AUCKLAND WOMEN'S HEALTH COUNCIL

NEWSLETTER

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PERINATAL & MATERNAL MORTALITY IN 2013

The Perinatal and Maternal Mortality Review Committee (PMMRC) recently released its report on perinatal and maternal mortality in New Zealand for the year 2013. This is the committee's ninth PMMR report. This year the report includes data on babies who died in New Zealand between 2007 and 2013, and mothers who died from 2006 to 2013.

Maternal mortality in 2013

There were five direct maternal deaths, and six indirect maternal deaths. A direct maternal death is one that is the result of obstetric complications during pregnancy, birth and up to 42 days postpartum, and from interventions, omissions or incorrect treatment. An indirect maternal death is one that is the result of a pre-existing disease or a disease that developed during pregnancy that was not due to obstetric causes, but was aggravated by the physiologic effects of pregnancy.

The causes of the five direct maternal deaths were two as a result of sepsis and two as a result of amniotic fluid embolism and one as a result of an ectopic pregnancy. The six indirect deaths included two suicides, two mothers with pre-existing medical conditions, one from sepsis and one mother who suffered an intracranial haemorrhage.

Eight years of data

The 89 direct and indirect maternal deaths from 2006-2013 included:

- 31 antepartum and 58 postpartum
- 57 occurred in hospital and 32 in the community
- 23 mothers died prior to 20 weeks gestation, and 66 died at or after 20 weeks
- 32 with potentially avoidable factors present, 53 with none and four were unknown.

Pre-existing medical disease, suicide and amniotic fluid embolism (AFE) were the most frequent causes of maternal mortality in New Zealand in 2006 – 2013. AFE is the cause of 40% of direct maternal deaths in New Zealand.

Suicide

Of the 54 indirect maternal deaths during this eight-year period 21 were the result of suicide.

Potentially avoidable deaths

The report notes that in the seven years from 2006-2013 the MMR working group believed that 36% of maternal deaths were potentially avoidable. The problems that were identified as having contributed to these deaths were caused by either organisational/management failings, personnel failings, barriers to access and or engagement with care in around a third of cases overall, but barriers were less often identified among direct deaths than among indirect.

Organisational problems

The major factors involved in the potentially avoidable deaths included 21 cases relating to lack of policies, protocols or guidelines, 13 relating to inadequate systems/ process for sharing of clinical information between services, 11 relating to inadequate education and training, six relating to poor organisational arrangements of

staff, four relating to a failure or delay in the emergency response, three relating to poor access to senior clinical staff, and two to a delay in procedure, eg caesarean section.

Clinical characteristics

Over the years 2006-2013 approximately 25% of mothers who died were having their first baby, while a further 25% had had more than four prior births. Nearly 60% of the mothers were overweight or obese. The report also reveals that just over a third of mothers were current smokers.

Perinatal mortality

In 2013 there was a total of 598 perinatal related deaths – perinatal mortality being foetal and neonatal deaths of babies born from 20 weeks gestation who die in utero, or within the first 27 days of life of any cause. Excluding the 181 perinatal related deaths caused by lethal and terminated foetal abnormalities brings the total of deaths down to 436.

PMMRC chairperson, Sue Belgrave, noted that spontaneous preterm births are the second highest cause of perinatal death in New Zealand was a special focus of this year's report.

The rate of babies dying from 20 weeks of pregnancy to 28 days has fallen to the lowest number since reporting began in New Zealand in 2007. The overall reduction in perinatal mortality included a significant reduction in stillbirths at term – from 117 in 2007 to 69 in 2013.

The report reveals that women who smoke in pregnancy, who have a BMI of over 25, live in areas of high socioeconomic deprivation and who are of Maori, Pacific and Indian ethnicity are more at risk of losing a baby.

The PMMRC found that the following district health board (DHB) areas have significantly higher unadjusted rates of perinatal related death than the New Zealand rate and may require additional assistance to address these issues:

- Counties Manukau – all perinatal related mortality
- Northland – stillbirth and neonatal death rate
- Bay of Plenty – neonatal death rate.

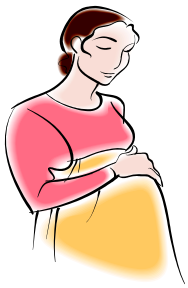
Recommendations

This year's report includes two recommendations relating to maternal mortality:

- Seasonal or pandemic influenza vaccination is recommended for all pregnant women regardless of gestation, and for women planning to be pregnant during the influenza season.

- All women with epilepsy on medication should be referred to a physician.

The PMMRC report can be found at:
http://www.hqsc.govt.nz/publications-and-resources/publication/2123/



Keytruda, Herceptin and PHARMAC

There have been numerous stories in the media recently about how those with invasive cancers – melanoma and lung cancer in particular – would be saved if only PHARMAC would fund their treatment with the latest potentially-life saving drug known as pembrolizumab, sold under the trade name Keytruda.

