



Mothers with Anal Sphincter Injuries in Childbirth

Supporting mothers, making the public aware, educating the profession

Registered with the Charity Commission for England and Wales no. 1169632

Website: www.masic.org.uk

IMPROVING CARE FOR MOTHERS WITH OBSTETRIC ANAL SPHINCTER INJURY

Report of and proposals for action that arose from the Workshop held on 23-24 November 2018, organised by the Sheila Kitzinger Programme at Green Templeton College, Oxford in collaboration with the MASIC Foundation

PROCEEDINGS OF THE WORKSHOP

Friday, 23 November 2019

MEETING OF OASI MOTHERS: EXPERIENCE AND DEMANDS

Chair: Julie Cornish

Rapporteur: Dr Lisa Hinton

Attendees: Dr Margaret Keighley MBE, Suzanne Ryan, Professor Robert Arnott, Julie Frohlich, Professor Lesley Page CBE, Professor Michael Keighley, Husna Hussein-Mohammed,* Belinda Bradford,* Rhiannon John*, Jenny Tighe* (*MASIC Ambassador)

1. There was a short presentation by Dr Hinton about the **NIHR/RfPB Grant proposal**, already submitted. *Healthtalk* would produce transcripts of interviews and videos of conversations with mothers to capture: (i) The acute impact of OASI; (ii) The medium term effects; and (iii) A cohort of older women who would inform about symptoms later in life. There would be interviews with partners. *Healthtalk* would try to generate twenty-five short essays, a blog for primary care, some visual images and a training manual for primary care and practice nurses.

2. **Views of mothers attending:** OASI was like a bereavement experience. These stories should be made available before a mother had a baby in order to inform about a birth plan. The stories should be used to educate health professionals especially General Practitioners and nurses working in primary care. The stories should go to NCT because their preparation of pregnant women could be unrealistic (NCT needed a process of audit). Mothers should be given more information: knowledge is power. Information should be transmitted by senior staff. There was a need for specialist clinics to support OASI mothers which should be multidisciplinary to avoid fragmentation, should be holistic and include social and psychological support. The role of the six week check in general practice was discussed but the only mandatory requirement from the commissioners was immunisation and checking the health of the baby. The six week check should enquire about faecal urgency: having to dash to the toilet. The six week check would be empowered if the *MASIC Map* was completed so that mothers would know where to go to obtain advice and support. We should be careful not to normalise issues at the expense of diminishing the impact of the condition on the lives of the mother.

A

3. **The Monkey Survey in Wales:** There were two hundred and three responders which was a small sample given the twelve thousand questionnaires distributed. Most responders were aged 31-40 years and 88% were women. Only one third had any colorectal experience and only two thirds had any obstetric experience, two thirds had no experience in anal incontinence. Only one in four had any idea about the value of physiotherapy, and only one in five felt that physiotherapy would help. Seventy three felt they had inadequate knowledge of OASI and eighty wished to be better informed. If a referral was needed for an OASI patient 88% would refer to an incontinence clinic but 12% felt they did not know where to refer their patients.

4. There were views about the **dispersal of information** about the consequences of OASI and how to obtain treatment. They included: (a) Posters in GP surgeries; (b) Screen savers; (c) GP Check-ups; (d) Menopause cafes; (e) Bowel and cervical screening; (f) Gynaecological lifelong screening; and (g) Ladies' lavatories at motorway service stations.

It was agreed that publicity could not take place without having generated the *MASIC Map* in which mothers by typing in their postcode could be provided with information about the most appropriate clinic for assessment and support. It was suggested that if there was no funding forthcoming from the BDRF we should explore engaging medical students.

5. There were ideas about various **birthing support organisations** with whom we might form an alliance. They include: Best Beginnings, Birth Talk, Better births, Community Midwife Hub; Birth Trauma Association; Making Births Better; Mumsnet; NCT, Baby Buddy App, Tears Hub, Maternity Voices Partnerships, Birthrights and the Sub-Committee on Maternity Services at the Royal College of General Practitioners. There were also suggestions about **commercial organisations** which might be worth approaching: Proctor and Gamble (pads), GSK (philanthropic), Renew (with stories), Medtronic (with stories), Johnson and Johnson (philanthropic), Unilever (Domestos) and Kimberley-Clarke (Andrex).

