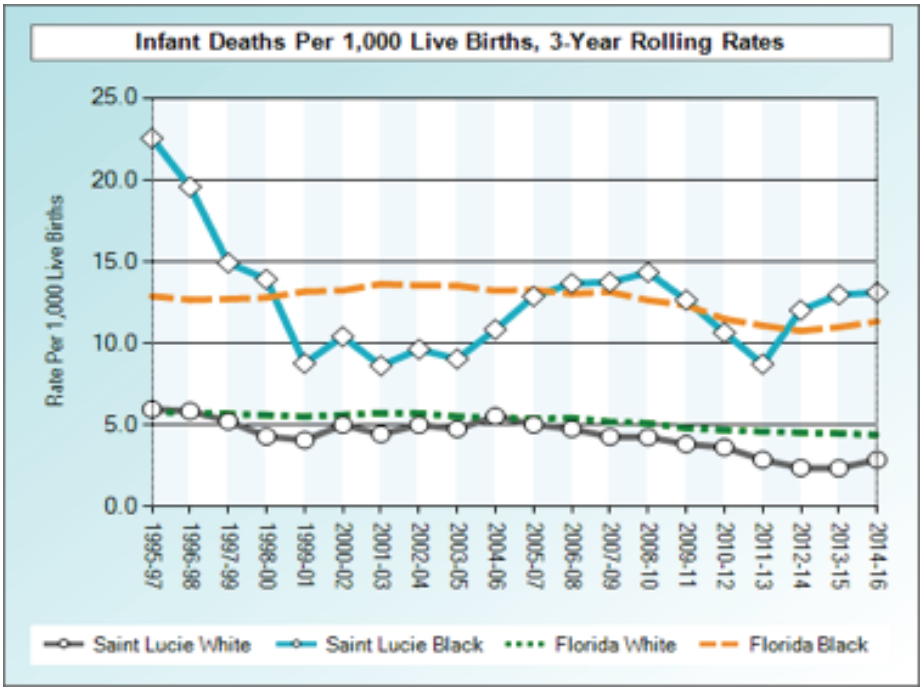
FDOH-St. Lucie hired a FIMR Coordinator in 2016 after a disturbing racial discrepancy in the Infant Mortality Rate (IMR) occurred in 2014. As is visible in the graph below the difference in black/white IMR exists every year and was pronounced in 2014. In that year, black families suffered an infant mortality rate of 18.5/1000, and white families 1.5/1000.



SOURCE: *FLORIDA CHARTS*

FIMR addresses both fetal and infant deaths. Rolling rates over time in St. Lucie County with racial disparities can be visualized in the graphs below. The discrepancies in IMR reveal social injustice and a need for action.





SOURCE: *FLORIDA CHARTS*

The FIMR Coordinator conducted family interviews and analyzed data from community agencies and providers, including:

- Florida Department of Health Bureau of Vital Statistics
- St. Lucie County Fire District
- Lawnwood Regional Medical Center, St. Lucie Medical Center and Martin Health System (e.g. ED, L&D, NICU, PICU, Post-Partum, Laboratory)
- St. Mary's Hospital in Palm Beach County
- Medical Examiner District 19
- Healthy Start Coalition of St. Lucie County
- Physician's offices (e.g. Pediatricians, OBs for Prenatal and Post-partum records).

The participants in the Case Review Team generously shared their expertise and knowledge to generate recommendations in the first year. Participants included:

- Physicians-Neonatologists, Pediatricians, Obstetricians
- Hospital Nurses Leaders and Staff nurses from labor and delivery and post-partum
- Grief Counselors
- FDOH-St. Lucie
- Certifed Nurse Midwives
- Lactation Consultants
- Clergy
- Nursing and Medical Professors, Instructors
- Office Managers for area Maternal/Child Practices
- Healthy Start Coalition of St. Lucie County
- St. Lucie County Fire District
- Circuit 19 Department of Children and Families
- SafeSpace
- Florida State University School of Medicine

SLEEP-RELATED DEATHS/SUDDEN UNEXPLAINED INFANT DEATHS

Sudden unexplained/unexpected infant deaths (SUID) usually sleep-related deaths and/or suffocation have been termed "the low hanging fruit" to reduce infant mortality rates. However, the issue of infant sleep was found to be complicated. Practices regarding sleep are shared on social media, rooted in culture and history, related to breastfeeding and modeling that occurs in the hospital, as well as other issues.

