



women's health

update

Diethyl Stilboestrol (DES) prescribed for pregnant women in the 1940s to 1960s: Why does it matter now?

Charlotte Paul, Department of Preventive and Social Medicine, Otago University Medical School, Dunedin

"Between 1966 and 1970, seven girls in their late teens were seen at the Vincent Memorial Hospital and the details of a unique lesion – clear cell adenocarcinoma of the vagina – were described and reported. ... Under the circumstances we were on the watch for an explanation, but none suggested itself until the mother of one of the patients reported ... that she had been prescribed DES during pregnancy to minimize the chance of loss of the fetus... Somewhat to my surprise, I found on questioning that several other mothers had also taken stilbestrol during pregnancy..."

H Ulfelder. The stilbestrol disorders in historical perspective. *Cancer* 1980;45:3008-11

Diethylstilboestrol (DES, a synthetic oestrogen) was prescribed to about 1,000 pregnant women in New Zealand in the 1940s, 50s and 60s – in the belief it would reduce the risk of miscarriage.¹ Nevertheless, from the 1950s there was evidence that it was ineffective.² In 1971 it was shown that daughters born to mothers who took the drug in pregnancy were at risk of clear cell adenocarcinoma (CCA) of the vagina or cervix.

The first reason that DES still matters is demonstrated by the quote from Ulfelder, above. Although the paper reporting the results of the case control study published in 1971 documented the elevated risk of vaginal cancer in DES-exposed daughters, according to scientific practice, no mention was made of the mother who made the first connection.³ It is a reminder that the person who experiences an adverse effect may be the first person to make the link with the medicine, and that clinicians need to remain aware of this too.

There has never been a systematic attempt to identify exposed women in New Zealand, though publicity over the years has made many people aware of possible exposure. But most women who think they may have been exposed find that their medical records no longer exist. This is a second reason that the issue matters. Regulations in New Zealand under the Health Act require health records to be kept for only 10 years after the last consultation. This is simply not long enough for

all adverse (or beneficial) effects of medicines to be recognised. The case control study in the US described above relied on the use of obstetric records to identify the medicines prescribed to the mothers of the affected daughters and of control daughters. If, in New Zealand, a new adverse effect in adolescent daughters (or sons) of mothers who took a medicine during pregnancy was suspected, records would not be reliably available to investigate it scientifically. And if the adverse effect was confirmed by research overseas, the exposed individuals could not reliably be identified and counseled here. Health records should be kept for longer.

The third reason DES still matters is that adverse effects are still being identified. The most recent reports are on long-term outcomes for daughters (i.e. women exposed to DES *in utero*) and on possible 'third generation' effects (i.e. grandchildren of DES mothers). Below is a summary of recognised adverse effects.

DES Mothers (i.e. women prescribed DES when they were pregnant)

Women who took DES during pregnancy have a modest increased risk of breast cancer of about 30% (or an extra 23 cases per 100,000 women per year).⁴ The risk of other cancers does not seem to be elevated.

DES Daughters (i.e. women exposed to DES *in utero*)

Clear cell adenocarcinoma (CCA) of the vagina and cervix

This cancer occurs in about 1 in 1,000 exposed daughters up to the age of 35 years,⁵ making the risk about 40 times that in the unexposed.⁶ The peak age of onset is late teens and early 20s, although cases have been reported in women up to their 50s.^{6,7} There is concern that there may be a second peak as these women age, because there is a second age peak for diagnosis for CCA in non-exposed women in their 70s,⁸ though the evidence is still uncertain. The US Registry of cases of CCA reported in 2007 that "currently cases up to age 55 have been accessioned and there is a

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suggestion of a possible increase in frequency among DES-exposed beginning to appear in those over 40 years of age."⁷

Breast cancer

An increase in risk of breast cancer in exposed daughters has been suggested,⁹ and further evidence to support such an effect has recently been published. Further follow-up of three cohorts of women demonstrated an increase in risk of breast cancer in women over age 40 of 80 per cent (relative risk 1.8), and the excess risk up to age 55 years was calculated to be 1.7%. That is, the cumulative risk up to age 55 of developing breast cancer was 2.2% in the unexposed and 3.9% in the exposed women.¹⁰ It is not clear whether the increase in risk of breast cancer is because of exposure to high levels of oestrogen before birth, or because these women are more likely to have no children or to have births at a later age, both risk factors for breast cancer.

