Stop, think, reflect, realise
first-time mothers’ experiences of taking part in longitudinal maternal health research

Dr Deirdre Daly, Assoc. Professor Margaret Carroll, Dr Monalisa Barros, Professor Cecily Begley
&
the MAMMI Study research team
Stop, think, reflect, realise

- Overview
  - Background to the Maternal health And Maternal Morbidity in Ireland (MAMMI) study
  - This study
    - Methodology
    - Findings – barriers to and benefits of taking part in research
  - Conclusion
The MAMMI study: Site 1 (2011-2014)

Aim

To identify the existence, extent and severity of maternal morbidities in nulliparous women before and during pregnancy and up to one year postpartum.

Research ethical approval

Granted by university’s and site hospital’s ethics committees.

1,600 primiparous women (A/N, 3, 6, 9 and 12 months postpartum)

Data collection from women’s records

One-to-one interviews with women experiencing a morbidity in each strand

- General health
- Mental health MSc
- Intimate partner violence
- Pelvic girdle pain
- Sexual health
- Urinary incontinence
- Anal incontinence

All participants gave written consent.
3,047 primiparous women (A/N, 3, 6, 9 and 12 months postpartum)

Data collection from women’s records

One-to-one interviews with women experiencing a morbidity in each strand

MAMMI 2
NUIG & GUH Research

MAMMI 3
CWIUH

Research ethical approval
Granted by university’s and site hospitals’ ethics committees.
All participants gave written consent.
Mixed methods design

A longitudinal (cohort) study with 3,047 first-time mothers

Survey 1
Antenatal
First booking visit
(includes sections on pre-pregnancy health and health problems)

Survey 2
3 months postpartum

Survey 3
6 months postpartum

Survey 4
9 months postpartum

Survey 5
12 months postpartum
Mixed methods design

A longitudinal (cohort) study with 3,047 first-time mothers

Data collection from consenting women’s records

Interviews with women experiencing a morbidity

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The MAMMI Study
Trinity College Dublin
Mixed methods design

A longitudinal (cohort) study with 3,047 first-time mothers

The MAMMI Study

Data collection from consenting women’s records

Interviews with women experiencing a morbidity

Identify factors that are amenable to intervention in future trials

Survey 1
Antenatal
First booking visit
(includes sections on pre-pregnancy health and health problems)

Survey 2
3 months postpartum

Survey 3
6 months postpartum

Survey 4
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Survey 5
12 months postpartum
## Recruitment and retention

<table>
<thead>
<tr>
<th>Time Point</th>
<th>Rotunda Hospital (RH)</th>
<th>Galway University Hospital (GUH)</th>
<th>Coombe Women and Infants University Hospital (CWIUH)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Antenatal</td>
<td>38.3% (1841/4809)</td>
<td>44.5% (333/748)</td>
<td>35% (873/2687)</td>
</tr>
<tr>
<td>3 months</td>
<td>86% (1484/1725)</td>
<td>92.8% (287/309)</td>
<td>88% (707/818)</td>
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<td>6 months</td>
<td>84.5% (1381/1634)</td>
<td>87% (260/299)</td>
<td>86% (656/791)</td>
</tr>
<tr>
<td>9 months</td>
<td>80% (1301/1627)</td>
<td>83% (239/288)</td>
<td>82% (608/770)</td>
</tr>
<tr>
<td>12 months</td>
<td>78% (1223/1568)</td>
<td>78.6% (214/272)</td>
<td>79% (561/738)</td>
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</tbody>
</table>

*Proportions based on number of women eligible for follow-up at each time point*
## Recruitment and retention

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<td><strong>Response Rate (n)</strong></td>
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<td><strong>Antenatal</strong></td>
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Why do pregnant and postpartum women take part in research?

What the literature says...

