USING ACTION RESEARCH AND DELPHI STUDY TO CREATE NATIONAL PROTOCOL

INTERDISCIPLINARY GUIDELINES FOR CARE OF THE WOMAN IN THE EMERGENCY DEPARTMENT WITH PREGNANCY LOSS

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OBJECTIVES

• Attendees will define action research and delineate how it can be used to change practice
• Attendees will define Delphi research and be able to explain its use
• Attendees will become familiar with the need for and creation of Interdisciplinary Guidelines for Pregnancy Loss in the Emergency Department
• Acknowledge audience
JOURNEY

• Tried for 8 years to get into ED to encourage bereavement support
• Had many protocols already: Stoke Protocol; Myocardial Infarction Protocol; Poisoning Protocol
• “We know how to take care of the specimens”
• “We treat and street”
• “We don’t do vaginas”
• Yet 75% of losses discharged from ED
ACTION RESEARCH

Goal: To Create a Position Statement and Interdisciplinary Recommendations to Support the Needs of Women and Families Who Present to the Emergency Department with Pregnancy Loss
ACTION RESEARCH (Craig, 2009)

Looking to Change Practice

Research to Provide Framework

Use Qualitative interview

Story is Told

Story is Examined
Identify Patterns/Views/Barriers
Hold Focus Group to Check Reality
What Will Work for This Group?
Program is Co-Created by Researchers and Participants
Policy Created
MANY TYPES OF PERINATAL LOSS

• Blighted Ovum
• Miscarriage (Complete, Incomplete)
• Ectopic
• In Utero Demise (Under & over 20 weeks)
• Assisted Reproduction and Multiples
• Stillbirth
• NICU or Home with Hospice
• Pregnancy Interruption (Medical/Social)
• Giving baby up for adoption
• Safe Haven
• SIDS
• Infertility
### USE OF TERMS MOTHER AND BABY

<table>
<thead>
<tr>
<th>Pregnant</th>
<th>Not Pregnant</th>
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75% of families losing an early pregnancy referred to the woman as the mother and the products of conception as a baby  

“He was a Real Baby;”  “He is Worthy of Memory;”  “He had Things”
EARLY LOSSES
(Cole, 2010)
Artwork and book by Stephanie Cole
DESIGN

• **Design:** A 3-year triangulated non-experimental exploratory action research design shaped the plan of collecting information upon which to base a solution.

• **Methods:**
  – 2014-Qualitative study of 16 emergency room nurses and physicians to assess beliefs/barriers to providing optimal care for pregnancy loss patients
  – 2015-Focus group of 40 national perinatal bereavement providers
  – 2016-Sponsored National Summit of 17 representatives from medical and nursing professional groups and 14 other professional and lay experts
  – 2016-Delphi Study of 4 rounds with 30 persons to craft language for national position statement
  – 2017-Publication, adoption, dissemination
LITERATURE REVIEW - WHAT DO WOMEN NEED

All references available

• ‘Be with” - compassionate care by all staff
• Understanding by staff that may be loss of dreamed-for child
• Coping skills, stages of grief, differing intensity, prevention of pathology
• Culturally sensitive care for their own interpretation - Choices
• Guidance specific to stage of loss from early miscarriage or ectopic pregnancy to stillborn or neonatal
• Allowing women to see products of conception from a miscarriage or ectopic pregnancy
• Ability to dress and hold the fetus/infant
• Photography and memento offering
• Funeral/Memorial Planning
• Lactation cessation and donation
• Referral to support groups
LITERATURE REVIEW - CARE IN THE ED FOR PREGNANCY LOSS

- Mismatch between emotional needs of patients & focus on physical care delivered by clinical staff
- Women received little to no emotional support when losing a pregnancy.
- ED nurses were at odds with patient’s perceived needs
- Death of a child, especially from child abuse, was one of the most stress-provoking issues in the ED
- ED nurses report high levels of stress in ED
- ED nurses needed more education and training on perinatal bereavement than other nurses in the healthcare system
- Using the Perinatal Grief Scale, two groups, one received trained care, one status quo, a difference of p<.0001 in the despair level in the two groups, showing that implementation of the bereavement support program made a difference.
GUIDANCE FROM GROUPS

• Emergency Room Nurses Association
  – Position Statement on *The Obstetrical Patient in the ED* directs care for pregnancies over 20 weeks to the labor and delivery department.
  – The paper states “the emergency department may not possess adequate resources and personnel to care for the obstetrical patient...”