6. We agreed that from now our mother support team would be termed **MASIC Ambassadors** and others **OASI Mothers**.

7. We discussed **the cost of OASI on the economy, the NHS and on society**, we believe this is huge and could include: (a) Life-long cost of drugs, sanitary equipment such as pads; (b) Cost of specialist equipment for treatment: (c) SNS (Capital cost is £20,000 and annual maintenance £1,000 per year); (d) Rectal irrigation annual cost with some supervision (£2,000 per year); (e) Secondary sphincter/pelvic floor repair (Visits and tests can be £5,000 per year); (f) Clinic visits (a figure of £53,000 for a patient over 14 years has been suggested); (g) Loss of income from employment (a survey has shown that this applies to 22% of OASI mothers); (h) Loss of income from days lost attending clinics, undertaking surgery, renegotiating fewer hours of work (a survey has shown that this applies to 60% of OASI mothers); (i) Time off from sickness; (j) Loss of Pension; (k) Social Security Costs; (l) Settlement costs to the NHS (50% of OASI mothers explore a claim and approximately 80% of these are settled out of court in which the pay-out ranges from £220,000 to £1,300,000 (the average being £380,000); (m) Legal costs, including solicitors and counsel, expert witnesses, court costs with and without a court hearing will be calculated and reported in due course.

Saturday 24 November 2019

Attendees: Jenny Tighe, Dr Margaret Keighley MBE, Elizabeth Duff, Vivienne Novis, Rowen Davies, Alessandra Orlando, Yvette Perston, Rhiannon John, Karen Evans, Kate Mann, Carolynne Vaizey, Julie Cornish, Husna Hussein-Mohammed, Dr Lisa Hinton, Professor Lesley Page CBE, Karen Nugent, Suzanne White, Belinda Bradford, Professor Robert Arnott and Professor Denise Lievesley CBE.

Morning Session

The session was opened by Professor Keighley as President of the MASIC Foundation and all participants were welcomed to Green Templeton College by Professor Denise Lievesley CBE the Principal.

WORKSHOP: OPTIMISING OASI INFORMATION AND CARE IN THE TWENTY-FIRST CENTURY: WHAT IS NEEDED AND WANTED?

Chair: Professor Michael Keighley

Introduction: Julie Frohlich

1. The proceedings of the morning session started with a short summary of the previous day's Meeting of MASIC Ambassadors by Dr Hinton.

2. There was an introduction by Julie Frohlich. She stressed that the rate of OASI has risen threefold in the last decade. The rate of OASI in first vaginal births was 6.1%. She reported that PEACHES programme had achieved a reduction of OASI in a single centre over 3 years from 6.1% - 2.1%. (In the last month they had achieved a reduction from twenty six to seven cases and that the average number of deliveries was three hundred and sixty per month. Translated into numbers in England and Wales in a year, this would be a reduction of over four thousand cases a year). She presented the case of Montgomery-v-Lanarkshire Health Board and explained that the law now made clear that there should be shared decision making which should address both physical and emotional needs.

3. The attendees then were allocated to one of three tables which were to tackle different issues and then to report back

4. **Feedback**

Group 1: How should a woman be informed during pregnancy about potential risk and potential morbidity of OASI?

The group indicated that there were both generalised and individual issues. The group recommended that:

- Risk factors were best discussed at thirty four to thirty-six weeks (as in the OASI Care Bundle and PEACHES). During discussion, it was agreed that this should be in written form conveyed in simple language (average reading age eight years) preferably visually (informatics/Instagram's). Even quite small risks needed to be covered. This information needed to be available in many languages: one charity (The Obstetric Anaesthetics Association) had material prepared in forty languages (translation undertaken by the local ethnic group). One survey indicated that 89% of pregnant women stated that *no one told me*. One of the problems was the lack of time that a midwife had to impart information.

