The impact of doctor–patient relationship & communication (on mastectomy rates)

Professor Malcolm W Reed

Department of Oncology, The University of Sheffield

The University Of Sheffield.

What is the standard of care for early operable breast cancer?

BCS

Choice

The University Of Sheffield.

BCS Vs. Mastectomy

Better body image

? Better health related quality of life

Radiotherapy not integral to treatment

Simpler treatment package

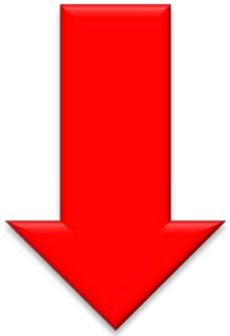
Lower local recurrence rates

Survival is equal

Risk of reoperation for margins

Radiotherapy integral to treatment

Higher local recurrence rates



Breast loss

Body image worse

Sexuality worse

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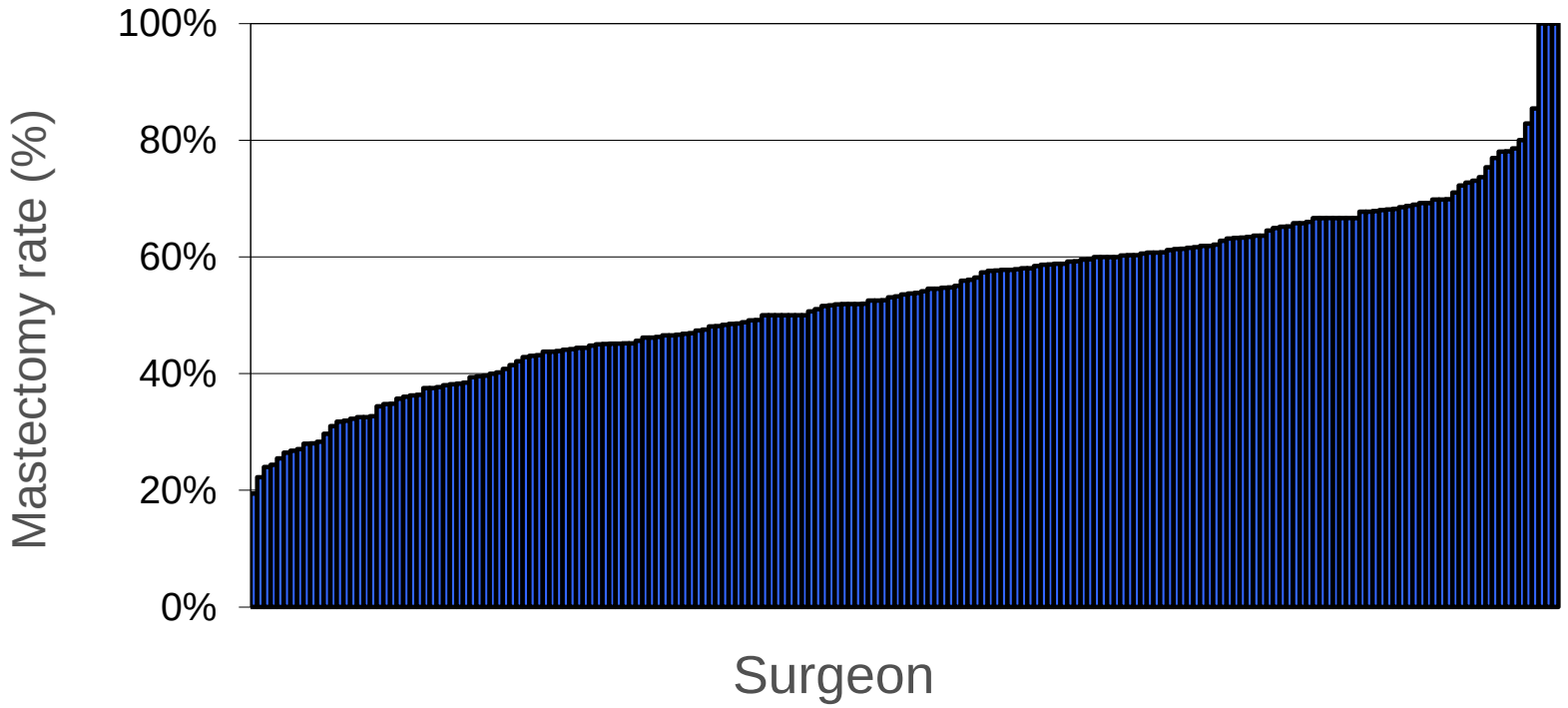
Variation in UK surgeons' mastectomy rates

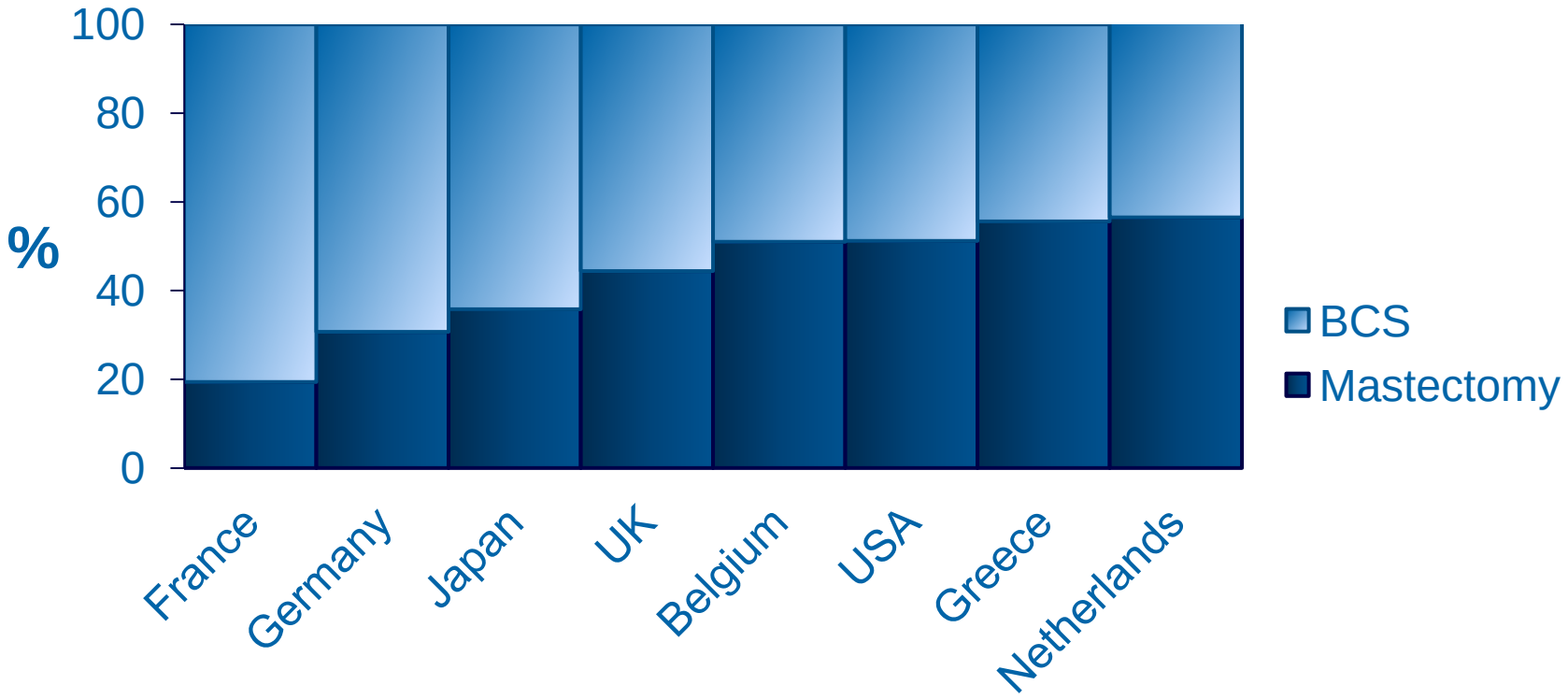


patients per surgeon 12 - 184

BCCOM Project Year 3:
The management of primary breast cancers diagnosed in 2004 in the UK

