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Methods of communicating a primary diagnosis of breast cancer to patients (Review)

Lockhart K, Dosser I, Cruickshank S, Kennedy C

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[Intervention Review]

Methods of communicating a primary diagnosis of breast cancer to patients

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ABSTRACT

Background

The method of delivering a diagnosis of breast cancer to women has the potential to impact on their level of interpretation, patient recall and satisfaction.

Objectives

To assess the effectiveness of different methods when used to communicate a primary diagnosis of breast cancer to women.

Search methods

We searched the Cochrane Breast Cancer Group Specialised Register on 7th September 2006, Cochrane Consumers and Communication Group on 27th October 2006, MEDLINE (1966 to present), CINAHL (1982 to present), EMBASE OVID (1980 to present), British Nursing Index (Jan 1984 to present), PsycInfo (1967 to present), Dissertation Abstracts International (2004 to 2006), Library and Info Science Abstracts (LISA) (1969 to present), ISI Web of Knowledge (conference abstracts) and reference lists of articles.

Selection criteria

Randomised controlled trials of women with a histologically confirmed diagnosis of breast cancer receiving a diagnosis of primary breast cancer. Trials should have used one or more of the following methods; face-to-face consultations, written information, telephone consultation, audio or video tapes of consultation.

Data collection and analysis

Two review authors independently assessed trials for inclusion in the review. Studies were to have been assessed using standardised data extraction and quality assessment forms.

Main results

The search strategies identified 2847 citations overall. A total of 30 citations appeared relevant however there were three duplicates which left 27 articles for further review. Articles reporting the same primary data accounted for 6 of the publications Brown 1997; Brown 1998; Brown 1999; Brown 2000; Hack 2000; Hack 2003 which left 23 original papers to be reviewed for inclusion. Of these, none met the inclusion criteria. Data extraction and assessment of methodological quality was therefore not possible.

Authors' conclusions

The review question remains unanswered as there were no randomised trials of methods of communicating a diagnosis of breast cancer to women. The authors have considered the possible reasons for the lack of research studies in this area and have considered that it is perhaps unethical to randomise women at such a vulnerable time such as waiting for a diagnosis. The design of ethically sensitive research to examine this topic needs to be explored to inform future practice. As some papers reviewed by the authors related to the first consultation visit, where treatment options are discussed, perhaps a review which focused on the methods of communication at the first consultation visit would provide more reliable evidence for the effectiveness of methods of communication and overcome the ethical dilemmas previously mentioned.

PLAIN LANGUAGE SUMMARY

Ways of communicating to a woman that she has breast cancer

For women to wait for and receive a first diagnosis of breast cancer (primary diagnosis) is an extremely stressful experience. Studies conducted to date suggest that what a woman is told at this time has the potential to influence her sense of well being, the way she copes with the news, how much she remembers of what was discussed (her recall) and her overall level of satisfaction with the encounter.

The diagnosis of confirmed breast cancer can be delivered in a variety of ways, including face-to-face consultation, telephone consultation, written or audiovisual materials. This information can be given by a range of health professionals, such as general practitioners or specialists.

The present systematic review set out to assess the effectiveness of various methods of communicating a first diagnosis of confirmed breast cancer. The review was particularly interested in how this would impact on what the patient remembered, the satisfaction with the information received, the coping strategies used as a result of the information given and the impact of receiving the information on the patient's quality of life. The review authors made a thorough search of the medical literature looking for controlled trials in which women receiving a first diagnosis of breast cancer were randomised to the intervention group. They retrieved 23 original reports of trials for further review but ultimately no trial could be included. A number of the trials focused on communication at the first treatment consultation rather than the method of delivering the diagnosis. In an area that is ethically sensitive, the authors suggest that a review which focuses on the various methods of communication at the first consultation visit may provide useful information as to which methods are more effective and beneficial for this patient group.

BACKGROUND

Breast cancer is the most common cancer among women worldwide WHO 2005. The incidence is estimated annually at 1,151,289 new cases (2002) with 410,712 patients dying from the disease each year Parkin 2005. In comparison to western cultures, the incidence of breast cancer is lower in developing countries however as with Western cultures the incidence is continuing to increase annually.

