An exploration of the experiences of mothers as they suppress lactation following late miscarriage, stillbirth or neonatal death.

Denise Mc Guinness
CMS Lactation
RGN RM MSc Dip N Admin. BMS IBCLC
Supervisor: Dr Barbara Coughlan UCD
Remembering
The Perinatal Statistics Report 2012

Ireland 2012

• 424 perinatal deaths (281 Stillborn babies and 143 early neonatal deaths)
• The perinatal mortality rate was 5.9 per 1000 live births and stillbirths

Great Britain 2013

• 10 babies are stillborn every day (Sands UK 2013)
• SANDS The stillbirth and neonatal death charity UK- in 2013 over 5700 babies died before, during or soon after birth which is approximately 100 babies every week
Research Questions

• What are the experiences of lactation suppression for bereaved mothers?
• What helped the bereaved mother best manage engorgement?
• Are non pharmacological methods of pain relief effective?
Research Questions

• What support do bereaved mothers need during their time in hospital and when they return home following the death of their baby? (in relation to breast care)

• How can the breast care leaflet currently available be improved?
1. Prior to pregnancy, few alveoli exist. 2. Early pregnancy: alveoli grow. 3. Mid pregnancy, alveoli enlarge and acquire lumen. 4. Lactation.
Engorged breasts
Pilot interview
Methodology

- Exploratory qualitative study
- Focused ethnographic approach
- A purposeful sample selection of 15 bereaved mothers who had experienced the loss of a baby within the previous 6-12 months were interviewed.
Qualitative Research

Focused ethnography- small scale ethnography

• Number of participants limited.

• Objective: Information from people with knowledge and experience subject (Meucke, 1994)

• Subcultural group-bereaved mothers with engorged breasts/breastmilk (Richard and Morse, 2007)

• Topic area known to the researcher (McNeill and Nolan, 2011)

• Field work omitted-Interviews.
Participants

- Purposeful sample- relevant to the research question
- Bereaved mothers: previous 6-12 months
- Age 28-44 years
- Para 0+1...5
- Para 1...... 6 mothers
- Para 2...... 2
- Para 3.......2
- Nationality ...Irish National/EU/ non EU
- Professional/non professional ........8:7
Ethics

• Study hospital
• UCD.... Exemption
• Clarify how initial contact with mother will occur.... gatekeeper
• Remove question on use of medication to stop lactation.
• Post interview protocol.
Data Collection

• Semi structured interviews- focus on bereaved mothers
• Location
• Time
• Humanistic approach... Carl Rogers(1967)
• Trust- CMS Lactation V Researcher
• Communication skills/clear guidance
• Research with bereaved ..educational /therapeutic (Dyregrov, 2004 Hynson, 2006)
• Gibbs – reflection/ Research diary
Response Rate

- Yes: 55.5
- No: 44.5
Data analysis

Coding framework
1. Mammogenesis
2. Attachment theory
3. Newer grief theories
4. Salient issues

Thematic Networks Analysis (Attride Stirling, 2001)
• Global
• Organising
• Basic
Findings


2. Motherhood.

3. Supportive care needs and the bereaved mothers experience.
1\textsuperscript{st} Global Theme

Managing Physically

Suppression of lactation: silent Tears

Managing Emotionally
Managing Physically

- Leaking milk
- Sore breasts
Managing Physically... sore breasts

“so painful and like rocks”.. Melanie  25/40 P1

•  ... “They felt heavy and sensitive... a dull pain”. Helen  42/40 P1

•  ...“I don’t know if it was the cabbage leaves or the coldness but just the relief from putting a cabbage leaf onto you...it was brilliant.” Cora 27/40 P3
Sore breasts at the wake and funeral

“...I do remember ending up structuring myself so that my left arm was doing the ...hug... I put my right arm in like in front of my chest almost able to push the person back if they were getting a little bit too close”. Anne 41/40 P1

“...It was a busy day I was expressing every 3 hours... I probably pushed it out to 5 hours at that stage.” Anna 24+6/40 P2
Managing Physically

Leaking milk
“I had 3 children and the milk was coming as I just gave birth...I feel it’s the same”. Asha 22+1/40
“I had to put in 2 or 3 pads at a time” Cora 27+4 P3

Sleep disturbances
“when I was in bed I woke up and I had a massive leak. My pyjamas were completely drenched, you could ring them out they were that bad”. (Janice 35+1/40 P1)