Variations in locoregional therapy in postmenopausal patients with early breast cancer treated in different countries

J. G. H. van Nes[1], C. Seynaeve[3], S. Jones[4], C. Markopoulos[5], H. Putter[2] and C. J. H. van de Velde[1] on behalf of the Tamoxifen and Exemestane Adjuvant Multinational (TEAM) trialists



BJS 2010; 97: 671-9

MEDICAL CARE
Volume 40, Number 3, pp 181–189
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Persistent Differences in Sociodemographic Determinants of Breast Conserving Treatment Despite Overall Increased Adoption

HEALTH SERVICES RESEARCH
•
RECHERCHE EN SERVICES DE SOINS DE SANTÉ

Variation in breast cancer surgery in Ontario

International Journal for Quality in Health Care 2002; Volume 14, Number 5: 411–418

A first look at variations in use of breast conserving surgery at five teaching hospitals in Japan

TATSURO ISHIZAKI, YUICHI IMANAKA, MASAHIRO HIROSE, KAZUAKI KUWABARA, TOSHIO OGAWA AND YOSHIAKI HARADA

Original article

The National Health Service Breast Screening Programme and British Association of Surgical Oncology audit of quality assurance in breast screening 1996–2001

Pergamon

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0895-4356(94)00148-0

APPROPRIATENESS AND VARIATION OF SURGICAL TREATMENT OF BREAST CANCER IN ITALY: WHEN EXCELLENCE IN CLINICAL RESEARCH DOES NOT MATCH WITH GENERALIZED GOOD QUALITY CARE

Pergamon

International Journal for Quality in Health Care, Vol. 6, No. 3, pp. 233–238, 1994
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Variation in Use of Breast Surgery and Characteristics of Hospitals' Surgical Staff

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ORIGINAL ARTICLE

URBAN–RURAL DIFFERENCES IN THE MANAGEMENT OF SCREEN-DETECTED INVASIVE BREAST CANCER AND DUCTAL CARCINOMA *IN SITU* IN VICTORIA

DAVID L. KOK,* JIU

Trends in Breast Conserving Surgery Among Asian Americans and Pacific Islanders, 1992–2000

Mita Sanghavi Goel, MD, MPH,[1] Risa B. Burns, MD,[2] Russell S. Phillips, MD,[2] Roger B. Davis, ScD,[2] Quyen Ngo-Metzger, MD, MPH,[3] Ellen P. McCarthy, PhD, MPH[2]

[1]Division of General Internal Medicine, Department of Medicine, Feinberg School of Medicine, Northwestern University, Chicago, IL, USA; [2]Division of General Medicine and Primary Care, Department of Medicine, Beth Israel Deaconess Medical Center, Harvard Medical School, Boston, MA, USA; [3]Division of General Medicine and Primary Care and the Health Policy Research Center, University of California Irvine College of Medicine, Irvine, CA, USA.

ROBERT
ANTONI
ANGELO
MAURIZ
LIBERAT

*Laborat
Richerche
Italy

‡Unità di
Negri-Su

Original article

Variations in locoregional therapy in postmenopausal patients with early breast cancer treated in different countries

J. G. H. van Nes[1], C. Seynaeve[3], S. Jones[4], C. Markopoulos[5], H. Putter[2] and C. J. H. van de Velde[1] on behalf of the Tamoxifen and Exemestane Adjuvant Multinational (TEAM) trialists

Departmens of [1]Surgery and [2]Medical Statistics, Leiden University Medical Centre, Leiden, and [3]Department of Medical Oncology, Erasmus Medical Centre – Daniel den Hoed Cancer Centre, Rotterdam, The Netherlands, [4]Texas Oncology, Dallas, and US Oncology Research, Houston, Texas, USA, and [5]Breast Unit, Athens University Medical School, University of Athens, Athens, Greece
Correspondence to: Professor C. J. H. van de Velde, Leiden University Medical Centre, Department of Surgery, K6-R, PO Box 9600, 2300 RC Leiden, The Netherlands (e-mail: c.j.h.van_de_velde@lumc.nl)

Background: The Tamoxifen and Exemestane Adjuvant Multinational (TEAM) trial is an international randomized trial evaluating the efficacy and safety of exemestane, alone or following tamoxifen. The large number of patients already recruited offered the opportunity to explore locoregional treatment practices between countries.

Regional Differences in Surgical Management of Breast Cancer

Robert T. Osteen, MD
Glenn D. Steele, Jr., MD
Herman R. Menck, CPh
David P. Winchester, MD

In an effort to investigate possible regional variations in the treatment of breast cancer, the 1988 National Cancer Data Base (NCDB) data for nine regions of the country were compared. A previous Patient Care Evaluation study by the Commission on Cancer of the American College of Surgeons had suggested the existence of regional variations in the treatment of breast cancer.[1] The rapidly changing concepts in the surgical treatment of breast cancer offered an opportunity to investigate regional variations, specifically with respect to the use of partial mastectomy with or without radiation therapy, as a substitute for total mastectomy.

Although the substitution of partial mastectomy and radiation therapy for total mastectomy began in some centers earlier, it was not until the 1980s that large randomized studies established the principle that, in certain circumstances, partial mastectomy with radiation therapy was an effective substitute for mastectomy in the treatment of early stage (0, I, II) breast cancer.[2,3]

The advantages of partial mastectomy are primarily cosmetic and psychological, and there are reasons why some patients and physicians might favor one treatment over another. We were interested to see whether or not these individual choices would result in differences in regional behavioral patterns. These initial results are presented to encourage more specifically targeted studies of problems related to the treatment of breast cancer.

Dr. Osteen is Vice Chairman of the Department of Surgery at the Brigham and Women's Hospi-

Methods

Special Article

THE EFFECT OF LEGISLATIVE REQUIREMENTS ON THE USE OF BREAST-CONSERVING SURGERY

ANN BUTLER NATTINGER, M.D., M.P.H., RAYMOND G. HOFFMANN, PH.D., ROBYN SHAPIRO, J.D., MARK S. GOTTLIEB, PH.D., AND JAMES S. GOODWIN, M.D.

ABSTRACT

Background We studied the effect of state legislation requiring the disclosure of options for the treatment of breast cancer on the use of breast-conserving surgery in clinical practice.

Methods The National Cancer Institute's Surveillance, Epidemiology, and End Results registry provided data on women from 30 through 79 years of age who underwent breast-conserving surgery or mastectomy for local or regional breast cancer from 1983 through 1990. We examined the trend over time in the use of breast-conserving surgery among patients in four sites (Connecticut, Iowa, Seattle, and Utah) where there were no state laws specifically requiring the disclosure of options for the treatment of breast cancer by physicians. For four additional sites (Detroit, Atlanta, New Mexico, and Hawaii) that had such legislation, we determined whether the rate of breast-conserving surgery after the legislation was different from the expected rate.

Results An attorney rated the legislation as giving most direction to physicians in Michigan, followed by Hawaii, Georgia, and New Mexico. The rate of breast-conserving surgery was up to 8.7 percent higher than expected in Detroit for six months after the passage of the Michigan law ($P<0.01$). The rate was up to 13.2 percent higher than expected in Hawaii for 12 months after that state's law was passed ($P<0.05$) and up to 6.0 percent higher than expected in Atlanta for 3 months after the passage of the Georgia law ($P<0.01$). After these transient increases, the surgery rates reverted to the expected levels. No significant effect was detected in New Mexico, where only a resolution without legal force was passed.