Alongside the increase in breast cancer there is a plethora of literature concerning what women do when they first discover a breast abnormality Lindop 2001. The anxiety and emotional responses of women whilst waiting for and on receiving a definitive diagnosis is well documented Fallowfield 1991; Greer 1991; Iwamitsu 2005. Little is known however, about women's psychological well-being, coping strategies and recall connected to the method and level of communication used to deliver a primary diagnosis of breast cancer. The initial diagnosis may be given by a variety of professionals, some of whom the patient may never see again. Some studies show that the majority of women perceive a diagnosis of breast cancer as life threatening and impacting on their quality of life Galloway 1997. A survey by Loge 1996 involving 497 Norwegian cancer patients revealed that the manner in which the diagnosis was presented limited conversation between physician and patient. These findings are substantiated by a recent Cochrane systematic review which concluded that many people with cancer find it difficult to recall information provided during consultations Scott J 2003.

A number of studies and reviews have been conducted on methods of communication with cancer patients and their findings sup-

port the view that the methods of delivering information has the potential to impact on patient recall and satisfaction. McPherson 2001 conducted a systematic review of the methods of information giving in cancer and concluded that interventions such as written information, audiotapes, audiovisual aids and other interactive medium improved at least one patient related outcome. The Cochrane systematic review assessing interventions for improving communication with children and adolescents about a family member's cancer concluded that many people find it difficult to remember information provided during medical consultations, thus supporting the view that additional communication methods may be necessary.

Current practice is influenced by a number of evidence based clinical practice guidelines. In the United Kingdom the National Institute of Clinical Excellence NICE 2002 guidance on improving outcomes for patients with breast cancer reviewed evidence for communication strategies used at diagnosis of various cancers. This guideline found that various communication interventions impacted differently on outcomes and as such there were inconsistent effects on patient knowledge and levels of satisfaction. The Cochrane Review however showed 90% of patients with cancer found recordings of summaries of their consultation valuable Scott 2003. Similarly, clinical practice guidelines for the provision of psychosocial care of patients with cancer published by the National Breast Cancer Centre and National Cancer Control Initiative NBCC/NCCI 2003 suggested that the patient's understanding, recall and/or satisfaction with care or all three was increased with communication aids. These included provision of a tape of the consultation, sending a summary follow-up letter and / or having a support person to be present during the consultation or both. The evidence to support each method of communication was taken from a single randomised controlled trial.

A thorough systematic review of the evidence surrounding methods of communicating a primary diagnosis of breast cancer to women is lacking. The consultation this review refers to is the initial consultation where the patient receives their diagnosis of breast cancer. The aim of this review is therefore to focus on the communication strategies used when delivering the initial diagnosis of breast cancer to patients and to make recommendations for practice and further research based on the findings.

OBJECTIVES

The objective of this review is to:

assess the effectiveness of various methods of communicating a primary diagnosis of breast cancer including:

- a) the patient's recall of information;
- b) patient satisfaction with information;

c) the patient's coping strategies;

d) the patient's quality of life;

e) service and economic indicators (such as length of hospital stay, number of admissions and cost).

METHODS

Criteria for considering studies for this review

Types of studies

Randomised controlled trials (RCT)

Types of participants

Patients with a histologically confirmed diagnosis of breast cancer receiving their diagnosis for the first time. Patients can be in a variety of settings, including hospital (inpatients and outpatients) and primary care.

Types of interventions

Interventions to communicate a primary diagnosis of breast cancer using one or more of the following methods:

verbal, face-to-face consultations versus:

- verbal, face-to-face consultation plus written information;
- verbal, face-to-face consultation plus audio-tape of the consultation;

• verbal, face-to-face consultation plus audio-tape of the consultation plus written information;

• telephone consultation.

Types of outcome measures

Primary outcome measures

- 1. Patient reported measures of recall of information
- 2. Patient reported satisfaction with information

3. Quality of life (QoL)

Primary outcomes should be measured using reliable and valid assessment tools.

QoL is an overarching term which is used widely in research to encompass a variety of factors that impact on a patient's wellbeing. QoL indicators include:

psychological distress (including levels of anxiety and depression); coping strategies (including level of social functioning, level of self care and employment status).

