EXPLAINING BREAST DENSITY TO PATIENTS

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What does "density" mean to you?



The quality or state of being dense; the quantity per unit volume, unit area, or unit length; the degree of opacity of a translucent medium, or the common logarithm of the opacity.

Merriam-Webster's dictionary

Merriam-Webster online dictionary. Density. http://www.merriam-webster.



Left vs. Right



"Like looking for a snowball in a snowstorm"





Grass Roots Movement

- "Eighteen lymph nodes were removed and thirteen contained cancer – AND REMEMBER - a "normal" mammogram just weeks before. Is that early detection?"
- "7 major studies with over 42,000 women that demonstrate that by supplementing mammograms with ultrasounds increases detection from 48% to 97% for women with dense tissue" Nancy Cappello

Language varies:

Breast density notification after mammography: Examples of required wording

Wording required in California

"Your mammogram shows that your breast tissue is dense. Dense breast tissue is common and is not abnormal. However, dense breast tissue can make it harder to evaluate the results of your mammogram and may also be associated with an increased risk of breast cancer...This information about the results of your mammogram is given to you to raise your awareness and to inform your conversations with your doctor. Together, you can decide which screening options are right for you. A report of your results was sent to your physician." a

Wording required in Connecticut

"If your mammogram demonstrates that you have dense breast tissue, which could hide small abnormalities, you might benefit from supplementary screening tests, which can include a breast ultrasound screening or a breast MRI examination, or both, depending on your individual risk factors. A report of your mammography results, which contains information about your breast density, has been sent to your physician's office and you should contact your physician if you have any questions or concerns about this report."

a California Legislative Information. SB 1538: Senate Bill Analysis, April 16, 2012. http://leginfo.legislature.ca.gov/faces/billNavClient.xhtml?bill_id=201120120SB1538

b CT Public Act 09-41. http://www.cga.ct.gov/2009/ACT/PA/2009PA-00041-R00SB-00458-PA.htm

But DOES adding Ultrasound save lives?

- 935 women w dense breasts mmg
- 935 U/S (hand-held, by technologist)

• 47 needed biopsies

• 3 cancers (1 DCIS, 2 infiltrating ductal)

Newer technology-Automated Whole Breast U/S

 4419 women with dense breasts underwent AWBU

 39 additional cancers found (yield 3.6/1000)

What about breast cancer?

- 5 yr incidence of invasive breast ca in 629,229 women:
 - Entirely Fatty: 7.5/1000 women
 - Scattered fibroglandular density: 12.4/1000
 - Heterogeneously dense: 16.5/1000
 - Extremely dense: 18.1/1000

But ...

- Breast density decreases with age
- Obesity is a risk factor for breast ca
- Obesity reduces breast density
- ?Methodologic Flaws?
- Not 3-D

So how do we explain this to patients?

Past studies tell us ...

- A large proportion of women don't know their correct mammogram result
- Mammogram letters are often written in a way that is difficult to understand
- Women are not aware of how common it is to be called back after a routine screening mammogram

Patient reaction and wishes

- Patient skepticism, fear, misunderstanding of implications
- Focus Groups:
 - Explain this to us BEFORE the mmg
 - Show us pictures
 - Avoid Medical Terminology
 - Don't make it too complicated
 - Explain what we can do to reduce our risk

Additional Resources

Online

- American College of Radiology Dense Breast Brochure:
- http://www.acr.org/~/media/ACR/Documents/PDF/QualitySafety/Resources/Breast%20Imaging/ Breast%20Density%20bro_ACR_SBI_lores.pdf
- http://www.ahrq.gov/qual/literacy/he althliteracytoolkit.pdf
- http://www.hsph.harvard.edu/healthl iteracy/index.html
- www.plainlanguage.gov
- www.ama-assn.org

To create materials:

Doak CC, Doak LG, Root JH. Teaching patients with low literacy skills. Philadelphia: Lippincott, 1996.