Conclusions Legislation requiring physicians to disclose options for the treatment of breast cancer appeared to have only a slight and transient effect on the rate of use of breast-conserving surgery. (N Engl J Med 1996;335:1035-40.)

©1996, Massachusetts Medical Society.

actions on the part of health care providers. Traditionally, legislation of this type has been restricted to public health measures, such as the reporting of cases of infectious diseases, but more recently it has been applied to other kinds of medical issues, such as the care of patients with the acquired immunodeficiency syndrome. Several state laws have been passed with the aim of promoting breast-conserving surgery for women with breast cancer in an early stage. The enactment of such legislation provides an opportunity to examine the effectiveness of legislative mandates in altering medical practice.

By 1985, several randomized trials had demonstrated the efficacy of breast-conserving surgery,[7-10] but the use of this treatment in clinical practice increased only minimally during the late 1980s.[11-13] The slow adoption of breast-conserving surgery and the identification of nonclinical factors that affect its use (such as geographic location and the type of hospital)[14,15] raised the question whether all women with breast cancer are adequately informed about their therapeutic options.

By 1990, 18 states had passed laws specifically addressing the disclosure by physicians of options for the treatment of breast cancer.[16] We assessed the effect of such legislation on the use of breast-conserving surgery in clinical practice.

METHODS

Sources of Data

The National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) registry data base[17] was the source of the clinical data we studied. The data were collected from nine geographically distinct, population-based tumor registries that include information on patients' demographic characteristics, the extent of disease, and initial treatment for approximately 10 percent of the patients with cancer in the United States. The sites in the SEER data base included the entire states of Connecticut, Hawaii, Iowa, New Mexico, and Utah and the metropolitan areas

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Case-mix fails to explain variation in mastectomy rates: management of screen-detected breast cancer in a UK region 1997–2003

LJM Caldon[1], SJ Walters[2], JA Reed[2], A Murphy[3], A Worley[3] and MWR Reed*[,1]

[1]Academic Surgical Oncology Unit, Division of Surgical Sciences (South), Section of Surgical & Anaesthetic Sciences, The University of Sheffield, Floor K, Royal Hallamshire Hospital, Sheffield S10 2JF, UK; [2]School of Health and Related Research, Sheffield Health Economics Group, SHARR, University of Sheffield, Regent Court, 30 Regent St, Sheffield S1 4DA, UK; [3]East Midlands Breast Screening Quality Assurance Reference Centre, Rufford Ward, Nottingham City Hospital NHS Trust, Hucknall Road, Nottingham NG5 1PB, UK

Wide variation in the surgical management of breast cancer exists at hospital, regional, national and international level. To demonstrate whether variation in surgical practice observed at aggregate level between breast units persists following adjustment for case-mix, individual patient-level data from the Trent Breast Screening Programme Quality Assurance database (1997–2003) was analysed. Expected case-mix adjusted mastectomy rates were derived by logistic regression using the variables tumour size, site and grade, patient age and year of presentation, employing the region's overall case-mix adjusted practice as the reference population. The region's 11 breast screening units detected 5109 (3989 invasive) surgically managed primary breast cancers over the 6-year period. A total of 1828 mastectomies (Mx) were performed (Mx rate 35.8%, 95% confidence interval: 34.5–37.1%). Significant variation in mastectomy rates were observed between units (range 25–45%, $P<0.0001$), and persists following case-mix adjustment ($P<0.0001$). Two-fold variation in observed to expected unit mastectomy rate coefficient is demonstrated overall (range 0.66–1.36), increasing to almost four-fold variation in cancers less than 15 mm diameter (range 0.55–1.95). Significant variation in surgery for screen-detected primary breast cancer is not explained by case-mix. Further research is required to investigate potential patient and professional causative factors.

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Keywords: breast cancer; mastectomy; screening audit; variation; case-mix adjustment

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AL ARTICLE

SURGICAL MANAGEMENT OF DUCTAL CARCINOMA *IN SITU* IN AUSTRALIA IN 1995

ACE SHUGG,* VICTORIA M. WHITE,[‡] PAUL R. B. KITCHEN,[†] MYEE PRUDEN,[‡] JOHN P. COLLINS,[§] AND DAVID J. HILL[‡]

*zies Centre for Population Health Research, University of Tasmania, Hobart, Tasmania, [‡]Centre for Behavioural rch in Cancer, Cancer Control Research Institute, The Cancer Council Victoria, Carlton, [§]Department of Surgery, Vincent's Hospital, Fitzroy, [‡]Department of Surgery, Royal Melbourne Hospital, Parkville, Victoria, Australia

und: In the present paper we describe the presentation and management of ductal carcinoma in *situ* (DCIS) of the breast n in Australia in 1995. This representative, national data set provides a historical comparator for studies examining DCIS ent that follow.

: Surgeons identified by population-based cancer registries as having treated a new diagnosis of DCIS between 1 April eptember 1995 completed a questionnaire on the presentation and management of each case.

Two hundred and five surgeons supplied treatment details on 418 DCIS tumours in 415 women. Half of all tumours were at BreastScreen clinics and a further 25% were detected at other mammography centres. Twenty-six percent of tumours pable at presentation, 33% were multifocal and 55% were high grade (including comedocarcinoma). Breast conserving BCT) rather than mastectomy was utilized in 260 (62%) of cases. Tumours that were of low grade, small in size and not l were more likely to be treated by BCT. Surgeons seeing six or more DCIS cases in the 6-month period were more likely to T. Of the conservatively treated cases, 22% were referred for a radiation oncology consultation. The most common reasons g DCIS with mastectomy were that the tumour was too extensive or multifocal (63%), it extended to margins of the speci-), or patient concerns about recurrence (34%).

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Why does treatment vary?

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- Case-mix
- Clinicians' choice
- Patients' choice

interaction

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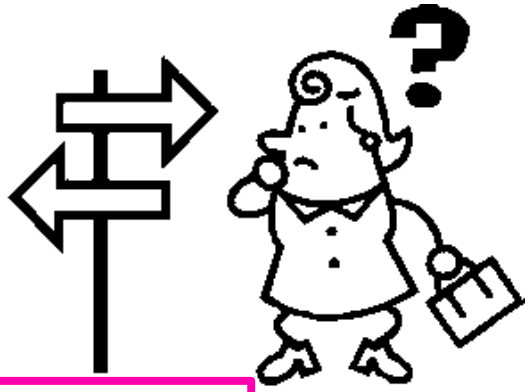
Decision-making approaches