Secondary outcome measures

- a) Service provision
- b) Economic data

Search methods for identification of studies

(1) Cochrane Specialised Registers

(a) We searched the specialised register maintained by the Cochrane Breast Cancer Group on 7 September 2006. Details of search strategies used by the group for the identification of studies and the procedure used to code references are outlined in the group's module (http://www.mrw.interscience.wiley.com/cochrane/clabout/articles/BREASTCA/frame.html). Studies with keywords 'Professional patient relations', 'interpersonal relations', 'physician patient relations', 'interpersonal relations', 'audio-tape', 'verbal', 'written information' or 'telephone' on the specialised register were extracted for consideration.

(b) The specialised register maintained by the Cochrane Consumers and Communication Group was searched on 27 October 2006 see Appendix 1 for search terms used (also see Consumers and Communication Group methods used in reviews (http://www.mrw.interscience.wiley.com/cochrane/ clabout/articles/COMMUN/frame.html).

(2) Electronic databases -no language restriction.

(a) MEDLINE (from 1966 to January 2006)

See Appendix 2

(b) Cumulative Index to Nursing & Allied Health Literature (CINAHL) (from 1982 to February 2006)

See Appendix 3

(c) EMBASE (from 1980 to March 2006)

See Appendix 4

(d) British Nursing Index (from 1984 to February 2006) See Appendix 5

(e) PsycInfo (from 1967 to May 2006)

See Appendix 6

(f) Dissertation Abstracts International (from 2004 to May 2006) Search terms used: Breast cancer.

(g) Library and Info Science Abstracts (LISA) (from 1969 to May 2006)

See Appendix 7

(h) ISI Web of Knowledge (conference abstracts) (from 1990 to August 2006)

Search terms used: breast AND cancer AND communication. (i) CancerLit (May 2006)

Search criteria:

Type of cancer - Breast cancer, female

Stage/subtype of cancer - breast cancer in situ

Type of trial - All

(3) Grey literature

We had planned to search the System for Information on Grey Literature in Europe (SIGLE), but SIGLE was no longer available in any European library. Google Scholar was substituted as an alternative for searching and locating grey literature. The search terms used for Google Scholar were 'breast cancer' and 'diagnosis' and 'communication'.

(4) References from published studies

We checked reference lists of all relevant studies. Where necessary we contacted authors of identified studies for further information Hoskins 2001.

(5) Handsearching

Handsearching of journals was not conducted as the key journals are all indexed in the electronic databases searched for this review.

Data collection and analysis

We reviewed the results of the searches in three phases. In phase one we reviewed the titles and abstracts of each study for their eligibility. This was done independently by at least two authors. Disagreements over inclusion did not occur but this would have been resolved through discussion with a third author. The search strategies identified 2847 citations overall. During phase two we excluded abstracts which were not relevant to the review, for example, there were a large number of abstracts relating to breast screening and treatment options.

We obtained full text articles for abstracts which appeared relevant to the review in the third phase. A total of 30 citations appeared relevant however there were three duplicates which left 27 articles for further review. Articles reporting the same primary data accounted for 6 of the publications Brown 1997; Brown 1998; Brown 1999; Brown 2000; Hack 2000; Hack 2003 which left 23 original papers to be reviewed for inclusion. We had developed a standardised data extraction sheet and intended to use this to record key information for each study such as the indices of quality, the setting, participants, interventions, duration of follow up, attrition rates and results. Grading of allocation concealment and scoring of the randomisation process was to be based on the standardised quality scale proposed by Jadad 1996. The Consort checklist was used to structure the overall critique of each study Consort 2006.

As no studies were identified which met the inclusion criteria, data extraction and assessment of methodological quality of each study was not possible. We have provided a table detailing the 'Characteristics of excluded studies'.

RESULTS

Description of studies

See: Characteristics of excluded studies.

We found no studies meeting the eligibility criteria described above.

Risk of bias in included studies

Not relevant as no studies were identified.

