

Familial breast (and ovarian) cancer in Asian women

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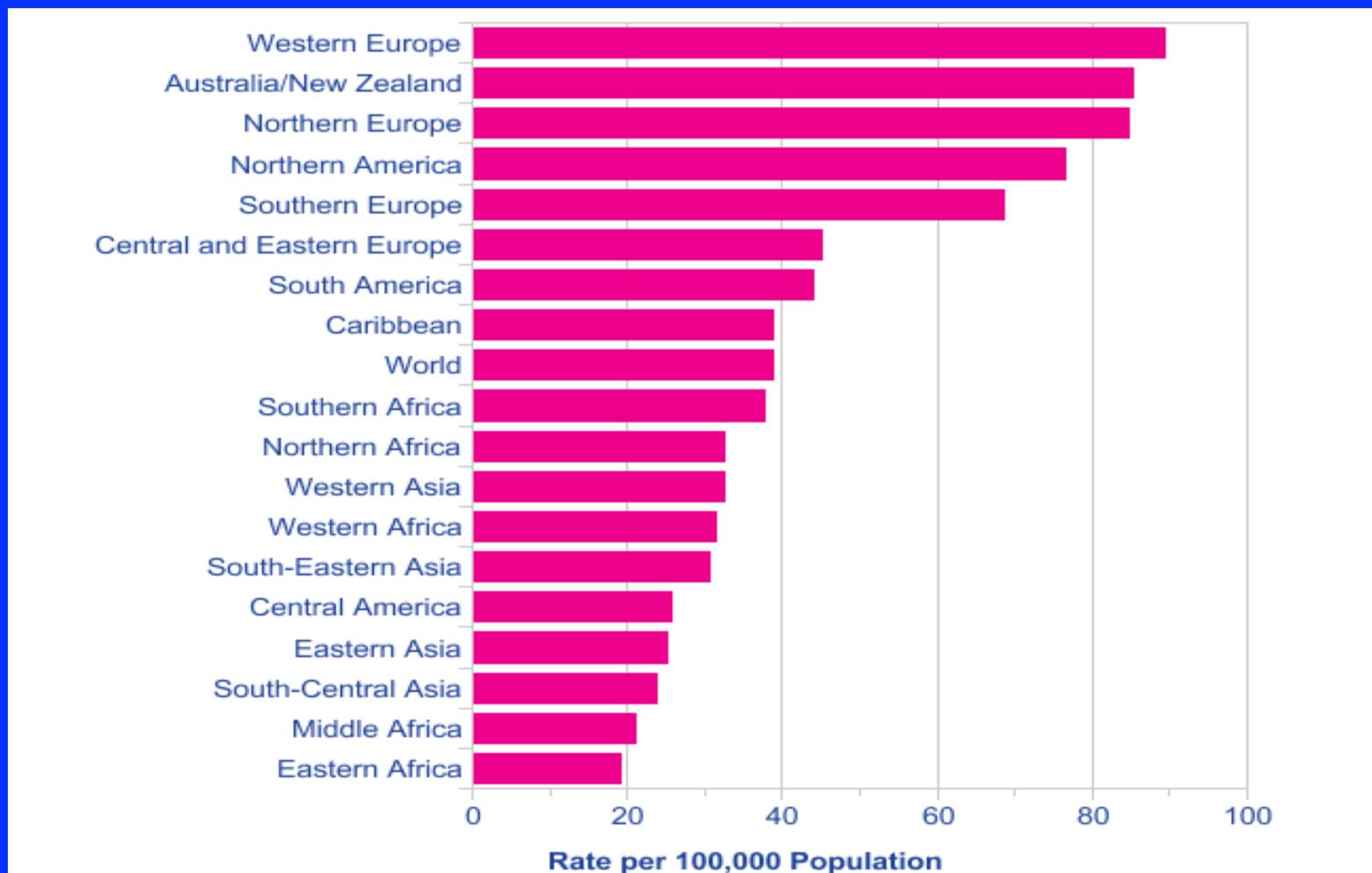
Session overview

- basic cancer genetics
- breast cancer susceptibility
- inherited predispositions to breast (and ovarian) cancer
 - BRCA1
 - BRCA2
- options for women at high risk

Basic cancer genetics

- cancer is common
- most cancers are sporadic
- all cancer is genetic
 - majority of cancer-causing genetic faults are the result of environmental damage to cells
 - most cancers occur in later life
- most cancers are **NOT** inherited
 - 5-10% of breast cancer due to a dominantly inherited cancer predisposing gene fault

World age-standardised incidence rates of breast cancer, 2008 (estimates)



Breast cancer susceptibility

- UK general population lifetime risk is 1 in 10
 - for women of White British/Western European origin
 - country and continent variation in incidence
 - migrants acquire incidence of new country within a few generations
 - breast cancer is less common in 1st and 2nd generation non-Pakistani Asian women
 - a limited family history may be more significant than for White British women

Differences in breast cancer risk for South Asian women in the UK

the risk of breast cancer depends on a woman's ethnicity

- 700 1st generation South Asian women
 - Gujarati Hindu; Punjabi Hindu; Punjabi Sikh; Pakistani and Indian Muslim; Bangladeshi Muslim
- Muslim women from India and Pakistan ~ twice as likely to develop breast cancer as Gujarati Hindu women
- differences in factors such as diet and body size?