Pembrolizumab is the first of a new class of immunotherapy drugs, called anti PD-1 inhibitors, which work by activating the body's own immune system to attack the cancer cells.

In trials pembrolizumab was shown to be twice as effective as chemo-therapy, halting and even shrinking tumour growth for 34% of patients with advanced malignant melanomas. The latest clinical trial results presented at ASCO 2015, showed 80% of advanced melanoma patients who had received no prior treatment, experienced tumour shrinkage and 14 percent had no detectable cancer, at a median follow up of 15 months.

The drug is so new that long-term survival data does not yet exist, but oncologists are reporting that around 30% of the patients who respond to the new drug can expect to see their lives significantly extended.

While the drug has been approved for use in New Zealand, it is not yet funded by Pharmac. Patients need a new cycle of treatment every three weeks and, at a cost of around $10,000 per patient, per cycle, depending on weight, the treatment remains out of reach for the vast majority of patients.

As PHARMAC's experts committee have given it a low-priority status because of the uncertainty about its benefits and its high cost – about $300,000 a patient for two years' treatment – the drug is likely to remain out of reach for most patients for some time.

Some media commentators have compared the campaign for the government to fund Keytruda with the campaign that resulted in the current government, as part of an election bribe, agreeing to fund 52 weeks of Herceptin as opposed to the nine weeks that PHARMAC had agreed to fund. (1)

While the former Health Minister Tony Ryall claimed that providing funding for 12 months of Herceptin was one of the highlights of his time as Minister of Health, there is now sufficient research evidence that overall the nine-week treatment regime is as good as 52 weeks, and the government was misguided in overruling PHARMAC's decision to refuse to fund the 52-week treatment option.

When the current Minister of Health, Jonathon Coleman was recently asked by TV3's Paul Henry whether overriding PHARMAC on Herceptin was "the right thing to do," Coleman said "I don't think it was actually, and I think history has shown that. The research shows that nine weeks which were funded previously was just as good as 52 weeks, but I think lessons have been learned." (2)

It also worth noting that many women, when faced with all that the 52-week chemotherapy regime involves have chosen the nine weeks, partly because of the serious side effects of

Herceptin and also because of the huge demands on their time and energy that 52 weeks of chemo-therapy entails.

With the National government having admitted it made a mistake overruling PHARMAC's decision on Herceptin, it is extremely disappointing to see Labour's Andrew Little and Annette King promising to take the decision on Keytruda out of PHARMAC's hands. As a recent editorial in the *NZ Herald* under the heading "We must put our trust in Pharmac" stated:

"If a Government provides additional funds to cover the costs of a particular drug, it does not upset the careful decisions that PHARMAC has to make about the best use of its budget. But each time a Government does so, it reduces the integrity and fairness of the public health system. It is easy to make emotional decisions, especially where cancer is concerned." (3)

It is also disappointing that the media is so reluctant to challenge the pharmaceutical industry's figures about the cost of getting a new drug to market. Claims that it can cost between $1 billion to $3 billion are hugely inflated. It has been common knowledge for over a decade that the drug industry's claims about their research and development costs are lies because of what they include in their expenditure columns. (4) (5)

Merck, Sharpe and Dohme, the manufacturer of pembrolizumab, is just one of the drug companies that is currently holding cancer sufferers to ransom. Their research, drug development and marketing practices have resulted in some eye-watering fines, including a $322 million fine for an illegal marketing campaign involving Vioxx, its blockbuster arthritis drug. And the costs of the drug company's marketing campaigns – legal and illegal – are included in the costs they quote.

As the author of a recent letter to the editor in the *NZ Herald* stated, "some of the nation's worst drug dealers aren't peddling on street corners, they're occupying corporate suites." In Merck, Sharpe and Dohme's case they occupy a pretty impressive building at 109 Carlton Gore Road in Newmarket, Auckland.

It is long past time for health consumer groups, patients, and cancer sufferers in particular, to take a stand. Instead of lobbying our governments we need to start campaigning against the deceipt and lies of the pharmaceutical industry which is currently holding the world to ransom with its overpriced drugs.

References

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NO ACTION FROM HDC

It is a year since the Health & Disability Commissioner, Anthony Hill finally responded to numerous letters from the AWHC about enrolling unconscious patients in clinical trials without their knowledge or consent. In a letter dated 5 December 2014, he stated that he would "commence a more fulsome public information and consultation process" and would be releasing details for this early in the new year.

Over the past few months the AWHC has emailed and written to the HDC but he has not replied. As the AWHC is still attending meetings of the Northern A ethics committee we know that this is still an important issue that needs to be resolved.

The AWHC recently received a copy of the HDC's latest Annual Report, but there is no mention of the issue or of any plans to undertake a fulsome consultation in there either.