• AWHONN-- Nothing from

• NPA – Perinatal Palliative Care /No ED mention

• NANN – Perinatal Palliative Care /No ED mention

• The American College of Emergency Physicians (ACEP) P
  – Policy Statement refers to providing emotional support to parents upon a child’s death.
  – The statement does not mention pregnancy loss or providing bereavement support in any population

• American College of Emergency Medicine--Nothing
THEORETICAL FRAMEWORK

• Complexity theory
  – Environment - chaos
  – Nonlinear thinking
  – Cannot impose order from above
STEP 1. QUALITATIVE INTERVIEWS IN PERSON/ON LINE

– Community Hospital in Northern California
– 5 pregnancy losses per week
– Nurses and physicians in ED (n=16)
– Questions:
  1. What is the care needed by those with pregnancy loss? and
  2. What are the barriers (if any) to providing this care?
METHOD

• NATURALISTIC INQUIRY  Miles and Huberman
  – Interview until Saturation
  – Transcribe
  – Line by Line Analysis
  – Immerse Self in Story
  – Codes \rightarrow Themes

• RIGOR/TRUSTWORTHINESS
  – Bracketing prior assumptions
  – Keeping a field notebook
  – Having a second person review the transcripts
16 INTERVIEWS to SATURATION

WHAT ARE THE NEEDS?

• Well aware of the emotional trauma that the women were undergoing

WHAT ARE THE BARRIERS?

• No training on provision of pregnancy loss support
• Poor support for women needing a dilation and curettage in the ED, citing both lack of adequate pain medication during the procedure and lack of any bereavement support afterwards
• Did not feel that the emotional component of this loss was their issue to treat, most often citing lack of time as a reason
• Suggested that the solution was to have others come into the ED to provide this service, such as the obstetric nursing staff, the chaplains, or the social workers
  Presently had no such relationship with the obstetric nurses
• Lack of designated chaplain and/or social workers on duty at night and on weekends
• Did not provide follow-up bereavement care nor notify anyone of a pregnancy loss that occurred in the ED for purposes of bereavement follow-up.
PLIDA
Pregnancy Loss and Infant Death Association

“Formal network and a unified international presence to increase awareness and education focused on the emotional experiences and needs of bereaved families”

International Conference in 2015
Verify Findings with Expert
Focus Group on ED and Pregnancy Loss
FOCUS GROUP METHODOLOGY

• Small group of people that have similar interests or experiences
• Can be used to
  – Solicit opinions on which to build programs
  – Evaluate programs you have built
• Information obtained more quickly and at lower cost
• Researcher/educator can interact directly with participants
• Flexible in direction
• Security for participant
  – Gives courage to speak up
• Spontaneity
• Snowball answers
• Synergy
• Allows for in depth scrutiny by recording and analyzing data
VERIFICATION

• 36 perinatal bereavement nurses, social workers and counselors
  – All had tried to bring support into the ED with low levels of success
  – Most had given up trying
  – 2 were admitting all losses to L and D
  – Verified my findings
  – Willing to continue working on this

• 2ND Verification: Jill Wilke, MSN, National Expert on ED and Loss
MUST COME FROM EMERGENCY NATIONAL ORGANIZATIONS THEMSELVES

- Will they accept perinatal bereavement part of their responsibility?
- They could say no
- Position paper –could say yes or no
- Must settle this to get women and families the care they needed
NATIONAL PERINATAL ASSOCIATION

• National, Interdisciplinary Organization
• Maternal Child Health, Woman’s Care
• Presented to Board of Directors about the problem and what I had tried
• Would they help me?
• They said yes
• 4 hour sponsored Summit
• 10 months to Plan
• Obtained funding from Kaiser Northern California Nursing Research Community Benefits Grant
  — Gretchen Summer Gafford, PhD, RN support
SUMMIT OF NATIONAL STAKEHOLDERS

- Sponsored by National Perinatal Association
- Funded by Kaiser Permanente
- Invited and funded 17 Professional associations to send leader
  - Am College of Emergency Room Physicians
  - American Academy of Emergency Medicine
  - Emergency Nurses Association
  - American College of Obstetricians and Gynecologists
  - National Association Perinatal Social Workers
  - American College of Nurse Midwives
  - Association of Women’s Health, Obstetric and Neonatal Nursing
  - Experts in field- Resolve through Sharing, PLIDA, SHARE
  - Deborah Davis, Sherokee Isle, Rana Limbo, Jill Wilke
- Opened to 17 other stakeholders such as obstetricians and nurses, social workers, parents who had loss and became activists
FOCUS GROUP METHODOLOGY