You will be having …

You can have … or …



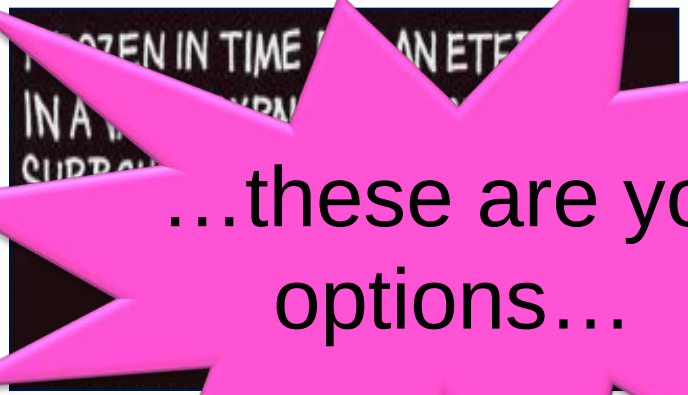
Paternalistic

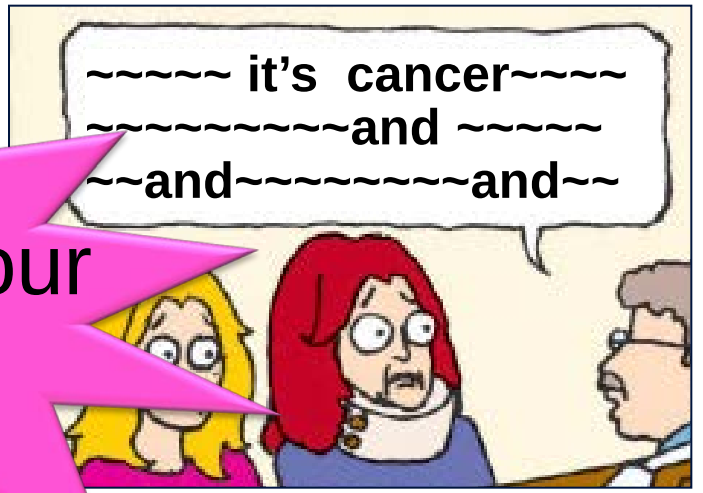
Information & support

Shared

Information only

Informed choice





…these are your options…

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Why give choices?

- No ‘best’ treatment
- Patients’ treatment preferences vary
- When provided with information & allowed to play the role they want in treatment selection patients
  - are more satisfied
  - have less regret about their treatment
  - make a better psychological recovery

Morris & Royle 1988, Fallowfield 1994, Keating 2002, Lam 2003, Lantz 2005, Hack 2006

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Research project overview

Identify factors influencing Mastectomy rates

Data collection 2003 - 2006

14 hospitals

3 Hospitals in-depth

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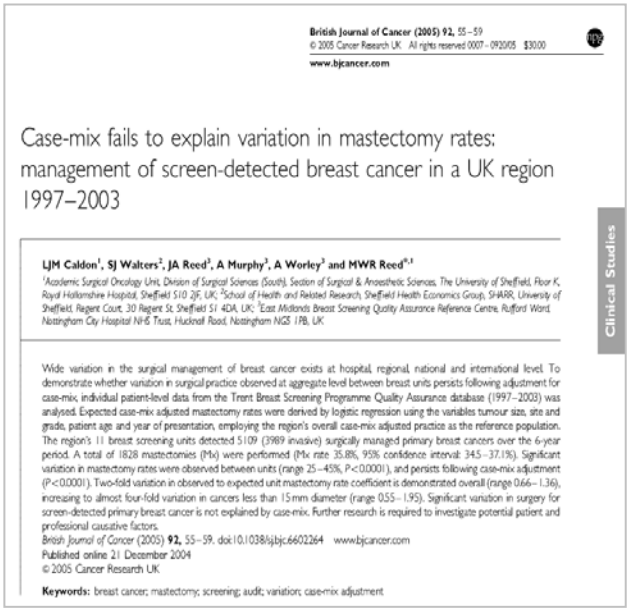
It is not the cancers

Clinicians' preferences vary

Women want more say in decisions



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Case-mix fails to explain variation in mastectomy rates: management of screen-detected breast cancer in a UK region 1997–2003

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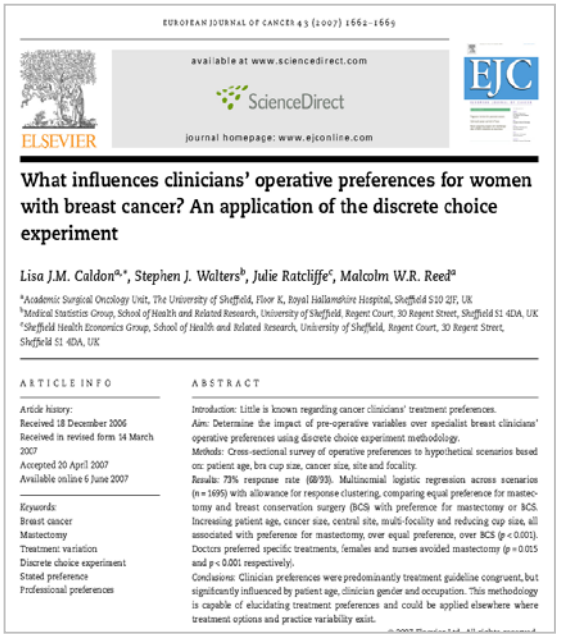
Clinical Studies



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EJC

What influences clinicians' operative preferences for women with breast cancer? An application of the discrete choice experiment

Lisa J.M. Caldon[a,*], Stephen J. Walters[b], Julie Ratcliffe[c], Malcolm W.R. Reed[a]

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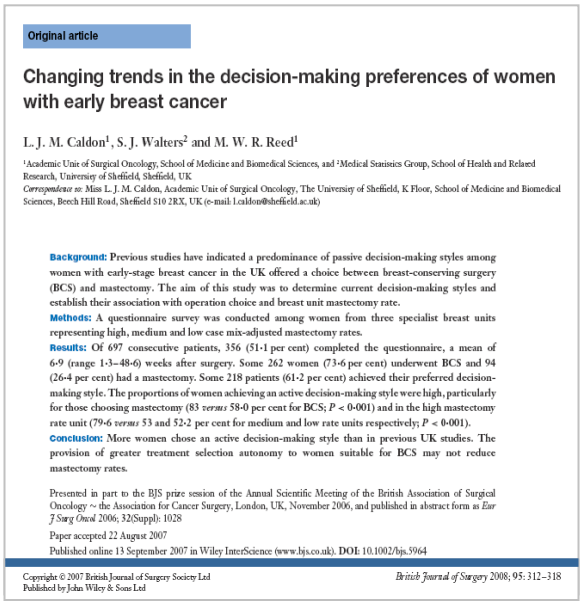
Discrete choice experiment
Stated preference
Professional preferences

ABSTRACT

Introduction: Little is known regarding cancer clinicians' treatment preferences.
Aim: Determine the impact of pre-operative variables over specialist breast clinicians' operative preferences using discrete choice experiment methodology.
Methods: Cross-sectional survey of operative preferences to hypothetical scenarios based on: patient age, bra cup size, cancer size, site and focality.
Results: 73% response rate (68/93). Multinomial logistic regression across scenarios ($n = 1695$) with allowance for response clustering, comparing equal preference for mastectomy and breast conservation surgery (BCS) with preference for mastectomy or BCS. Increasing patient age, cancer size, central site, multi-focality and reducing cup size, all associated with preference for mastectomy, over equal preference, over BCS ($p < 0.001$). Doctors preferred specific treatments, females and nurses avoided mastectomy ($p = 0.015$ and $p < 0.001$ respectively).
Conclusions: Clinician preferences were predominantly treatment guideline congruent, but significantly influenced by patient age, clinician gender and occupation. This methodology is capable of elucidating treatment preferences and could be applied elsewhere where treatment options and practice variability exist.