Other cancers

There has also been a concern that stilboestrol might increase the risk of squamous cell carcinoma of the cervix, but as yet there is no definitive answer. There is evidence of an increase in high grade squamous intraepithelial neoplasia in exposed daughters, though this may be due to more intensive screening.^{10,11} Another cohort study with a low (and hence potentially biased) ascertainment of outcomes showed a three fold increased risk of invasive cervical cancer among exposed daughters.¹²

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Women's Health Update features women's health news, policy and scientific findings, to enable health care professionals and community-based workers to be at the forefront in women's health.

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Reproductive tract abnormalities

The following abnormalities are very common in DES-exposed daughters: vaginal adenosis, cervical ectropion, transverse cervical and vaginal ridges, hypo-plastic uterus, and a T-shaped uterus.¹³ Recently, increases in paraovarian cysts,¹⁴ endometriosis,¹⁵ and uterine fibroids¹⁶ have been observed, but these associations are unconfirmed.

Reproductive function and pregnancy outcome

The structural abnormalities in the anatomy of the reproductive tract have been shown to affect reproductive function. Primary infertility and pregnancy loss are both more common in exposed daughters.¹⁷ Long-term follow-up has confirmed an increased frequency of pre-term delivery, first trimester spontaneous abortion, second trimester pregnancy loss, and ectopic pregnancy. Nevertheless among all exposed women in one cohort, 75% became pregnant and among these women 85% delivered at least one live full-term infant.¹⁵ The excess risk of adverse reproductive outcomes among exposed women compared to unexposed women has recently been assessed. For infertility the excess risk was 18%, for miscarriage 12%, ectopic pregnancy 12%, loss in second trimester 15%, pre-term delivery 35%, and pre-eclampsia 13%.¹⁰

DES Sons (i.e. men exposed to DES in utero)

An increased risk of testicular cancer was suggested in earlier studies, but is not confirmed. The largest cohort study to date reported a two to three times elevation in risk amongst exposed sons, though this finding was not statistically significant.¹⁹ Abnormalities of the urogenital tract have been reported but study findings have been inconsistent.¹³

Third generation effects (i.e. grandchildren of DES mothers)

Studies in animals support the possibility of multi-generational carcinogenesis due to *in-utero* DES exposure.²⁰ These effects have begun to be studied in humans. A number of studies have suggested an increased risk of hypospadias (a relatively common abnormality of the penis) in the sons of exposed daughters.^{21, 22, 23} The increase in risk may be up to four times that in the non exposed.²³ The mechanisms proposed for this effect are either that DES-related abnormal reproductive structures of the DES daughters interfere with normal fetal development, or that DES daughters have disturbed hormonal balance, or that genetic or epigenetic effects are transmitted.²³

A small study of DES granddaughters, which included a detailed history and pelvic examination, showed that none of these granddaughters had changes usually associated with DES exposure.²⁴ A recent study of birth defects found an excess overall among granddaughters and a significant increase in heart defects. As these were self-reported (by parents) reporting bias was considered a possibility.²⁵

Clinical monitoring recommendations for DES exposed daughters

The Royal Australian and New Zealand College of Obstetricians and Gynaecologists have developed screening recommendations, as shown below. They can also be found at: <http://www.ranzcog.edu.au/womens-health/statements-a-guidelines/college-statements/491-diethylstilboestrol-des-exposure-in-utero-c-gen-8-.html>

- Women who have been exposed in utero to

DES should have an annual gynaecological examination consisting of a general examination, separate cervical and vaginal Pap smears and a bimanual examination of the pelvis to detect any pelvic tumours or vaginal induration. Four quadrant Pap smears of the vagina are unnecessary and uncomfortable. A single sweep of the spatula or brush over the whole of the upper vagina is sufficient. Separate 4 quadrant vaginal smears would not be accurate enough to localize an abnormality and colposcopy would be required anyway if any abnormal cells were detected.