• Planning by key stakeholders
• Inviting the right people (professions, lay experts and parents)
• Choosing a moderator
• Preplanning and mental preparation
• Giving license to differing points of view
• Capturing the conversation
• Summarizing
• Conscientiously analyzing the results
• **Overall Goal**: Provide quality standard of care for women and families with a threatened or ended pregnancy, which includes these medical diagnoses: ectopic pregnancy, blighted ovum, complete or incomplete spontaneous abortion (miscarriage), in utero fetal demise, fetal stillbirth, which occurs in or is presented to the Emergency Department.
PRE-AGREEMENT REGARDING EMERGENCY DEPARTMENT

- The ED is a busy, stressful, department for the staff who work there
- Nurses and physicians are often handling multiple patients/situations at once
- Providing care for unexpected events, often outside of regular doctors’ hours, is an essential role of the ED
- Saving lives appropriately is main function
- Personnel well trained for emergency life saving, trauma procedures
- Triage is based upon ability to provide life saving or essential care to restore normal physiological function
- Ability to interpret presenting signs and diagnostic tests are crucial
- Moving patients through and out of the Emergency Department is an essential goal, as is decreasing wait time
CONSENSUS STATEMENT ON RELATIONSHIP

• Early pregnancy kits allow for early relationship building
• Ultrasound has given identification, naming, and parenting a new face
• The concept of mothering/parenting may begin early in gestational development, or earlier, in a dreamed-for wish.
• Many families may consider a fetus as significant as a born child and begin to bond very early in pregnancy
• Wilke has termed the loss of a desired pregnancy as an “Emotional Emergency”
• After 20 weeks gestation, this loss most often invokes an entire bereavement protocol within maternal child departments
• In most hospitals, prior to 20 completed weeks, this loss is treated in the Emergency Department
• Approximately 75% of all pregnancy losses are discharged from the Emergency Department
4 Hours-Prereading, Ground rules, Agreements, Moderator, Didactic Speakers on Facts, Legislation, Small Groups, ED provider in each group, Large Group

QUESTIONS
• Who should do this?
• Where should this be done?
• How can it be done?

ANSWERS
• The ED Staff
• In private space in the ED
• Through training and creation of protocols
• No preconceived ideas
• Respectful of chaos
• Lay people who had become activists were most influential
• Listened carefully and took notes

• Result: ED would provide the appropriate care, ED would be the place, ED would accept training, Position paper would be written
STEP 4: DELPHI

- Notes from Summit
- Based upon position statement for ED Physicians on a Child’s Death in the ED
- Drafted 27 statements
- Delphi Process
  - Excellent modality for consensus building
  - 15% physicians, 55% nurses, 9% social workers, 8% counselors, 12% parents/lay leaders (22 per round)
  - Targeted language for the guidelines that was inclusive, accurate, sensitive, and achievable
  - Done by mail (post or email)
  - Sent, accepted, resend, consensus
  - Lobbying
DELPHI PROCESS  4 months

Sent 27 statements

ROUND 1
Over 70% agreement=Accept
Less than 70% Revise or Reject
12 accepted
16 revised
1 rejected

ROUND 2
16 sent out
12 accepted
4 revised
One physician dropped out

ROUND 3
4 accepted
2 added

ROUND 4
Paper Finalized
100% acceptance
GUIDELINES
nationalperinatal.org

27 sections
• For some, loss of a pregnancy is as serious as the loss of child
• ED staff responds dependent upon response of the patient and family, her culture, spirituality, and attachment
• Meet both physiological and emotional needs of the patient with pregnancy loss both in the ED and at home
• ‘Wait and Watch’ period is described
• How to care for products of pregnancy, from miscarriage to fetus, in suction canister or bedpan, with dignity
• Although focused upon the gestation under 20 completed weeks, instructions for care of the full-term fetal demise in the ED included
• Family resources cited
• Creating bereavement support mementos
• ED administration support for this initiative
• Debriefing support for staff in difficult cases.
Interdisciplinary Guidelines for Care of the Woman with Pregnancy Loss in the Emergency Department

- Adoptions by Nursing Organizations
- Publications in Nursing and Medical Journals
- On Line Websites
- Presentations, including at ENA
- Influence on Quality of Care
USE OF COMPLEXITY THEORY TO EFFECT CHANGE

Tiny drops of water
Continuous Relationships

Impression and change can be made
NURSES CAN ADVOCATE

- Can change health policy
- Have colleagues and mentors who support you
- Do not be afraid
- Pay your dues
- Be a member of your professional organization
- Act nationally
- Let others know that standard of care is expected
- Do not give up (Published first paper on this in 1986)
- It will happen