SUID and/or sleep related deaths have been referred to as "SIDS" or Sudden Infant Death in the past. The term SIDs has come under scrutiny since 2000 and has been excluded from the terminology of some Medical Examiners in Florida since 2001. "Medical officials argue there is not a mysterious unknown, syndrome, rather the culprit is suffocation" (Stanley, 2015).

SUID or sleep related deaths are preventable but do occur every year in St. Lucie County at an average of 2 per year. Data collected by FIMR regarding sleep related deaths is presented in the table on the next page.

SUID & SLEEP RELATED INFANT DEATHS IN ST. LUCIE COUNTY

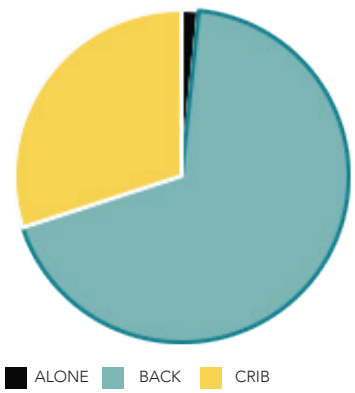
Year	# of Cases	Cause of Death
2013	2	1 Probable suffocation. 1SUID
2014	2	2 Positional asphyxia
2015	2	1 Positional asphyxia 1 Unknown
2016	1	Undetermined
2017	4	1 Pending 3 Positional asphyxia

The National Institute for Children's Health Quality (NICHQ) reported that SUID deaths are up 2% recently (www.nichq.org). Causes for sleep related deaths include: overlay by parents when co-sleeping, incorrect sleep position (on the stomach or side), wedging between wall, mattress, pillows and soft sleep surface. If after the investigation is performed and cause cannot be determined the death may be attributed to SUID.

A brief (3-question) sleep survey (borrowed with permission from Pinellas County FIMR) was administered in the Women, Infant and Children (WIC) nutritional program waiting rooms at two FDOH-St. Lucie locations. Although the sample size is too small to draw any conclusions, among this sample many parents did know the baby should sleep on his/her back. Responses to the 3 questions posed to parents are illustrated as follows:

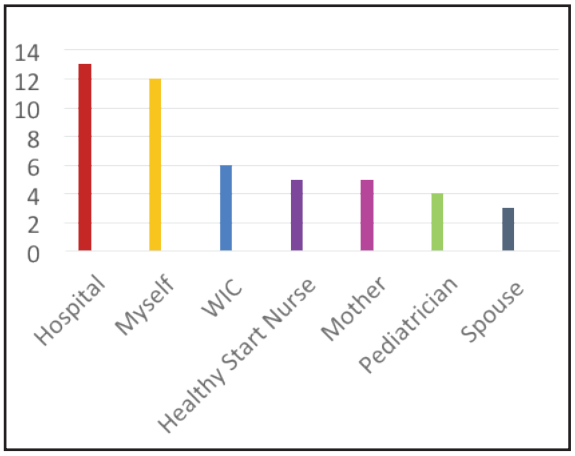
QUESTION #1.

Responses to 3 ways to put baby to sleep safely?



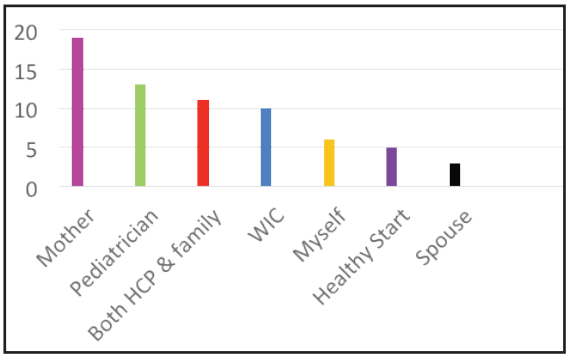
QUESTION #2.

From whom did you learn about safe sleep?



QUESTION #3.

Who do you consider a trusted source of information regarding child care?



Among this sample of new parents, hospitals were the primary location where they learned about sleep. New parents also trusted advice from their own parents regarding child care. Disseminating uniform safe sleep information in the hospital to the entire family is an opportunity to reach spouses, grandparents and others who will serve as caretakers and are considered trusted.

Four of the five sleep related deaths reviewed in SLC did include babies who were found on their stomachs. Only one infant was co-sleeping with their parents. Three of the sleep related deaths in St. Lucie County since 2014 occurred when the baby was left alone, unsupervised for 6-8 hours. A recommendation was made to elaborate the "ABC" alone, back and crib message. The word "alone" is vague and can lead to confusion.