Effects of interventions

No RCTs assessing methods of communicating a primary diagnosis of breast cancer to women were identified. A total of 2847 potentially relevant studies were identified and screened for retrieval. The majority were excluded at this stage due to the study design or intervention. Only 23 original studies were retrieved for further assessment but none met the criteria for inclusion. Reasons for exclusion are detailed in the table of 'Characteristics of excluded studies'.

Of the studies reviewed 20 were excluded as they did not focus on method of communication at the time of diagnosis, and a further three studies were not RCTs. A number of the excluded studies were concerned with communication at first treatment consultation rather than the method of delivering the diagnosis Bruera 2003; Hack 1999; Hack 2003; Lobb 2002. These studies investigated a variety of approaches to communication which included providing audiotapes of treatment consultations Hack 1999; Hack 2003; Lobb 2002 and the use of a prompt sheet to facilitate communication between patient and doctor Brown 2000; Bruera 2003. The provision of audiotapes of the consultation demonstrated a significantly greater level of recall and satisfaction with information Hack 1999; Hack 2003. The use of prompt sheets to encourage patient participation during consultations was found to significantly increase the amount of questions asked regarding tests and treatment and the amount of prognostic information provided to patients. Findings from these studies would indicate that patients find such interventions helpful for recall of information but satisfaction with communication, mood state or quality of life may not be significantly influenced. This supports the findings of the Cochrane systematic review by Scott I 2003.

Three further studies focussed on the psychological adjustment to a diagnosis of breast cancer Hoskins 2001; Lowery 1993; Mager 2002 and two studies reported findings of video taped simulated consultations of delivering the diagnosis and assessed the reactions and preferred styles by participants Dowsett 2000; Mast 2005. The findings of the latter two studies suggest that participants preferred a patient centred approach to consultations, particularly when the prognosis is poor. These findings have implications for the design of future studies.

DISCUSSION

This review found no RCTs assessing methods for communicating a primary diagnosis of breast cancer to women. Our search strategy included a comprehensive search of electronic databases and we also contacted key authors for further information. Although no RCTs were identified, findings from previous studies and reviews which have been conducted on methods of communicating with cancer patients, generally support the view that the method of delivering information has the potential to influence a number of factors such as patient recall and satisfaction. Some of the findings also suggest that a patient centred approach to communication was favoured.

The lack of relevant studies for this review have however, highlighted the possible ethical issues related to obtaining informed consent from women before they have a confirmed diagnosis. The reviewers consider that at a time of possible heightened anxiety for women awaiting a diagnosis, it is unlikely that approaching them to take part in an RCT would gain ethical approval. As some papers reviewed by the authors related to the first consultation visit, where treatment options are discussed, perhaps a review which focused on the methods of communication at the first consultation visit would provide more reliable evidence for the effectiveness of methods of communication.

AUTHORS' CONCLUSIONS

Implications for practice

We are unable to recommend implications for practice based on this review.

Implications for research

The design of ethically sensitive research to examine this topic needs to be explored to inform future practice.

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Bruera 2003 {published data only}

* Bruera E, Sweeney C, Willey J, Palmer JL, Tolley S, Rosales M, et al.Breast cancer patient perception of the helpfulness of a prompt sheet versus a general information sheet during outpatient consulation: A randomised controlled trial. *Journal of Pain and Symptom Management* 2003;**25**(5):412–8.

Buddegberg 1991 {published data only}

* Buddeberg VC, Bergant A, Wolf, UC. How do breast cancer patients experience the participation in a prospective psychooncological research project [Wie erleben Brustkrebspetientinnen die Teilnahme an einer psychhonkologischen Verlaufsstudie?]. Zeitschrift fur Psychosomatische Medizin 1991;**37**:172–84.

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Lowery 1993 {published data only}

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Mast 2005 {published data only}

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McWilliam 2000 {published data only}

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Poole 2000 {published data only}

* Poole K, Lyne PA. The 'cues' to diagnosis: describing the monitoring activities of wmoen undergoing diagnostic investigations for breast disease. *Journal of Advanced Nursing* 2000;**31**(4):752–8.

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early breast cancer and their doctors. American Society of Clinical Oncology www.asco.org. 2001. [: Abstract number 119]

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Ubhi 1996 {published data only}

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Brown 1999

Brown R, Butow PN, Boyer MJ, Tattersall MHN. Promoting patient participation in the cancer consultation: evaluation of a prompt sheet and question-asking. *British Journal of Cancer* 1999;**80**:242–8.