- The use of colposcopy to accurately assess the cervix and vagina should be offered to the woman although it is not strictly necessary in all women particularly if the transformation zone has receded into the endocervical canal. However, in view of the possible risk of a second peak in the development of vaginal CCA and the difficulty of obtaining thorough vaginal sampling via cytology alone would make it highly desirable that a careful colposcopic evaluation of the cervix and vagina be included in the annual examination.
- A breast examination should be performed at each annual check-up. Annual mammography is recommended for women aged 40 years and over in view of the recent reports of increased breast cancer risks in these age groups. Although radiation levels in mammography are low, women are encouraged to seek information from the Radiologist about risks of radiation exposure during mammography.
- DES Granddaughters (and grandsons) do not require any specific follow up but any abnormal bleeding should be carefully investigated along the usual lines.

Specialist advice on individual patients may be sought through the Royal Australian and New Zealand College of Obstetricians and Gynaecologists, who have a list of specialists with particular expertise.

Information is available for DES-exposed people

Authoritative and well presented information for affected mothers, daughters and sons is available at the following websites:
<http://www.cdc.gov/DES>
www.DESfollowupstudy.org
www.health.nsw.gov.au/des
www.cancer.gov/cancertopics/causes/des/daughters-exposed-to-des

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Improving women's health by addressing abortion stigma - new research

Christy Parker, WHA Policy Analyst, reports on new research identifying the causes and consequences of abortion stigma and how its elimination can improve women's health.

Abortion services are an essential part of women's health services in New Zealand. In 2010 approximately 21% of the pregnancies in New Zealand ended with a termination¹, and one in four women will terminate a pregnancy at some point in their reproductive lives making it one of the most common gynaecological experiences². Research in recent years suggesting a link between abortion and mental health effects has been largely discredited. The Task Force on Mental Health and Abortion, charged by the American Psychological Association, evaluated all empirical studies in English that compared the mental health of women who had and hadn't had an abortion. They found that among adult women who have an unplanned pregnancy the relative risk of mental health problems is no greater if they have a single elective first-trimester abortion than if they continued the pregnancy³. However it is recognised that some women do experience sadness, grief, and feelings of loss following abortion. The major factors identified in the Task Force review that were predictive of negative psychological responses in women following an abortion included perceptions of stigma, the need for secrecy, and low or anticipated low social support for the abortion decision⁴. Perceptions of stigma and concealment of abortion were strongly correlated. Clearly it is the environment in which abortions take place that plays the critical role in determining women's experience of, and/or recovery from abortion.

Understanding abortion stigma

Abortion stigma is the discrediting of individuals as a result of their association with abortion, and affects women who have had an abortion, those who provide abortion and abortion supporters. Because the experience of abortion is concealable, abortion stigma can become a vicious cycle where stigma results in women concealing having had an abortion which in turn helps to perpetuate the stigma. A similar dynamic exists for the providers of abortion care. Stigma, combined with the perceived threat to safety posed by some anti-abortion groups or individuals, can result in secrecy around abortion services and their separation from other women's health services. This in turn contributes to the stigma of using such services. In a new research paper "Abortion stigma: a reconceptualisation of constituents, causes, and consequences" Norris, Besset, Steinberg, Kavanaugh, De Zordo & Becker observe "The clinic, itself a stigmatised place, can reinforce stigma for women: set off from other medical practices and beset by picketers, the institutional arrangements of abortion provision may validate abortion stigma"⁵. Abortion stigma also contributes to workforce challenges by reducing the number of providers willing to work in abortion services¹. Abortion providers themselves are not always free of stigmatising attitudes, and women may experience self-stigma, where they feel judged even by those who support their decisions¹. Providers need to be attentive to this because abortion stigma may impact on how

empowered women feel to ask questions and raise issues with the quality of the care they receive².

Causes and consequences

The experience and dynamics of stigma in all its forms are highly contextual. However Norris et al have identified some causes and consequences of the stigma surrounding abortion. According to their research there are five aspects of the environment in which abortion takes place that contribute to the stigmatisation of what should otherwise be understood as an essential and common women's health procedure. Norris et al argue that abortion is stigmatised: because it violates "feminine ideals" of womanhood; as a result of the attribution of personhood to the foetus; because of the legal restrictions surrounding abortion services; because of the legacy of backstreet abortions; and because anti-abortion forces have found stigma to be a powerful tool and work to perpetuate it.