Length of time
‘...I’m nearly sure it went on for 2 weeks’... Jill 20/40 P1

“the leaking ended after 2 weeks but I could get milk out of my breasts 6 weeks later”. (Sarah, 26+6/40 P2)

Ergot alkaloids
Managing Emotionally

Upset

Unexpected
Managing Emotionally

Unexpected
• Early gestation.. Book!
• first time mothers
• “why can’t this go with the baby” Melanie 25+4

‘The pain was just painful and the fullness was just uncomfortable but I found the fact that it started to leak was emotionally very difficult’…Cait 23/40

Upset
Breast pads‘…I’m sure it would invite questions from the chemist’…
‘… I hated having a shower, I would put it off. I am in the shower with no baby and full breasts… so I would cry in the shower regularly, it was just a very, very hard time’…Sarah 26/40
Recommendations reported directly from mothers interviewed

1. Give us as much information as possible. Sore breasts and leaking milk are not on the top of your mind when your baby dies but it’s something you have to look after. Tell us around the time of the baby’s funeral we are going to be expecting these things.
Recommendations from mothers

2. I didn’t realise my body was going to react so badly. I didn’t realise I was going to be as emotional as I was. That information should be given to the next person.
Breast Care following the loss of a baby: Tell mothers....

One of the most distressing physical symptoms following the death of a baby can be breast pain and the production of breast milk.
Engorgement

Tell Mothers...

• The breasts may become engorged (feel full, tender and hard) between 2-5 days following the birth of their baby.

• The breasts may feel uncomfortable and leak milk for up to 7-14 days.
How to relieve engorged breasts

• Take regular pain relief
• Wear a support bra all the time
• Use breast pads to absorb leaking milk
• Use cold compresses on the breasts
• Apply washed and chilled cabbage leaves to the breasts
• Have a warm shower but ensure water jets are not directly on the breasts
• Sleep in a semi upright position (pressure from heavy breasts)
Other helpful suggestions

• If the breasts feel very full.... Express a little milk for comfort.
• Wear breast pads.
• Wear a patterned top.
• At the funeral....Sit down
  ...Support breasts with your arm
Reducing Your Milk Supply

A. Express a little milk for comfort  OR
B. If mother was expressing regularly for a premature or ill baby suggest the following:
   Day 1. Pump each breast for 5 minutes every 4-5 hours
   Day 2. Pump each breast for 3-5 minutes every 6 hours
   Day 3. Pump each breast just long enough to relieve discomfort.
Milk Donation

• Enniskillen Milk Bank in Northern Ireland

Helping other babies
2nd Global theme

Mothering

Shortened mothering

 Mothers and grief
Shortened Mothering

- Baby names
- Mementoes
- Family bonding and the journey
- Connecting
- Time with the baby
- Holding the baby
Shortened Mothering

<table>
<thead>
<tr>
<th>Connecting</th>
<th>Time with the baby</th>
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<tr>
<td>• 20 weeks... missed feeling</td>
<td>• Autopsy</td>
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<td>• “...that was the one thing on my mind, OK, rest and express milk. He needs milk straight away...” Melanie 25+4/40 Para 1</td>
<td>• “…We thought he was going to be there the next day...he went downhill so quick...I saw him and he died within 2 minutes....” Melanie 25+4/40 P1</td>
</tr>
<tr>
<td>• Expressing milk</td>
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<tr>
<td>• Separation</td>
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Shortened Mothering

Holding the baby
“... I was frightened... I was frightened about seeing this...nothing prepares you for that....” Sinead 23/40 P1+0

“... it all came through, yes! Please I do want to have her blessed.... I was really appreciative of that...” Sinead 23/40 P1+0

Family bonding
• Young children...photo
• Shopping for an outfit
• Home for night
Shortened Mothering

Mementoes
Create memories
Short window of opportunity...photo’s
“...it was the hardest thing having to smile in the photo holding your baby....”
Mothers were the lead figure

Baby Names
• Refer to baby’s name
• Returned to work..
Mothers and Grief

Other children to look after

Unviable Baby

State of Being
Mothers and Grief

State of being

• Shock, numbness, helplessness

• “...I still can’t and I would love to be able to remember holding Ronan...”

• “…the hospital are really good at guiding you as to what to do next....”