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Greer S. Psychological responses to cancer and survival. *Psychological Medicine* 1991;**21**:43–9.

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Iwamitsu 2005

Iwamitsu Y, Shimoda K, Abe H, Tani T, Okawa M, Buck R. Anxiety, emotional suppression and psychological distress before and after breast cancer diagnosis. *Psychosomatics* 2005;**46**(1):19–24.

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Loge 1996

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McPherson 2001

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NICE 2002

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Parkin 2005

Parkin DM, Bray F, Ferlay J, Pisani P. Global Cancer Statistics, 2002. *CA: a Cancer Journal for Clinicians* 2005; **55**(2):74–108.

Scott 2003

Scott JT, Harmsen M, Prictor MJ, Entwistle VA, Sowden AJ, Watt I. Recordings or summaries of consultations for people with cancer. *Cochrane Database of Systematic Reviews* 2003, Issue 2. [DOI: 10.1002/14651858.CD001539]

Scott J 2003

Scott JT, Prictor MJ, Harmsen M, Broom A, Entwistle V, Sowden A, et al.Interventions for improving communication with children and adolescents about a family member's cancer. *Cochrane Database of Systematic Reviews* 2003, Issue 4. [DOI: 10.1002/14651858.CD004511]

WHO 2005

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* Indicates the major publication for the study

CHARACTERISTICS OF STUDIES

Characteristics of excluded studies [ordered by study ID]

Study	Reason for exclusion			
Ambler 1999	Action research not RCT. Nurse advocacy at consultation			
Brown 2000	Not method of communication at diagnosis			
Bruera 2003	Not method of communication at diagnosis. Time since diagnosis more than 2 months			
Buddegberg 1991	Not method of communication at diagnosis. Attitude to research			
Dowsett 2000	Not RCT. Not method of communication at diagnosis. Simulation of communication using videotapes			
Dunn 1995	Not method of communication at diagnosis.			
Geyer 1992	Not method of communication at diagnosis.			
Hack 1999	Not method of communication at diagnosis. Pilot study included patients with both breast and prostate cance and focussed on first consultation treatment which was on average 1.5 months after diagnosis			
Hack 2003	Not method of communication at diagnosis. First treatment consultation. (follow up paper from 2000 publica- tion)			
Hoskins 2001	Not method of communication at diagnosis. Focus on psychological adjustment to diagnosis			
Liang 2002	Not method of communication at diagnosis. Focus on treatment consultation			
Lobb 2002	Partcipants do not have confirmed diagnosis - genetic counselling consultation			
Loge 1997	Not RCT, survey of how diagnosis is given			
Lowery 1993	Not method of communication at diagnosis. Focus on psychological adjustment to diagnosis			
Mager 2002	Not method of communication at diagnosis. Focus on psychological adjustment to diagnosis			
Maslin 1998	Not method of communication at diagnosis			
Mast 2005	Not method of communication at diagnosis. Simulation of communication using videotapes			
McWilliam 2000	Not RCT. Not method of communication at diagnosis			
Poole 2000	Partcipants do not have confirmed diagnosis. Not method of communication at diagnosis			
Ravdin 2001	Not method of communication at diagnosis. Computer assisted package to aid treatment decision making			

(Continued)

Sepucha 2002	Not method of communication at diagnosis. Focus on consultation planning		
Stanton 1999	Not method of communication at diagnosis. Simulation of communication using videotapes		
Ubhi 1996 Not method of communication at diagnosis - Focus on timing of delivery of diagnosis			

DATA AND ANALYSES

This review has no analyses.