Norris et al argue that abortion challenges dominant notions of femininity in which the desire to mother is central to being a "good woman" and in which sex is for procreative purposes. They argue "abortion, therefore, is stigmatised because it is evidence that a woman has had 'nonprocreative' sex and is seeking to exert control over her own reproduction and sexuality, both of which threaten existing gender norms"³. Norris et al also argue that technological changes over the past three decades- foetal photography, ultrasound, and foetal surgery - have led to the personification of the foetus. This has resulted in the erosion of the distinction between the foetus and infant. One of the problems of foetal imagery is that it erases pregnant women from view, "decontextualising the foetus and overstating its independence from the woman who carries it and the social circumstances of her life"². Anti-abortion activism centred around the "rights of the unborn child", which includes legislative initiatives to establish foetal personhood, has worked to entrench abortion stigma. Norris et al argue that "by constructing the foetus as a person and abortion as murder, anti-abortion forces argue that women or providers - or both- should be seen as murderers"⁵. Abortion stigma also results from how the foetus as a separate person has come to shape wider cultural understandings about pregnancy.

Legal restrictions surrounding abortion have also been found to contribute to stigma. They do so by making abortion more difficult to access and by reinforcing the notion that abortion is somehow morally wrong and must be managed differently to "normal" women's health services. That abortion is yet to be decriminalised in New Zealand, and the resulting impact on how and where services are provided, would provide an interesting case study of this. Norris et al also argue that in the absence of safe and legal abortions the history of back street abortions have left the perception that abortion "hurts women" as their legacy. This perception has been a useful tool for anti-abortion campaigns. Norris et al note for example that "Unsubstantiated links between abortion, breast cancer, and impaired fertility have been used to frame a 'woman-centered' anti-abortion strategy" that constructs women as needing to be "rescued"

from abortions. The irony is that where abortion stigma flourishes women are actually less likely to access safe and legal abortion services and/or be more vulnerable to emotional distress following abortion. Finally Norris et al argue that it is abortion opponents' awareness and deployment of these causes of abortion stigma that helps perpetuate them.

Eliminating abortion stigma in support of women's health

Abortion stigma is neither natural nor essential but is produced by the environment in which abortions take place. Efforts to counter it therefore need to be similarly located. Norris et al propose several recommendations for addressing abortion stigma. These include efforts to normalise abortion within public discourse; the design and delivery of abortion services; and attention to the language used when discussing abortion. Normalising abortion involves ending the silence around abortion and vice versa. Approaches in the United States have involved encouraging women to talk openly about their abortion experiences including in the popular media. Kumar et al³ recommend that abortion services can do much to reduce abortion stigma through their architecture, policies and norms including ensuring a similar quality of environment as other health services and by integrating abortion services into broader women's health services. Norris et al recommend careful attention to language by those who work in abortion services and by pro-choice groups and individuals. This means avoiding language that endorses "good" and "bad" reasons for having abortions or talking about abortion in ways that suggests its "specialness" or "separateness" from other women's health services. Finally Norris et al identify the need for more research to evaluate the extent of abortion stigma, how it is experienced between different groups of women, and what are the best interventions for countering it. While there is a risk that focusing on stigma may inadvertently heighten it, so does silence. Getting the balance right will mean important gains for women's health.

1 Abortion Supervisory Committee. 2010. Report of the Abortion Supervisory Committee. Presented to the House of Representatives pursuant to Section 39 of the Contraception, Sterilisation, and Abortion Act 1977

2 Statistics New Zealand 'Abortion statistics: year ended December 2009'

3 American Psychological Association, Task Force on Mental Health and Abortion. (2008). Report of the Task Force on Mental Health and Abortion. Washington, DC: Author. Retrieved from <http://www.apa.org/pi/wpo/mental-health-abortion-report.pdf>

4 Ibid.

5 Norris, A. Besset, D. Steinberg, J. Kavanaugh, M. De Zordo, S. Becker, D. 2011. 'Abortion stigma: a reconceptualisation of constituents, causes, and consequences', *Women's Health Issues*, Vol 21-3S, S49-S54.