Original article

Changing trends in the decision-making preferences of women with early breast cancer

L. J. M. Caldon[1], S. J. Walters[2] and M. W. R. Reed[1]

[1]Academic Unit of Surgical Oncology, School of Medicine and Biomedical Sciences, and [2]Medical Statistics Group, School of Health and Related Research, University of Sheffield, Sheffield, UK
Correspondence to: Miss L. J. M. Caldon, Academic Unit of Surgical Oncology, The University of Sheffield, K Floor, School of Medicine and Biomedical Sciences, Beech Hill Road, Sheffield S10 2RX, UK (e-mail: l.caldon@sheffield.ac.uk)

Background: Previous studies have indicated a predominance of passive decision-making styles among women with early-stage breast cancer in the UK offered a choice between breast-conserving surgery (BCS) and mastectomy. The aim of this study was to determine current decision-making styles and establish their association with operation choice and breast unit mastectomy rate.
Methods: A questionnaire survey was conducted among women from three specialist breast units representing high, medium and low case mix-adjusted mastectomy rates.
Results: Of 697 consecutive patients, 356 (51·1 per cent) completed the questionnaire, a mean of 6·9 (range 1·3–48·6) weeks after surgery. Some 262 women (73·6 per cent) underwent BCS and 94 (26·4 per cent) had a mastectomy. Some 218 patients (61·2 per cent) achieved their preferred decision-making style. The proportions of women achieving an active decision-making style were high, particularly for those choosing mastectomy (83 *versus* 58·0 per cent for BCS; $P < 0.001$) and in the high mastectomy rate unit (79·6 *versus* 53 and 52·2 per cent for medium and low rate units respectively; $P < 0.001$).
Conclusion: More women chose an active decision-making style than in previous UK studies. The provision of greater treatment selection autonomy to women suitable for BCS may not reduce mastectomy rates.

Presented in part to the BJS prize session of the Annual Scientific Meeting of the British Association of Surgical Oncology – the Association for Cancer Surgery, London, UK, November 2006, and published in abstract form as *Eur J Surg Oncol* 2006; 32(Suppl): 1028

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What about the patients?

…Do women want to choose their operation?

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Patient survey

- **Sample (n=365/697)**
  - Patients from 3 Breast Units: high, medium & low Mx rates
  - Purposive sampling: women given a choice of surgery
- **Questionnaire** 2 validated tools
  - Decision-making styles *Strull et al. 1984, Degner et al. 1997*
- **Data analysis**
  - Frequency, Chi-square, One way ANOVA SPSS version 12.0

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Decision-making styles

*1990s	Now **
> 50% women wanted decisions making for them	> 80% wanted to participate in treat decisions
~30% Collaborative	< 20% Passive
~20% Active	> 40% Active

Women choosing mastectomy were the most active decision-makers 83% vs. 58% p<0.001

*Degner & Sloan 1992 & 1997, Beaver et al 1996

** Caldon et al. 2008

…but what happens in practice?

Who determines the treatment?

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Semi-structured interviews

- **Sample**
  - 3 Breast Units: high, medium & low Mx rates
  - Specialist doctors & nurses (n=29)
  - Patients: purposive sampling - given a choice (n=65)
- **Data**
  - Interviews recorded & transcribed verbatim
- **Data analysis** 'Framework' approach
  - Rigorous, systematic, comprehensive

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Treatment variation themes

Low MR unit	Medium and high MR units
• Ethos of conservation	• Ethos of choice

• Active direction of choice
  • Less comprehensive, more directive information
  • More recommendations
	• Reluctance to direct choice
	  • More comprehensive, less directive information
	  • Less recommendations

• Less support of autonomous patient decision-making	• Active support of autonomous patient decision-making
• Time pressure for decision-making	• Lack of time pressure
• ('Informed') compliance	• Shared decision making (informed consent)

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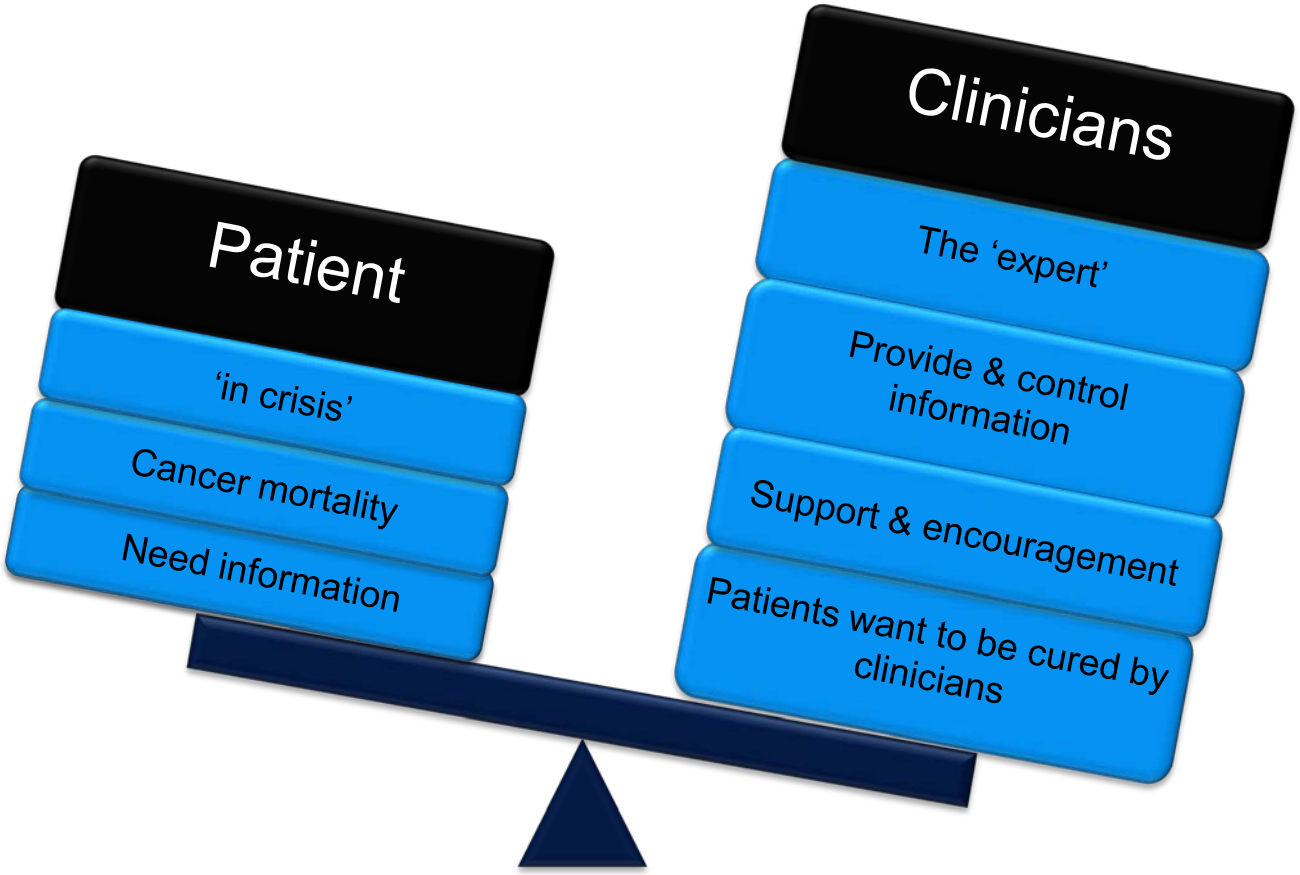
Skewed power relationship