- **Altruistic reasons** (Baker et al 2005; Ballantyne et al 2017)
- Motivated by *perceived benefits of taking part*, especially with information received during medical examinations (Mein et al 2012)
- A sense of *loyalty* (Mein et al 2012)
- To *improve their or their child’s health* (Barnett et al 2016)
- *Receive better health care* through participation (Barnett et al 2016)
- Because the study is *important to friends’ or family health* (Barnett et al 2016)

Participants are seldom listed as beneficiaries
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Methods for this study

Content analysis of the free-text comments women wrote on the final page of each survey

Conventional approach used (Hsieh & Shannon 2005)
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Findings
1,000 free-text comments were made in the five surveys

- **Survey 1 (Antenatal) (AN)** (n=240/2174)
- **Survey 2 (3 months postpartum) (PP3)** (n=301/1771)
- **Survey 3 (6 months postpartum) (PP6)** (n=136/1641)
- **Survey 4 (9 months postpartum) (PP9)** (n=142/1540)
- **Survey 5 (12 months postpartum) (PP12)** (n=181/1437)

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676 related to taking part in the study

Proportion of study-related comments in each survey

- Survey 1 (Antenatal) (AN) (n=180/240)
- Survey 2 (3 months postpartum) (PP3) (n=144/301)
- Survey 3 (6 months postpartum) (PP6) (n=98/136)
- Survey 4 (9 months postpartum) (PP9) (n=86/142)
- Survey 5 (12 months postpartum) (PP12) (n=168/181)
Barriers (potential and real) to taking part

*Antenatally* (n=33/180, 18%)

Survey was

‘Long’/‘very long’ (n=17); some questions were ‘personal’/‘intimate’ (n=8), ‘repetitive’ (n=5), ‘ambiguous’/‘unclear’ (n=3).

*Antenatal survey asks women questions about their health at three time points: as a child and as adult, in the 12 months before pregnancy and during pregnancy.*

*All surveys are 65-80 A4 pages in length.*
Barriers (potential or real) to taking part

Antenatally

‘Week 16 - *feeling very tired to point of exhaustion*...5/6 trips a night to toilet first 14 weeks - very little sleep’. [AN-ID1-0023]

‘Apologies for delay in completing. *I experienced unforeseen events unrelated to pregnancy recently*. At early stages of pregnancy *I was not confident in pregnancy to complete the form*. [AN-ID1-0958]
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Barriers (potential or real) to taking part

*Postnatally*

Comments (n=88/760, 11.6%) in all postpartum surveys related to delays in returning them and/or experiencing personal health issues.
Barriers (potential or real) to taking part

Postnatally

‘I finished very slow [Re returning the survey]...the baby starts crying during feeding. It was a hard time for me’. [PP3-ID2-0714]

‘Hard to complete [section on labour] - traumatic and I am still very emotional’. [PP3-ID2-0318]

‘Just wanted to apologise for taking so long to fill them out. As you know I have postnatal depression and have found this year extremely hard as I never expected to get depressed’. [PP12-ID5-1179]
Benefits of taking part

Many women said they benefitted personally by having the opportunity to have their voice heard, from reviewing their own progress as they completed each survey, and from getting information.

Four sub-themes emerged

Access to information

‘This is a nice way to get information on many things and...I have learnt a lot of things...thanks’. [AN-ID1-1926]

‘I thought this survey was very helpful and the questions were v. good. I think it's great you have numbers to ring for everything to help young mothers in need. [Re inclusion of notices on where to get help for each problem]’. [AN-ID1-0994]
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Access to information

‘This is a nice way to learn. I think I learnt a lot from you.’

Example

If you are experiencing any problems with your emotional health and wellbeing and wish to talk to someone, you can telephone the mental health team at the Rotunda hospital - telephone: 01- 817 1700 bleep 472

Or you can call the Aware (Depression) Helpline on 1890 303 302

Text messaging

Information on where to go for help in a crisis is now available through your mobile phone. Text the word HeadsUp to 50424. The HeadsUp text service is run by RehabCare and sponsored by Meteor.