6 Ibid.

7 Ibid.

8 Ibid.

9 Ibid.

10 Ibid.

11 Ibid.

12 Kumar, A. Hessini, L. Mitchell, E. 2009. Conceptualising abortion stigma. *Cultural, Health & Sexuality*. 1-15.

Menopause – a positive perspective

Menopause, or last menstrual period, signals the end of a woman's fertile years. It is a significant physical transition and an undeniable marker of maturity. Although it can take some years to complete, the body orchestrates the changeover with mysterious precision, something like puberty in reverse. Common to all women, menopause ultimately brings freedom from the influence of hormonal fluctuations, and a new energy and perspective.

Menopause has tended to carry a certain stigma, in part because it is associated with growing older, and also because it has long been labelled a clinical condition requiring intervention. Decades of the medicalisation of menopause and the prescribing of hormone replacement therapy (HRT) have left the legacy that treatment is necessary to manage it. Since the discrediting of HRT as a safe treatment, the culture of the 'worried well' mid-life woman persists through articles, books, and the wide-spread marketing of 'natural' hormones, supplements and herbs. Women continue to get the message that it is advisable to seek professional help once they reach this stage of life.

Certainly menopause can seem to be an alarming dismantling of the normal and the familiar, and women can find themselves daunted by it and unsure of what to expect. But talking to others, education through group seminars, and

the sharing of experiences can be enormously reassuring – particularly the realisation that much of the challenge is to do with a stage of life when fulltime work, juggling the care of elderly parents, children leaving home (and coming back again), and managing relationships all require enormous amounts of energy and focus. With hormonal changes added to the equation, women often have no choice but to reassess their lifestyle and prioritise their own needs more in order to create a balance. It can be a very positive wake up call.

The majority of women – around 80 percent – do not have serious difficulties with menopause. In fact many sail through it without noticing anything at all. There may be times of overwhelming tiredness, periods of bothersome hot flushes and night sweats, and less ability to cope. But for most, menopause is entirely manageable – particularly with additional rest, careful nutrition, regular exercise and stress management strategies in place. We are, after all, those who have managed menstruation, childbirth, lactation, child rearing and relationships for all these years. We are certainly well equipped to deal with the relatively minor challenges of menopause. Sometimes if discomfort is considerable, temporary treatment may be helpful. And in rare cases where symptoms are genuinely unmanageable, medical involvement may be appropriate, along with an assessment of other health issues that may be complicating the

situation.

And menopause passes! In a well-kept secret, women report that life afterwards is liberating and immensely enjoyable. Margaret Mead, delighted by how well she felt, coined the term 'post-menopausal zest'. Menopause heralds a new phase of adulthood where we can follow our own passions and interests. It is a rite of passage from which we emerge as wise women in our families and communities.

Gill Sanson is author of "Mid-life Energy and Happiness" and "The Myth of Osteoporosis" and is a menopause educator.

Women's Health Action is holding a seminar facilitated by Gill, on *Managing Menopause: Naturally* on Wednesday the 4th April at Mama Inc, Auckland from 6pm until 9pm.

The seminar is designed for women who want to find out more about the transitional time of menopause and is designed as a safe space for women to discuss their experiences and thoughts. The cost of the seminar is \$30 which includes a light meal and a menopause information pack to take home. If you would like to register for the seminar please call Kerry on 09 520 5295 or visit <http://www.womens-health.org.nz>.

Noticeboard

● NEW CLASSES AT AUCKLAND WOMEN'S CENTRE

February onwards
Grey Lynn, Auckland
A new range of low cost classes for 2012 include water element belly dancing, mosaic making, a course on budgeting and a 6 week memoir writing course. Yoga and Pilates classes at AWC will continue to run every week. All women are welcome. For more information phone 09 376 3227 or go to <http://www.awc.org.nz>

● NEW ZEALAND DISABILITY SUPPORT NETWORK (NZDSN) ANNUAL CONFERENCE

6 - 8 March 2012
Te Papa, Wellington
"Light the Fire for Action on Inclusion".
The 2012 NZDSN Conference encompasses three days of learning, exploration and networking.
Visit <http://www.nzdsn.org.nz>, call 04 473 4678 or email info@nzdsn.co.nz to find out more.