~20% of breast cancer diagnosed in Pakistani women under the age of 40 is thought to be due to recessively inherited genes

Scottish women of Pakistani origin at risk of late diagnosis of breast cancer

- 140,000 records from 2002-08 of women aged 50+ who were invited to have breast screening for the 1st time
- women of Pakistani origin are least likely to take up the invitation
- proportion not attending
 - 41.9% of women of Pakistani origin
 - 37.4% of women of African origin
 - 35% of 'other' South Asian (including women of Bangladeshi origin)
 - 32.7% of women of Indian origin
 - 23.1% of White Scottish women

Awareness of breast cancer among women living in inner London, 2010

- Asian women had lower breast cancer awareness than White women
 - knowledge of symptoms, how to do breast checking, confidence in detecting changes and knowledge of the NHS Breast Screening Programme
- Asian women were more likely than White women to report they might be put off by
 - worry about what the doctor might find, embarrassment and lack of confidence talking about symptoms
- Asian women were more likely to know that the risk of breast cancer increases with age

Barriers to cancer screening

- beliefs about susceptibility to cancer influence preventive behaviour
- culture, religion and social/family relationships play a part in forming these beliefs
- fatalism: the belief that cancer is predetermined
 - talking about cancer enhances its power
- cancer: a taboo subject
 - shame and stigma
 - worse for some cancers than others
- language and cultural barriers

Family histories suggestive of a breast (and ovarian) cancer susceptibility

- familial clustering of breast (or ovarian) cancer
- early age at diagnosis(<50yrs)
- women with more than 1 primary breast cancer
- male breast cancer

Assessing a family history of cancer: what do we need to know? (1)

we need a family tree that includes children, brothers, sisters, parents, aunts, uncles and grandparents

- number of affected and unaffected individuals
- types of cancer in the family and age at diagnosis
- biological relationship between affected individuals

a history of on the father's side of the family can be as significant as that on the mother's side of the family

Assessing a family history of cancer: what do we need to know? (2)

- individuals with more than one primary cancer
- family's ethnic origin(s) and/or consanguinity
- histological confirmation of (some) cancer diagnoses

Options for women at high risk of breast (and ovarian) cancer

- breast screening
 - mammography
 - MRI
- genetic testing
- risk-reducing surgery
 - removal of the breasts (with reconstruction)
 - removal of the ovaries and fallopian tubes

BRCA1

- the gene was identified in 1990; genetic testing has been available in the UK since 1994
- lifetime risks for women with BRCA1 gene faults
 - breast cancer ~ 80%
 - ~ 60% risk of more than 1 breast cancer
 - ovarian cancer ~ 60%
- no particularly increased cancer risks for men

Four BRCA1 gene faults are relatively common in Pakistan



Birthplaces of the grandparents of those with these BRCA1 gene faults

BRCA2

- the gene was identified in 1994
- genetic testing has been available since 1995
- lifetime risks for women with BRCA2 gene faults
 - breast cancer 60-80%
 - ovarian cancer 10-30%
- lifetime risks for men with BRCA2 gene faults
 - breast cancer ~ 10%
 - prostate cancer ~ 14%

Genetic testing

- (usually) only possible if a DNA sample is available from an affected relative
- laborious, time-consuming, expensive
 - only performed in families with a reasonable chance of finding a gene fault
 - some testing through research studies
 - take into account family's ethnic origin
- if a gene fault is found, we can offer a genetic test to relatives

Counselling issues for affected individuals who donate DNA

- usually approached by their relatives
- rarely decline
 - act out of concern for relatives and because they want to help

but

- they need to be aware of the implications for themselves
 - risk of second primary breast cancer
 - risk of ovarian cancer
- psychological impact of knowing s/he is a gene carrier

Psychological and social impact of genetic diagnosis/testing

- wish to end uncertainty
- helps with risk management decisions
- information for children

but

- may maintain/increase anxiety about own/other's risk
- limited/radical preventive options
- difficulty disclosing information to relatives
- potential impact on family relationships
- guilt about children's risk

(Non)disclosure of genetic information in families with BRCA1/2

disclosure

- most pass information on to all their close relatives and many tell more distant relatives
 - relatives' right to know
 - own responsibility to disclose
 - disclosure prevents worry
 - promote trust and openness
 - sense of generational responsibility
- women are more likely to pass information on

non-disclosure

- difficulties deciding to whom, when and/or how to disclose the information
- lack of contact with near/distant relatives
- assumption the information will 'filter through'
- concern about causing, rather than preventing, problems

Risk-reducing breast surgery (usually unaffected women)

- removal of the breasts (followed by reconstruction) reduces the risk of breast cancer by $\sim 95\%$
- series of appointments over at least 6 months
 - genetics
 - psychologist
 - breast surgeons
 - breast nurses

Risk-reducing ovarian surgery

- removal of both ovaries and fallopian tubes
- decreases the risk of ovarian cancer by $\sim 90\%$
- decreases the risk of breast cancer by $\sim 50\%$ if it takes place when a woman is under the age of 45
- women can consider it to reduce their breast cancer risk even when they do not have an increased risk of ovarian cancer

Factors affecting decisions about risk-reducing surgery

- health benefits of risk reduction, control over disease, lowering of anxiety
 - risk reduction \approx health promoting
 - surveillance \approx potential health threat
- sense of self and body image
 - identity as women **and** exposure to risk
- having choices other women in the family did not have
- attitudes of other family members