An aggregation of the information from the Baby Abstracting System and Information Network (BASINET) indicated missing information, possibly impeding accurate assessment of how and why some sleep related deaths occurred. Law Enforcement and Medical Investigators records have not reported reenactments of the circumstances of the death. A grant was received by the Child Abuse-Death Review CADR19 in October 2017 to provide reenactment training and 11 dolls to the 4-county area including St. Lucie County, which will improve assessment of these cases and illuminate strategies to prevent sleep related deaths. Training will occur in Spring 2018.

FIMR DATA RETRIEVED FROM RECORDS

Hospitals, medical practices, EMS and other agencies have provided their records to the FIMR program in a timely and confidential manner. Both the Administrator of the Florida Department of Health in St. Lucie County and the Surgeon General and Secretary of Health have written letters to disseminate to agencies explaining the FIMR program, and delineating the statutes that provide access to records for public health research. Data from all agencies involved are collected, kept under quadruple lock, de-identified for review and then shredded after the review process. The data received from health and other agencies were entered into the BASINET system along with the data collected in interviews.

DATA GATHERED FROM INTERVIEWS

FIMR is a unique program in that families who experience fetal and infant loss are interviewed to elicit their perspective. Although it is difficult for parents to relive their sad experiences they often express gratitude to be able to discuss the situation and are hopeful that sharing might expand knowledge and prevent fetal and infant loss in the future.

Parents were asked to "tell their story" in interviews. They discussed many issues regarding their experience. The valuable information they shared enhanced data interpretation. Parents relayed positive and negative incidents. One issue that parents often mentioned as a problem during pregnancy was access to care. Parents had to travel distances to see their Health Care Provider (HCP). Some did not have transportation or found it difficult to drive far. Parents also discussed problems with day-care and missing work to go to appointments. If moms had referrals for high-risk care, they sometimes had to visit their regular HCP in addition to the high-risk provider which compounded the issue.

Lack of finances also hindered care. Mothers discussed insurance running out during pregnancy when they were on temporary Medicaid or getting insurance late in the pregnancy. Parents reported having to pay for tests, transportation and appointments out-of-pocket which was prohibitive.

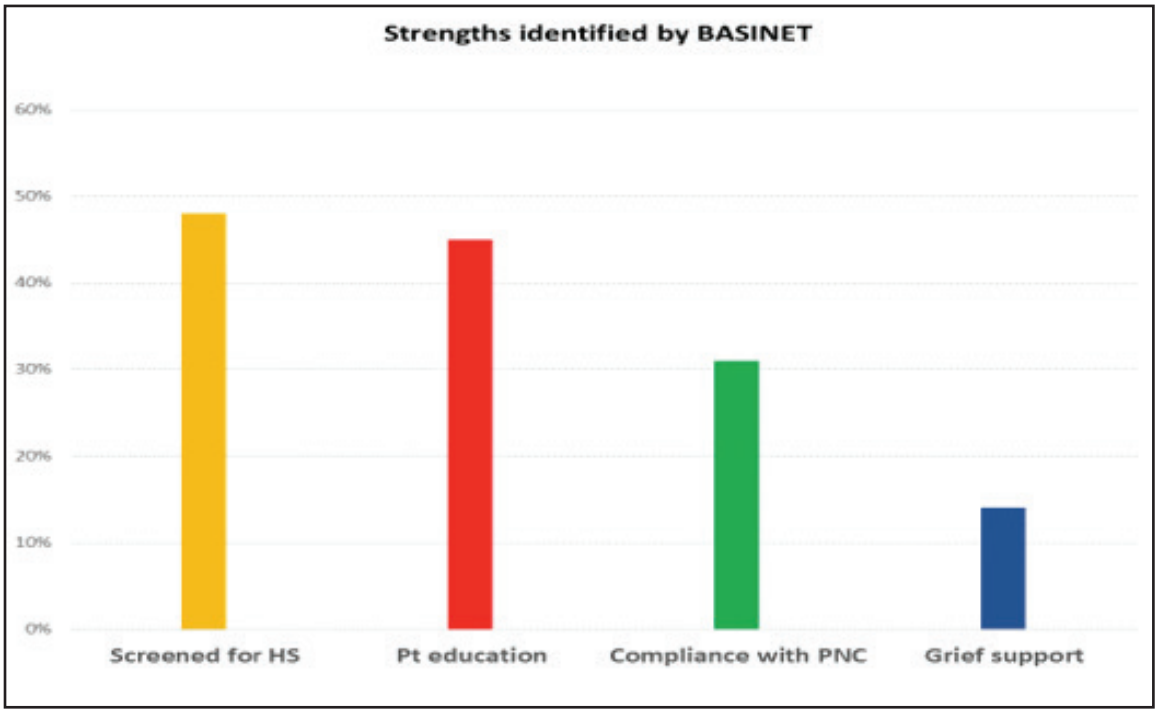
Communication was another problem identified during interviews. Parents' reports of their experiences and care differed from the written records. These 3 areas; access to care, finances and communication were issues discussed by the participants in the Case Review Team (CRT) meetings.