● INTERNATIONAL WOMEN'S DAY

Thursday 8th March
The International theme is "Connecting girls, inspiring futures". In New Zealand, IWD 2012's theme is "Equality means Business". This is the subtitle of the Women's Empowerment Principles that will be launched in New Zealand in February 2012, visit UN Women NZ for more info and details of events around the country - <http://www.unifem.org/nz/>

● BREASTFEEDING SEMINAR WITH DR. JACK NEWMAN

Wellington, 10th March 2012
Topics Include:
When breastfeeding is not contra- indicated, Colic in the breastfed baby, When a baby refuses to latch on, Tongue tie and Breastfeeding the premature baby and more
For more information contact Ruth Martis at ruth-martis@clear.net.nz

● MĀORI CONCEPTS OF HEALTH PROMOTION

15 March 2012
9.30am - 3.30pm
Motel Sierra, 26 Western Hills Drive, Whangarei
The Health Promotion Forum is holding an upcoming workshop in Whangarei to highlight and build on shared understandings of traditional Māori concepts, ideologies and practices in relation to health and wellbeing.
Further information visit <http://www.hauora.co.nz>.

● MANAGING MENOPAUSE: NATURALLY

Wednesday the 4th April
Mama Inc, Taylors Road Morningside, Auckland
6pm until 9pm
The seminar is designed for women who want to find out more about the transitional time of menopause and is designed as a safe space for women to discuss their experiences and thoughts.
The cost of the seminar is \$30 which includes a light meal and a menopause information pack to take home. If you would like to register for the seminar please call Kerry on 09 520 5295 or visit <http://www.womens-health.org.nz>

● NEW ZEALAND NATIONAL DOMESTIC VIOLENCE CONFERENCE

Ellerslie Event Centre, Auckland
2-4 May 2012
First national conference hosted by the Global Coalition Against Domestic Violence (GCA-DV) is designed to be the largest national gathering of community based groups, government and non-government agencies who are all devoted to highlighting and showcasing successful programs in the area of domestic violence, with the united goal of eradicating domestic violence in society through the empowerment of people and workers in the field of Domestic Violence.
<http://www.domesticviolenceconference.net/latestnews.htm>

● LCANZ CONFERENCE 2012

7-9 September 2012, Sydney, Australia
Have Your Say - Call For Abstracts
The Scientific Committee invites you to submit an abstract for consideration as an oral paper or a poster for possible presentation at the LCA NZ Conference 2012 – For more information go to www.lcanz.org/conference2012.htm

● DIABETES SELF MANAGEMENT EDUCATION (DSME)

Auckland Region
FREE courses monthly in local venues, various times and dates
HealthWEST are running informative, free of charge courses about managing and living with type 2 diabetes. Supporters are also welcome to attend.
Contact: Denise Trotman Ph 822-8012, mobile 021-993-439 or email deniset@healthwest.co.nz for more information.

● GRADUATE DIPLOMA IN NOT-FOR-PROFIT MANAGEMENT

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Various national centres available throughout the year
The Graduate Diploma in Not for Profit Management is a qualification for managers, coordinators and board members working in Community, Voluntary and Tangata Whenua organisations. Develop the knowledge and skills to increase your not-for-profit organisation's effectiveness. Improve your ability to analyse your organisational challenges, mobilise resources, develop strategies for raising funds, manage staff and volunteers, and build effective governance.
Visit <http://www.unitec.ac.nz/social-health-sciences> to find further details.

● YOUNG PARENTS BREASTFEEDING GROUP

Every second Friday and last Saturday of each month
5A Waipuna Road - Mt Wellington Community Rooms (next to the Church) Mt Wellington - Auckland
This group has been established to provide mother to mother breastfeeding support for young Auckland parents (around 25 and under). Provides the opportunity for young parents to get together without judgment to share advice and celebrate the great work young parents are doing in Auckland. Dads, Grandparents, Pregnant women and other support people are also most welcome. There is plenty of free parking and a fenced playground for the kiddies. If you are a young parent and would like to join this supportive group please come along or email Kat at katheringlover@rocketmail.com. Snacks and refreshments provided.



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