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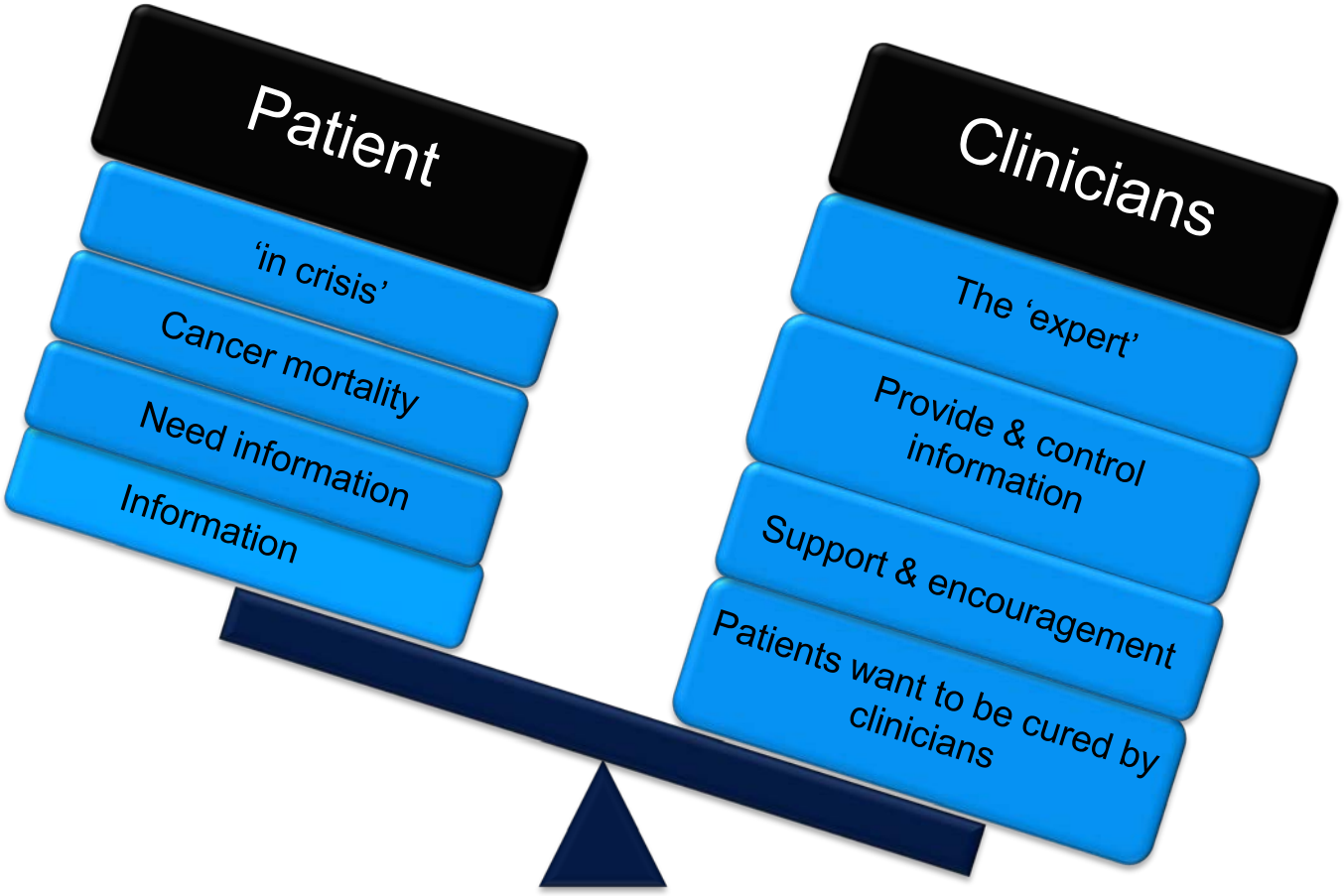
Skewed power relationship

…which can be exaggerated



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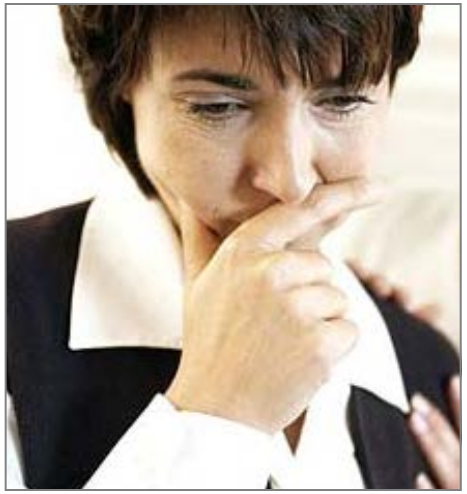
"…personally …I've always tried to conserve breasts … I find the concept of open choice when it's perfectly possible to do a simple breast conserving operation …giving the same results as mastectomy …quite peculiar…"

"…Mr__ said to me, and I will never forget this, 'I don't like doing mastectomies' ... it really upsets him … So …there was no discussion ...he really wasn't listening to what I was saying..."

Preference mismatch



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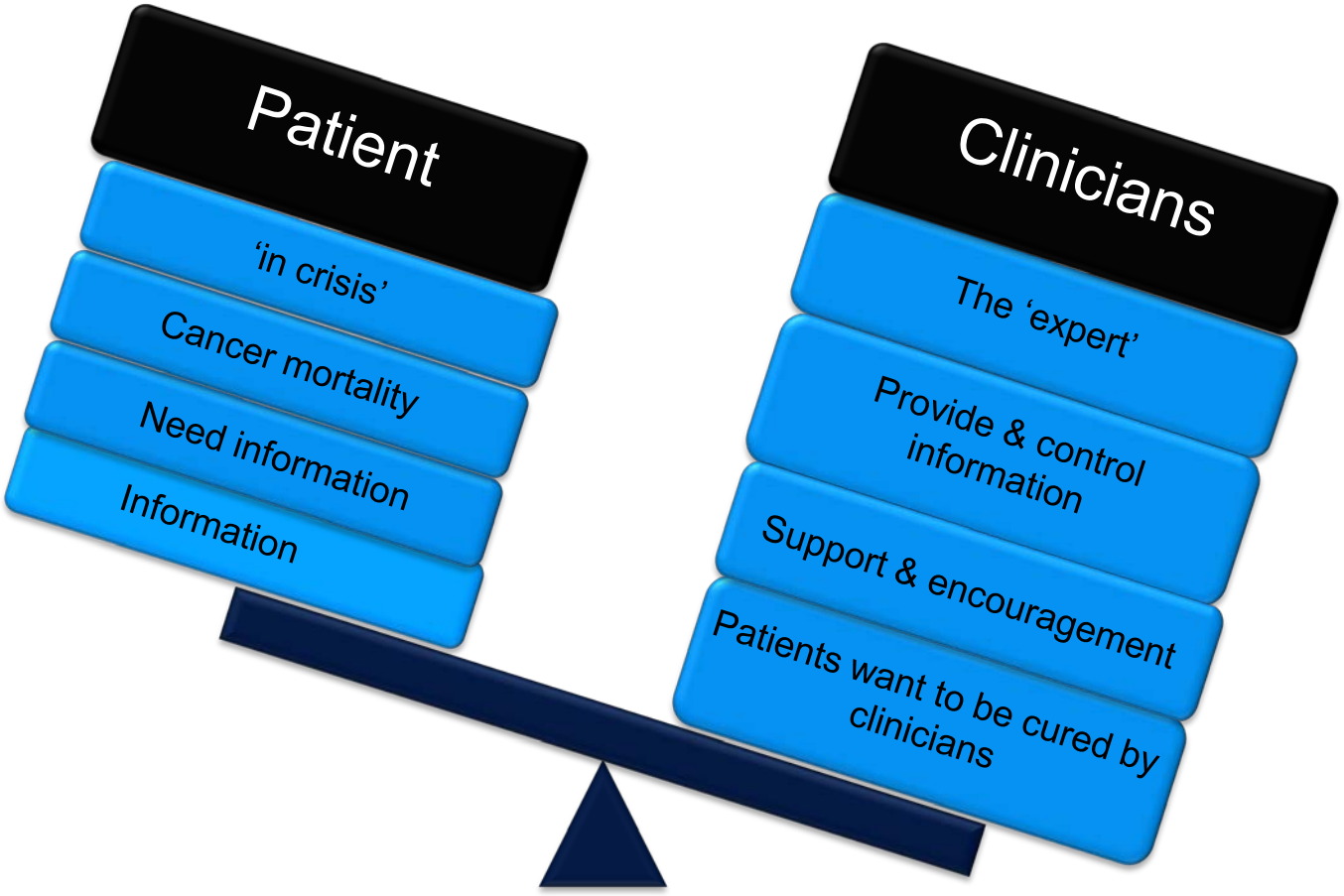
CANCER RESEARCH UK