CASE REVIEW TEAM

Data from medical records and interviews were entered into BASINET and presented at the CRT meetings. Twenty-six cases were reviewed. Brief demographic data is listed below:

DEMOGRAPHIC DATA	# CASES
Age 17-19	4
Age 21-25	7
Age 28-31	3
Age 32-34	3
Age 36-39	5
Hispanic	6
Caucasian	1
Black/African American	15
Single	18
Married	4
High school diploma or higher	14
Zipcode 34947	8
Zipcode 34950	9
Other zipcodes 34953, 34982, 34983	5

At the CRT meetings, participants considered and expanded on strengths of each case, contributing factors that affected the outcome and made recommendations, in addition to those generated by BASINET. Strengths, as aggregated by BASINET, can be visualized in the following graph.



Being screened for Healthy Start was the most common strength identified by BASINET. The importance of Healthy Start services was discussed at CRT meetings. Healthy Start is a valuable program in which education, referrals and assistance is provided to expectant mothers. Some of the mothers who suffered a loss had declined Healthy Start, were not found for services or did not complete a screening. Perhaps receipt of Healthy Start services would have improved outcomes.

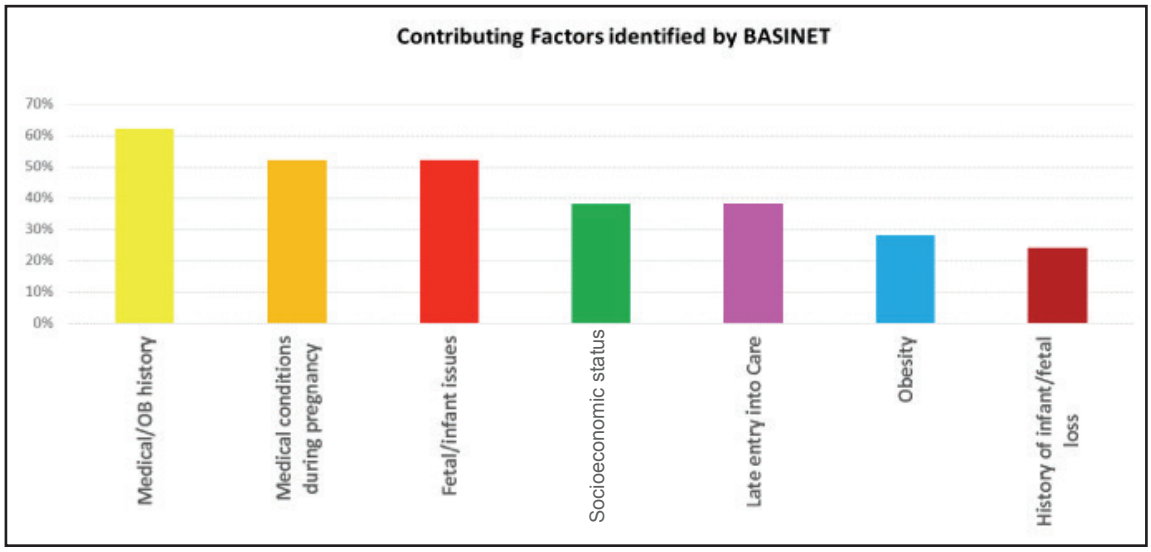
Patient education, another strength detected in BASINET, is a common component of prenatal services. However, the notation of education in records reviewed, varied. Some prenatal visits included narrative summations of education, others had a check list and some had little notation regarding education. In CRT meetings, the issue of patients' not understanding, language barriers, lack of time to provide education were discussed as those issues were apparent in the case abstracts.

Compliance with scheduled prenatal visits and entry into prenatal care in the first trimester did not always occur in the cases reviewed. According to BASINET compilation of the data, 31% of mothers (whose cases were entered into BASINET) had prenatal care as recommended and scheduled, 69% did not. Inadequate prenatal care occurred when either the mother entered care late (in the second or third trimester) or missed appointments.