ONLINE information and support. A number of support services are now using the internet to reach out to people. For example, www.yourmentalhealth.ie
Access to information

‘These surveys have highlighted for me the huge gaps in my knowledge regarding postpartum care for myself...’. [PP6-ID3-2072]

‘The recent release and publicity of some of the findings is making me and others realise we are not alone and that we should talk about it and share the less desirable physical issues after having a baby...’. [PP9-ID4-0750]

Headings from some of the publications in the National press

- New mums not reporting their own health issues
- First-time mums don’t know what is normal – and don’t have the vocabulary to ask
- First-time mums suffer in silence
- First-time mothers ‘suffer undiagnosed and untreated health issues’
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Relaxation and enjoyment

‘This survey relaxed me and took my mind off work + home life for 40 minutes so thank you, and [it] made me have a good think when answering the questions’. [AN-ID1-1669]

‘I enjoyed filling out the surveys, for me I found it relaxing because it was about me and my experiences...nobody tells you the ‘after affects’ after you have a baby...I suffered with depression and I can see I have come a long way since first writing in the survey several months ago and now I almost feel back to normal’. [PP9-ID4-1996]
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NB - this is in the context of being asked sensitive and intimate questions on urinary & anal incontinence, sexual & mental health issues & partner violence
Relaxation and enjoyment

‘It was nice to be asked questions that may not have been put to me by [the] hospital or my GP. It was good to go back over my labour and weeks after baby's birth and answer questions of how I am dealing with being a new mother’.

[PP3-ID2-2151]
Stopping to think

‘I found this survey asks some questions where you have to ‘stop & think’ about your answer and think “hang on, have I actually felt like this”…’ [AN-ID1-1570]

‘Enjoyed completing the survey...It became a great talking point between my partner and I and it allowed me to stop and think about things....can't describe it really but the questionnaire allows me to stop and think about my own health etc.’ [PP6-ID3-1904]
Stopping to think

‘I find this survey brilliant, it gives you a good insight into how you are feeling emotionally and physically cause you do not stop and think about how you are really feeling on the inside until you read the questions... The surveys are brilliant, can’t wait to fill in my next survey’. [PP6-ID3-1102]

‘This can be the only opportunity I am asked about how "I" am’. [PP9-ID4-1723]
Prompt to get help

‘I realised by doing this survey about my urinary leakage during the pregnancy and feel a bit worried for the future. I will talk to the physiotherapists at the [hospital] about the problem’. [AN-ID1-1962]

‘I just went to the GP this morning as this survey forces/encourages me to examine how I am feeling, I discussed [listed several health issues]...will call a doctor at the [hospital] to arrange an appointment. I kept putting off visiting the doctor but feel glad I have told her now...’ [PP6-ID3-1091]
Prompt to get help

‘I really enjoyed completing the surveys...It was highlighted to me that things I am not happy with (bowel) I should see someone about. Thank you for asking these questions...I don't feel that people ask how we are post labour, it's all about the baby. The silence makes you think that you must be alone in your worries, but reading your findings I know I am not, I just wish we were talking about it more’. [PP12-ID5-2002]
Conclusion

Women got access to and learnt new information and took time to reflect on their health as they completed the surveys. The survey content encouraged some women to take better care of themselves, and prompted others to seek professional help.

Points for practice and research

Practice: findings point to deficits in the way information is provided within maternity care.

Research(er): findings highlight the type & amount of information that should be given to childbearing women participating in research.
Stop, think, reflect, realise—first-time mothers’ views on taking part in longitudinal maternal health research

Deirdre Daly, Margaret Carroll, Monalisa Barros, Cecily Begley

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The MAMMI Study

Special thanks to our funders

Development of a suite of resources for women

Coming in 2019

WHAM (MOOC)
MESSAGES
ON-TRACK
The MAMMI Study
would not have been possible without building/developing relationships

The midwives and midwifery students
The IT Midwives
The medical records staff
Administrative and other staff who supported the MAMMI study

Sites

Trinity College Dublin,
The University of Dublin
The MAMMI Study

would not have been possible without building a team & research capacity

Sincerest thanks to the MAMMI study team

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Francesca Wuytack and Patrick Moran (Follow-up studies)

Others who worked/are working on the MAMMI study

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References