Meanwhile throughout New Zealand unconscious patients in ICUs are still being enrolled in clinical trials, despite the lack of clarity about whether this is legal.

Last year the Ministry of Health's chief legal advisor, in a letter to the Ministry's ethics committee chairs and members, dated 7 April 2014 but not posted on the ethics committee website until months later stated:
"Research involving participants who do not have the capacity to consent (and where no-one legally authorised to give consent on behalf of the participant does so) is not lawful unless it satisfies Right 7(4) of the Code of Health and Disability Services Consumers' Rights (the Code). Committees do not have the authority to give consent on behalf of participants." (1)

It also said: "Investigators must satisfy the committee that proposed research is lawful before the committee approves an application. Committees are not required or able to give legal advice to investigators; it is the responsibility of the investigator to ensure that the research is lawful."

The issue of patients being enrolled in research trials without their knowledge or consent was at the very heart of the Cartwright Inquiry. Following the release of the Cartwright report in August 1988 major changes were made to the New Zealand heath system to ensure that patient rights and informed consent were legally embedded into how patients receive health care. The Code of Consumers' Rights came into effect in 1996 and those involved in these events presumed that all health and disability consumers were not protected from being enrolled in research without their prior consent.

However, the health care environment has changed dramatically over the past two decades. There is now big money involved in industry-sponsored clinical trials, and both the investigators and the DHBs have a huge conflict of interest when it comes to deciding what research is lawful and what is not when it comes to unconscious or other vulnerable patients.

Somehow over the past two decades we lost this basic human right, and the consumer watchdog appointed to uphold patient rights is not coming to our rescue any time soon.

Redefining Family

13-14 January 2016
AUT Campus, Auckland

This conference is for families that have used – or are thinking about using – adoption, foster care, donor conception, or surrogacy. Professionals are also welcome.

Three plenary sessions are planned that will interest attendees from across the different family contexts.

- **Redefining family in the modern world.** This session considers trends in family formation, with emphasis on new family forms that separate the once combined biological, genetic and social parenting, including adoption, donor conception, surrogacy, foster care, kinship care and whangai.
- **The socio-economic issues in non-traditional families.** This session looks at the developmental trajectory common in many of these alternative family forms, with a particular focus on children's and parents' experiences.
- **The legal processes involved in non-traditional families.** This final session considers the legal frameworks for each family type, and looks at the challenges and barriers that must be negotiated in forming families via surrogacy, donor conception and adoption.

Panel Discussion. A panel session is planned for the last day where leading researchers, lawyers, and practitioners from the 3 domains will take questions.

Further information is available at – www.redefiningfamilyconference.co.nz

AWHC GENERAL MEETING 10 December 2015

Detailed minutes of this meeting are available on request. Matters discussed included:

- Financial reports
- Lottery Community grant
- HPV screening
- Ethics committee meeting
- MACSAG
- DHB meetings

Further information on some of the topics listed above is contained in this issue of the AWHC newsletter.

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UP AND COMING EVENTS

DISTRICT HEALTH BOARD meetings for January/February 2016:

Waitemata DHB (Website address: www.waitematadhb.govt.nz)
The Waitemata Hospital Advisory Committee meeting starts at 11am on Wednesday 16 December 2015 and will be followed by the DHB Full Board meeting which starts at 1.30pm. Both meetings will be held in the DHB Boardroom, Level 1, 15 Shea Terrace, Takapuna.

The **combined Waitemata DHB and Auckland DHB** Community & Public Health Advisory Committee meeting starts at 2pm on Wednesday 3 February 2016.

Auckland DHB (Website address: www.adhb.govt.nz)
The Hospital Advisory Committee meeting will be held at 9.30am on Wednesday 17 February 2016 followed by the Full Board meeting at 2pm. Both meetings will be held in the A+ Trust Room in the Clinical Education Centre, Level 5, Auckland City Hospital.

Counties Manukau DHB (Website address: www.cmdhb.org.nz)
The Hospital Advisory Committee meeting will be held at 9am on Wednesday 10 February 2016 at Ko Awatea and will be followed by the Full Board meeting at 1.30pm.

The Community & Public Health Advisory Committee meeting will be held at 1.30pm on 20 January 2016 at 19 Lambie Drive, Manukau.

ETHICS COMMITTEE meetings – dates for the four MOH ethics committees are at:
http://www.ethics.health.govt.nz/about-committees/meeting-dates-venues-minutes

NZ LACTATION CONSULTANTS CONFERENCE 2016 will be held on 26 - 27 February 2016 at the Holiday Inn, Auckland Airport, 2 Ascot Road, Mangere, Auckland.

The theme is “Home Grown: Simply the Breast”

Further information is available at www.nzlca.org.nz/conferences.html