Participants in the CRT discussed that every mother and/or family has strengths; the most common being their support system. Mothers discussed their offspring, significant other, spouse, and mother as being present and mitigating their pain, in interviews. Other strengths not calculated by BASINET but discovered in interviews and CRT meetings related to strengths in the community. They included the resiliency of families in the SLC community, their willingness to revisit the difficult situations they experienced to help others and the concerned group of citizenry, generous with their time and knowledge who come together every other month to review cases, interpret situations and make recommendations.

CONTRIBUTING FACTORS

After strengths were considered, the contributing factors for each case were compiled. The contributing factors that were identified for the deaths and demises reviewed are as follows:



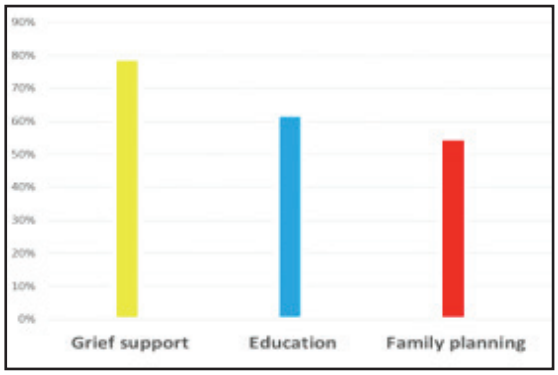
The most common contributing factors identified by BASINET for the cases reviewed of fetal demises and infant deaths were medical and obstetric history and conditions of the mother. Examples of medical problems included hypertension (HTN), diabetes and infections. Infections reported in cases reviewed at CRT meetings included Chlamydia, Group B Streptococcus, Herpes simplex, Cytomegalovirus, yeast and chorioamnionitis.

Fetal and infant issues also contributed to demise and death. Low birth weight of the infant was a common contributing factor as noted on fetal death certificates. Low birth weight may be the result of prematurity (preterm birth), intrauterine growth restriction (IUGR) and/or a health issue of the mother.

Other problems identified as contributory to poor birth outcomes in BASINET were late entry into care, history of prior fetal or infant loss and socioeconomic (SES). In BASINET, SES issues are defined as mother's age under 18 or over 35 years, emotional and childhood stressors, abuse, poverty and lack of support. The problem of weight was also identified in BASINET for the cases reviewed. Of the 26 cases, 2 of the mothers were underweight, 8 were normal BMI, 3 were overweight and 9 were considered obese. In the FIMR process the next step to solve these problems to improve birth outcomes is the generation of recommendations.

RECOMMENDATIONS

Recommendations and suggestions to improve birth outcomes were created by both BASINET and the CRT.



Education that is needed in the community according to the data entered into BASINET by FIMR for St. Lucie County included:

- Safe sleep
- Importance of Healthy Start services
- Risks of obesity
- Importance of early prenatal care
- STD prevention

Services that were recommended for inclusion in family planning included:

- Genetic counseling
- Appropriate birth spacing
- Importance of being healthy prior to pregnancy

The recommendations/suggestions generated from BASINET overlap with the recommendations identified from the case reviews at the CRT meetings. The recommendations identified at CRT meetings are displayed below and are grouped according to the entity most capable of addressing the issue:

COMMUNITY ACTION TEAM (CAT)

- Improve access to prenatal and high risk prenatal care.
- Expand mental health and genetic counseling services.
- Increase autopsy rates for infant deaths.

HEALTH CARE PROVIDERS

- Treat diabetes more aggressively as appropriate, perhaps with Insulin.
- Provide (and/or note) education regarding weight gain, exercise.
- Increase use of contraceptives (long acting reversible contraceptives (LARC) before discharge.
- Offer support resources for moms informed of poor prognosis.
- Assess communication issues when providing families information on diagnosis, treatment.
- Contemplate ways to suggest supplementing breastfeeding with formula when necessary, to avoid moms switching completely to formula.
- Promote safe sleep.

HEALTHY START/FIMR

- Collect and analyze data regarding maternal infection rates.
- Gather information regarding environmental, occupational risks, cooking practices, folk medicine.
- Prolong breastfeeding.
- Empower moms to request what they need; more time with HCP, extra prenatal visits, etc.