- There were clear risk factors for OASI these should be made available to the profession and the public. This information could be displayed in the workplace, the GP surgery and in Mother and Baby Groups. There was a proposal that there should be consent clinics. Information was needed to be presented imaginatively: podcasts
- There was a short but important discussion about the difficulty in obtaining realistic consent during the second stage of labour. The mother was exhausted and in pain and could not realistically make decisions. The obstetrician was between “a rock and a hard place” and would be criticised for intervening if he or she did and criticised if he or she did not act. There is a need to discuss the choice of options before they occur. Women should have the opportunity to consider their preferences beforehand if there was a need for a trial of instrumental delivery: forceps, ventouse or caesarean section for maternal exhaustion, abnormal lie or foetal distress. The problem is that every situation is different. Also there are different types of forceps available, likewise different types of ventouse are used and the risks of an emergency caesarean section are difficult to explain to the mother in these circumstances. The conclusion was that there was no perfect answer but that the risks of Emergency C Section needed to be explained.

Group 2: Optimal follow-up and support for women who have sustained OASI

- The group reported that there was a need for two different types of clinic: (a) An acute perineal clinic to check the wound and the progress of the mother who had sustained an injury that has been repaired; and (b) A clinic for persistent symptoms or those with new symptoms which should ideally encompass all the relevant specialists but where the first assessment and advice would be provided both by a colorectal nurse and a physiotherapist trained in pelvic floor disease. In an ideal world this clinic should also provide access to the following: (a) Specialist investigation; (b) Urogynaecologists; (c) Psychiatrists; (d) Psychosexual counsellors; (e) Colorectal surgeons; (f) Dieticians; (g) Neuromodulation facilities; and (h) Biofeedback. No one agreed a name for these clinics, the best suggestion was “The Pelvic Health Clinic”. The problem for a woman or a GP wishing to access a suitable clinic is that they are all called different things: (a) A functional bowel clinic; (b) A pelvic floor clinic; (c) An incontinence clinic; or (d) An OASI clinic,
- Any follow up should be preceded by information about risk, this should be with leaflets, bounty packs, NCT etc.
- Many women develop anal incontinence because a tear has been missed and therefore not repaired at birth. These women are in a bad place because they are not in an OASI follow up, they discover they are incontinent but do not know where to go and nor do their GP’s.
- Identifying women with anal incontinence should be achievable during the six week check in primary care, but most GP’s just say, “you are doing alright aren’t you?” This is no good! There should be a mandatory ask about urgency with examination of the perineum probably by a practice nurse who has been specifically trained. This should be a target that MASIC should try to have accepted by Clinical Commissioning Groups.
- Many midwives were completely ignorant about anal incontinence.
- There has been a pilot scheme amongst seven hundred physiotherapists to explore self-referred support for women.

- There needs to be information at follow up needed to take into consideration: ethnicity, social background and language of the mother (see Copperfield information on breast cancer).
- Follow up need to be face-to-face but could be reinforced by an app.
- Some Primary Care Centres have a physiotherapist that would take self-referrals, but many may not be trained in pelvic floor therapy.
- It was suggested that there should be a screening questionnaire to enquire about psychological morbidity before starting treatment for OASI, as some women would need psychological support before attending an OASI follow up.
- OASI clinics might exacerbate PTSD, if a woman was to attend the same hospital where the injury took place. One suggestion was that under these circumstances, follow up should be in a neighbouring hospital.

Group 3: Raising awareness of OASI. Is this needed and if so how might this be achieved?

- The group reported that awareness could be generated in a variety of ways: (a) NHS England and Public Health England; (b) The BBC; (c) Education about OASI for undergraduates in medicine, physiotherapy, nursing and midwifery (the latter who do not have a defined curriculum); (d) Reintroducing mandatory obstetrics into General Practice training; (e) Bowel awareness in schools; (f) Social media; (g) Celebrity tag; (h) Posters; (i) Events; (j) Media Outlets and Medical Journals; (k) All 4 Maternity; (l) BBC Women's Hour; (m) The Victoria Derbyshire Programme; (n) Postgraduate education in the various specialities; (o) Encouraging health professionals to attend a Pelvic Health Clinics; and (p) Lobbying parliamentarians, such as Dr Sarah Wollaston MP and Jess Phillips MP.
- Barriers: The episiotomy thing, over sensationalising OASI or normalising these injuries.