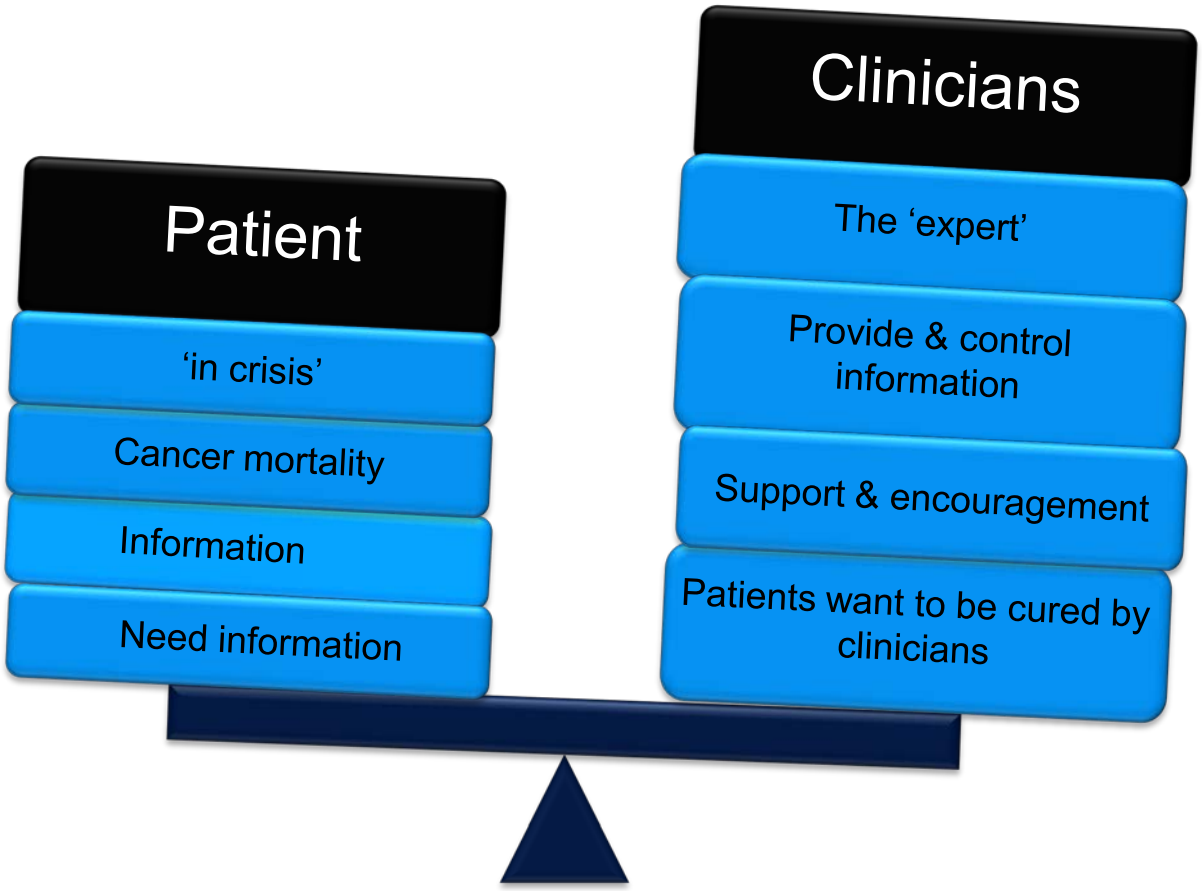
Skewed power relationship

…which can be exaggerated

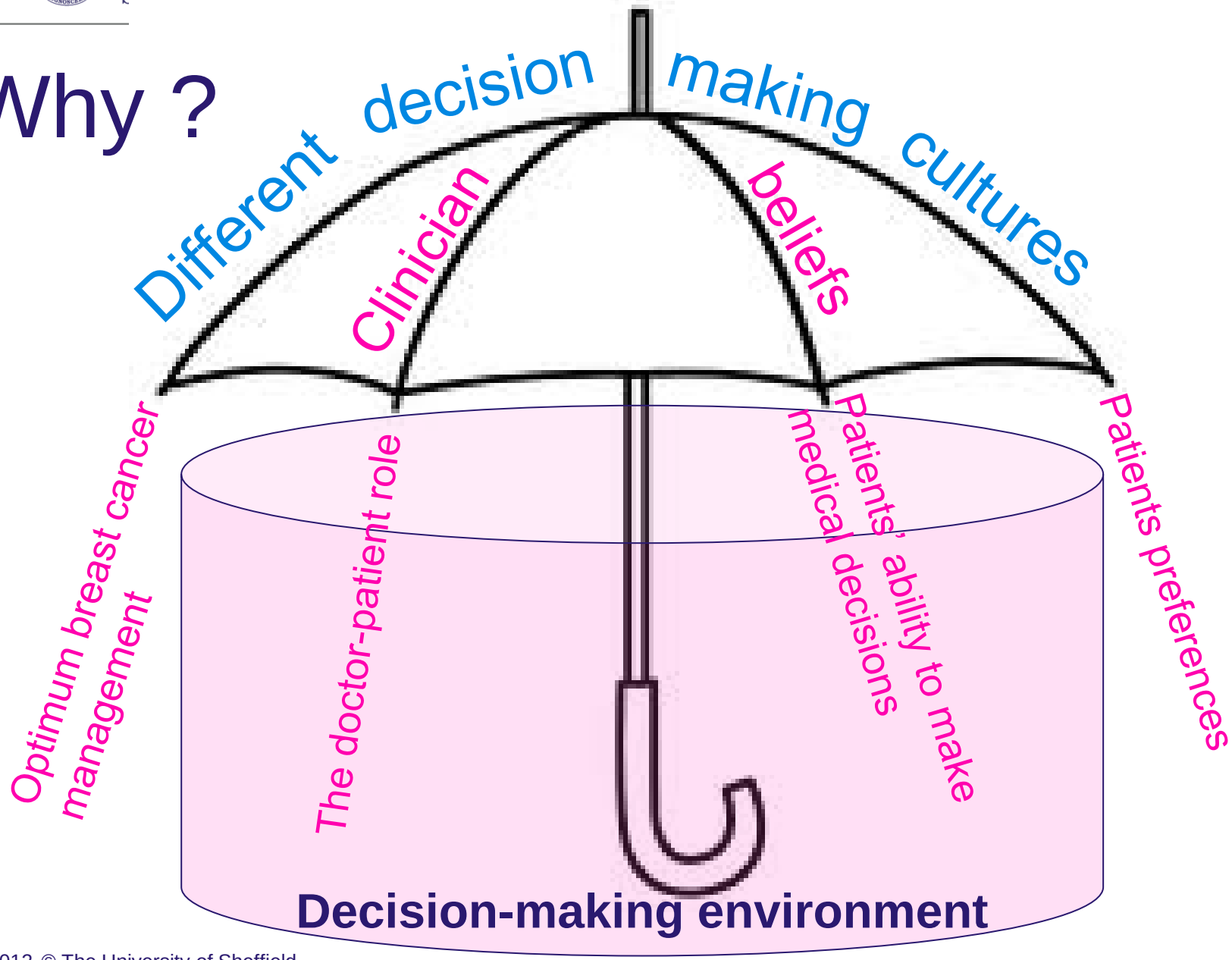


Skewed power relationship

…**or** ameliorated by the decision-making environment



Why ?