HOSPITALS

- Champion valuable, free Healthy Start services.
- Model safe sleep in the hospitals.
- Inquire as to sleep arrangements for baby prior to discharge from the hospital.
- Teach CPR to all new parents (don't limit CPR to parents of babies in the NICU).
- Arrange post-partum (PP) appointments for mothers, prior to discharge.
- Add PP home visit notes to hospital records, which includes breastfeeding assessments and support

All recommendations generated by data collected through the FIMR process, entered into BASINET and reviewed with the CRT will be addressed and implemented in year 2 of FIMR by the CAT and on a one-on-one basis with the agencies as noted. Implementation of the identified recommendations will hopefully decrease racial disparities in infant mortality rates in St. Lucie County.

Community Action Team

The CAT will be composed of community members, including elected officials, community leaders, representatives from the health department, justice system, transportation, health care professionals and others who are key to system change. St. Lucie County is fortunate to have the presence of a Roundtable, whose members have been instrumental in making positive changes in St. Lucie County. Their expertise will be solicited, too. The first meeting of the CAT was February 23, 2018.

The participation of the community and their ability to execute recommended interventions is crucial to decreasing the racial disparities in St. Lucie County. Priorities for the CAT, illuminated after one year of FIMR case reviews, include improving access to prenatal and high-risk prenatal care, to improve health problems in expectant Mothers, thereby improving birth outcomes. Expansion of current high risk services to north St. Lucie County and/or recruitment of new high risk providers to service the area will be attempted. Other interventions include partnering with the Florida State University Medical School and the Indian River State College Nursing program to determine the possibility of projects incorporated into course work to interact with mothers in need of education, monitoring and referral. Another need in St. Lucie County is increa ing access to genetic and diabetes counseling.
Genetic counseling sevices are available one day/ week in St. Lucie County. Expanding those services or acquiring new counseling services is a task that will be pursued by FIMR.

Provision of education including early prenatal care, proper nutrition and obesity, signs of problems in pregnancy and safe sleep are areas which need to be uniform, constant and prolific. Securing informational videos for waiting rooms and obtaining buy-in to run them in offices will be solicited. Streamlining, updating and standardizing educational literature on pregnancy, childbirth, breastfeeding, safe sleep and childcare has been discussed and will be implemented in the second year of FIMR.

The need to modernize pregnancy and childcare education and make it accessible in social media is urgent. Attendance at on-site classes has dwindled. Perhaps providing more education on-line will provide access in a more palatable medium for new Mothers. Ascertaining the use, utility and effectiveness of the app text4baby in our community is necessary. After assessment, the need to create new apps or expand advertisement for text4baby will become apparent.

The Direct On-site Education (DOSE) program from Broward County will be provided to First Responders to educate families during non-emergency calls on safe sleep. DOSE advocates first responders inquire as to the baby's sleeping arrangements and partners with community agencies to obtain cribs and bassinets.

Working with the wonderful health care providers and families in St. Lucie County has been an honor and a privilege. It is hoped that in Year 2 of FIMR we can make progress in reducing the racial disparities by implementing the recommendations created through the diligent efforts of the Case Review Team.

THANK YOU

A special thanks to those who participated in the case reviews of St. Lucie County's FIMR. We could not have implemented FIMR without your willingness to share your vast knowledge as we reviewed the difficult cases that the families of St. Lucie County have suffered. Discussion of losing babies before their first birthday has been emotionally strenuous. The CRT participants looked towards the goal; reducing the fetal and infant mortality rate, and can take solace in knowing that their assessment and recommendations hopefully will ensure that parents, siblings and families will not have to endure the pain of losing the one they were awaiting with great expectation and joy.

CRT Participants 2017

Michelle Akins
Angela Bell
Chief Brian Blizzard
Heather Brigance
Jennifer Chandler
Mally Chrulski
Robyn Connor
Raymond Correa
Jim Dwyer
Sonya Gabriel
Tricia Goulet
Amy Gregory
Jennifer Harris
Beth Hawn
Pastor Hazel Hoylman
Dr. Ruth Kim
Kim Kossler
Dr. Juliette Lomax-Homier
Erin Mercado
Dr. Rebecca McPherson
Edgar Morales
Michelle Peaslee
Laurie Prim
Mary Ranier
Angela Roberson
Daphne Shaffer-Petersen
Lorna Sinclair
Angela Smith
Clint Sperber
Mikaela Stoessel
Dr. Ruel Stoessel
Kathy Swan-Fitch
Lisa von Seelen
Dr. Sofia Thomas
Dr. David Walters
Dr. Silvestris Zarins

Dr. Charles Zollicoffer

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FETAL & INFANT MORTALITY MATTERS

FETAL & INFANT MORTALITY REVIEW

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