Unviable baby

• 20 week scan
• Pregnancy...home country.
3rd Global Theme

Supportive care needs and the bereaved mothers experience
Hospital Support

• “...She was really very good at listening, just listening at what I am saying....it meant a lot...just for someone to listen, that’s all...” Asha 22+1/40 P3

• “... I needed most ... warmth, friendliness, support, care and sensitivity...understanding, that you felt a bit precious... people who were nice to you... that meant everything... Sinead 23/40 P1+0
Hospital Support

• ...Mary, Is there any chance I could have the cardigan? I will replace it with new stuff, I will get you a basket of stuff....” Cora 27+4/40 P3

• ...“everyone was extremely kind and were very supportive and I think went over and above the call of duty”. Cait 23/40

• ...Its only afterwards you appreciate what it is they had done...” Sally 28+6/40 P1 +0
Family Support

• Irish national mothers/non national mothers
• “...our wedding party” Helen 42/40 P1
• “...I sadly, you know remember that I had no one around me”... Asha 22+1 P3

• Mothers and fathers grieving.
• “...I found it very, very hard when he went back to work... I just couldn’t understand how he could go back to work”. Cora 27+4/40
• “...It was a difficult time and still is”. Sarah 26+6
Community Support

• “I wasn’t even expecting to see the district nurse, she just called one day... it could have been maybe 2 weeks after. She was just literally here for a chat to see how I was and to make sure I was looking after myself and everything...” (Cora 27+4/40 P3)
Community Support

• “... it was a physical conversation, 5 minutes and that was it.... My husband had left the room to see if she wanted to check me over... and my scar. She didn’t do any of it...”

Melanie 25+4/40 P1
Clear communication

Specific to breast care
Communication

Breast Care

Less of a shock where information was received...

• “you will feel the fullness and you will probably get a bit of milk and the best thing probably would be to not let water run off them in the shower...” Melanie 25+4/40

• “because I was told like.. to get some of the breast pads... that kind of prepared me” Alison 20+5/40 P0+1

Breast care leaflet

Pilot leaflet was reviewed during interviews.

• “I used the timetable and it worked...” Anna 24+6/40 P2

• “read like a less significant experience than I was having... particularly the 3-4 days and that the pain would relieve itself after 24/48 hours...” Anne 41/40 P1
Hand expression technique on leaflet

• “... I was reading the leaflet and it said when they got really sore you should try massage it out but it just didn’t seem, nothing seemed to be working and its just they were so tight, it felt like they were going to explode... and I didn’t really know what to do...” Jill 20/40
“...I think maybe if that information is given to the next person... these are the things that when you are feeling low they just push you even lower, make you feel a little bit lower, so if you are more prepared for it when it happens it won’t be the thing that makes you cry that day...”
Communication skills
Role of the midwife

“Bereaved parents never forget the understanding, respect and genuine warmth they receive from staff. The care can be as lasting and important as any other memory of their lost pregnancy or their baby’s brief life” (Leon, 1992).
3. Give us as much information as possible. Sore breasts and leaking milk are not on the top of your mind when your baby dies but it’s something you have to look after. Tell us around the time of the baby’s funeral we are going to be expecting these things.
Recommendations from mothers

4. I didn’t realise my body was going to react so badly. I didn’t realise I was going to be as emotional as I was. That information should be given to the next person.
Mother’s Recommendations

5. Tell us more about recovering physically following the birth. You don’t have people giving you the same advice as they would if you had a healthy baby.

6. A phone call a few days later with information regarding the physical aspect of care. A letter of condolence from the doctor would be appreciated.
Mother’s Recommendations

7. I think there should be more support for mothers when they are in another hospital and separated from their baby.

8. Tell us about the labour and where and when we will deliver.

9. I think a mother should see her baby straight away regardless of what state they or the baby is in.
Mothers’ Recommendations

10. I think women who have a late miscarriage or stillbirth should get the same quality of care that other women with term babies have. Women should have a designated place for their own privacy.

11. I think counselling should be more readily available locally.
Mothers’ Recommendations

12. I think information regarding the autopsy should be told as it is. People should be more true to you.

13. Take as many photographs as you can.

14. I suggest a photographer who takes pictures. Take the photos soon afterwards. Tell us the right kind of pictures to take... your hand with his hand..... Looking at his foot on your hand.
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Any Questions ?
REFERENCES