Different decision making cultures
Clinician beliefs
Optimum breast cancer management
The doctor-patient role
Patients' ability to make medical decisions
Patients preferences
Decision-making environment

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What can/should be done?

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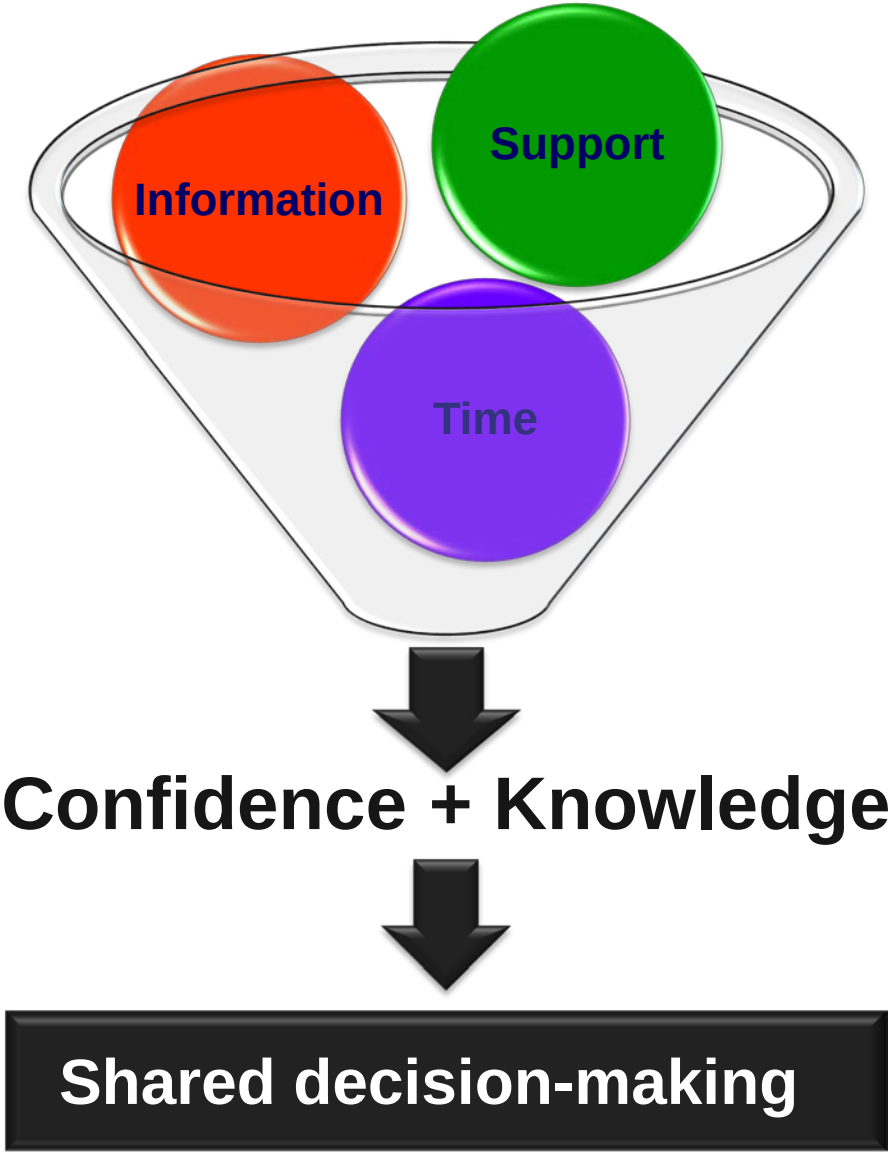
Recipe



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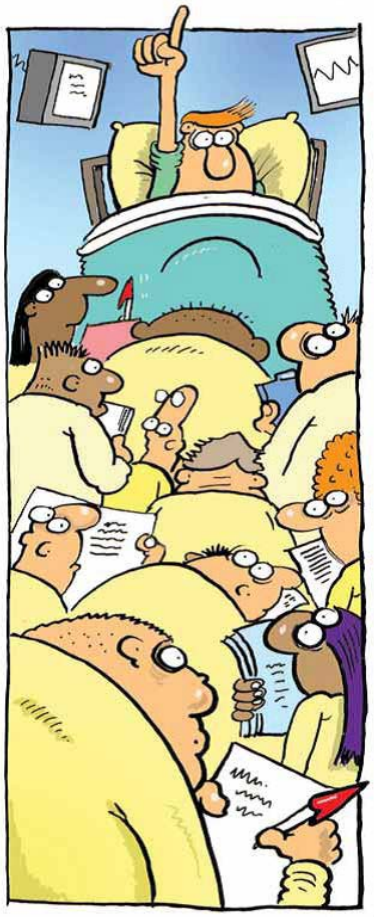
- Define the ‘correct’ mastectomy rate, or an acceptable range?
- Should patients only have mastectomy if conservation is contraindicated?



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- If patient choice paramount?
  - Improved awareness & identification of preferences
  - Tailor decision-making
  - Communication skills training
  - Methods to empower patient decision-making

BresDex
BREAST CANCER DECISION EXPLORER

Helping you choose...

Click here to send comments

Search... Search


Surgery Options


Weighing it Up


Forum

Ctrl + Ctrl - changes text size

BresDex is for women recently diagnosed with breast cancer and who have been given a choice between:

Lumpectomy* with Radiotherapy or **Mastectomy**

*also known as Wide Local Excision or Breast Conserving Surgery

Professor Malcolm Reed
Consultant
Breast Surgeon

Julietta Patnick
Director, NHS Cancer Screening Programmes

Helen McGarrigle
Clinical Nurse Specialist in Breast Care

Helen Sweetland
Consultant
Breast Surgeon

In many cases women will have been offered this choice if the cancer is less than 5 centimetres wide.

In some cases, women may have chemotherapy to try and make the cancer smaller to allow the possibility of lumpectomy.

Many women diagnosed with DCIS (Ductal Carcinoma in Situ or pre-invasive cancer) also have the choice between lumpectomy and mastectomy and can use this website.

BresDex is not for you if you have two or more cancers in the breast, or if you are a man with breast cancer.

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Treatment decision-making variation is

- **Not** due to the cancers (Br J Cancer 2005; 92(1): 55-9)
- **Associated** with clinician preferences (Eur J Cancer 2007;43(11):1662-9)
- **Associated** with patients being more or less active in their roles in choosing treatments (Br J Surgery 2008; 95(3): 312-8)
- **Predominantly** dependant on patients' understanding of clinicians' preference (Br J Cancer 2011; 104: 1551-7)

The University Of Sheffield.

Thank you

Funding

Cancer Research UK

The Royal College of Surgeons of England

Trent Breast Units

Barnsley District General Hospital

Bassetlaw District General Hospital

Chesterfield Royal Hospital

Derby City General Hospital

Doncaster Royal Infirmary

Glenfield General Hospital

Grantham & District General Hospital

Kings Mill Hospital

Lincoln County Hospital

Nottingham City Hospital

Pilgrim Hospital

Rotherham District General Hospital

Sheffield Teaching Hospitals

Trent region's patients

The research team

University of Sheffield

- Lisa Caldon
- Sam Ahmedzai
- Bill Noble
- Stephen Walters
- David Wilde

Sheffield Hallam University

- Karen Collins

Consumer representatives

- Hazel Marshall-Cork
- Gillian Speed

East midlands QA (formerly Trent QA)

- Jacquie Reed
- Alison Murphy
- Anne Worley

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