Afternoon Session

WORKSHOP: COMING TOGETHER

Chair: Professor Lesley Page CBE

Introduction: Karen Nugent

1. The proceedings of the afternoon session started with Professor Page giving a short summary of the life and work of Sheila Kitzinger and the work of the Sheila Kitzinger Programme at Green Templeton College, Oxford.
2. Karen Nugent opened the session. She explained what had been achieved over twenty years in one unit which had now established a multidisciplinary group to investigate and support women with OASI with a regular professional Multi-Disciplinary Team (MDT). She stressed that many women had said there was *no one to talk to*. There was a need to establish sustainable care. Getting started had had a ripple effect.
3. The participants were then divided into three groups, similar to the morning session and that each group needed to identify two targets. All groups were encouraged to consider their remit within the context of *replacing blame by support*.

Group 1: Co-ordination of support groups - how could this be achieved?

- The group reported that co-ordination of organisations was complicated and was not always necessary or desirable, alliances often involved different individual agenda.
- However, achieving change was often more successful by groups. Groups could inform the profession and the public about risk factors.
- Visual information was often more effective than the written word.
- Groups with a common theme should meet with parliamentarians but establishing change in the NHS was a slow and difficult process. The group agreed that the six week postnatal check was worth promoting both to address physical and emotional consequences of childbirth, this should be by a practice nurse (other candidates were physiotherapy, community midwifery, health visiting and general practice), who had been effectively trained (there is a cost implication).
- There was a template supported by a number of GP's through Dr Stephanie di Gorgio, which might be promoted through PROMS
- If one *Googles* Incontinence the MASIC Foundation is not there. To place it on page one of Incontinence would be possible through special efforts.
- The MASIC Foundation should work with the roll out of the OASI Care Bundle.
- We should lobby parliamentarians when the results of the OASI care bundle are published, explain this is effectively free of charge except for the training needed but would save on the consequences of injury.
- There must be a press statement/conference when the results of the OASI Care Bundle are published. There should be a plan to lobby the appropriate minister at the DHSC. We should use House of Commons and Lords Select Committees on Health and APPGs to get the message across. Stress the impact on women's health and the cost of OASI. This could be supported by PROMS, by way of the obstetric emergency training programme.
- There should be a mandatory six-week postnatal check in general practice which enquires about urgency and examines the perineum using an agreed template and tagged to the psychiatric needs of the mother.
- It would be wise to co-ordinate dates of events with other allied groups.
- We must get ethnic groups on board: the South Asian communities and groups from Poland, the Yemen and Vietnam.

Group 2: Engaging Primary Care

- Most of this had been covered by earlier discussions and no feedback was considered necessary (see comments on Friday and Group 2 in the morning).

Group 3: Media outlet opportunities and a Celebrity

- Plan a line up when the OASI Care Bundle results are published. These should include: (a) MASIC Ambassadors; (b) Social media; (c) Press Statement by the MASIC Foundation; (d) Website information and stories with optimiser; (e) Blogs; (f) Coordinated activity with the RCOG and the RCM; (f) Publications and Media - *Health Journey, Fingle Wash*, popular women's magazines; (g) Conversations; and (h) Radio and television programmes.
- Seek sponsors for financial support.
- Suggestions for celebrity support, Suggestions include Kate Winslet, Sandy Toksvig, Paula Radcliffe MBE, Sue Perkins and Suzie Verrill. We did not think it worth at this stage, trying to engage any member of the Royal Family.

4. The meeting concluded with Professor Keighley thanking all participants for attending and especially to Green Templeton College, Oxford for their support through the Sheila Kitzinger Programme.

Professor Michael Keighley, President
Professor Robert Arnott, Secretary
The MASIC Foundation
admin@masic.org.uk