APPENDICES

Appendix I. Search strategy - Cochrane Consumers and Communication Group Specialised Register

"Breast cancer" AND verbal
"Breast cancer" AND "face-to-face"
"Breast cancer" AND "face to face"
"Breast cancer" AND audio-tape"
"Breast cancer" AND audiotape
"Breast cancer" AND tape-recording"
"Breast cancer" AND tape recording
"Breast cancer" AND audiotape AND "written information"
"Breast cancer" AND audiotape AND "written information"
"Breast cancer" AND telephone
"Breast cancer" AND consultation
"Breast cancer" AND consultation
"Breast cancer" AND consultation

"Breast cancer" AND "patient participation"

Appendix 2. Search strategy - Medline (Ovid) (1966 to January 2006)

1. exp breast cancer/ 2. exp neoplasms/ and medullary.mp. 3. exp fibrocystic disease of breast/ 4. or/1-3 5. exp breast/ 6. breast.tw. 7.5 or 6 8. (breast adj milk).ti,ab,sh. 9. (breast adj tender\$).ti,ab,sh. 10. or/8-9 11.7 not 10 12. exp neoplasms/ 13. 11 and 12 14. exp lymphedema/ 15. 14 and 11 16. 4 or 13 or 15 17. exp mastectomy/ 18. exp mammary neoplasms/ 19. exp breast self examination/ 20. exp mammography/ 21. or/17-20

- 22. 16 or 21
- 23. exp clinical trial/
- 24. comparative study/
- 25. drug comparison/
- 26. major clinical study/
- 27. randomization/
- 28. crossover procedure/
- 29. double blind procedure/
- 30. single blind procedure/
- 31. placebo/
- 32. prospective study/
- 33. ((clinical or controlled or comparative or placebo or prospective or randomi#ed) adj3 (trial or study)).ti,ab.
- 34. (random\$ adj7 (allocat\$ or allot\$ or assign\$ or basis\$ or divid\$ or order\$)).ti,ab.
- 35. ((singl\$ or doubl\$ or trebl\$ or tripl\$) adj7 (blind\$ or mask\$)).ti,ab.
- 36. (cross?over\$ or (cross adj1 over\$)).ti,ab.
- 37. or/23-36
- 38. audio\$.tw.
- 39. exp tape recording/
- 40. (tape\$ or taping).tw.
- 41. exp videotape recording/
- 42. (recording\$ or video\$).tw.
- 43. (patient adj summar\$).tw.
- 44. (written or letter\$).tw.
- 45. or/38-44
- 46. (consultation\$ or interview\$ or discuss\$ or advise\$ or disclos\$ or visit\$).tw.
- 47. (bad adj new\$).tw.
- 48. exp truth disclosure/
- 49. or/46-48
- 50. exp office visits/
- 51. exp referral/ and consultation/
- 52. or/50-51
- 53. exp patient education/mt
- 54. exp consumer participation/
- 55. exp patient participation/
- 56. ((patient\$ or consumer\$ or famil\$ or parent\$ or sibling\$) adj3 (education or participation)).tw.
- 57. or/53-56
- 58. 45 or 48 or 57
- 59. 22 and 58
- 60. 59 and 37

Appendix 3. Search strategy -CINAHL (Ovid) (1982 to February 2006)

exp breast neoplasms/
 exp neoplasms/ and medullary.mp.
 exp fibrocystic disease of breast/
 or/1-3
 exp breast/
 breast.tw.
 5 or 6
 (breast adj milk).ti,ab,sh.
 (breast adj tender\$).ti,ab,sh.
 or/8-9

11 7 not 10 12 exp neoplasms/ 13 11 and 12 14 exp lymphedema/ 15 14 and 11 16 4 or 13 or 15 17 exp mastectomy/ 18 exp breast self examination/ 19 exp mammography/ 20 or/17-19 21 16 or 20 22 exp clinical trials/ 23 comparative studies/ 24 double-blind studies/ 25 single-blind studies/ 26 placebos/ 27 prospective studies/ 28 ((clinical or controlled or comparative or placebo or prospective or randomi#ed) adj3 (trial or study)).ti,ab. 29 (random\$ adj7 (allocat\$ or allot\$ or assign\$ or basis\$ or divid\$ or order\$)).ti,ab. 30 ((singl\$ or doubl\$ or trebl\$ or tripl\$) adj7 (blind\$ or mask\$)).ti,ab. 31 (cross?over\$ or (cross adj1 over\$)).ti,ab. 32 or/22-31 33 audio\$.tw. 34 exp audiorecording/ 35 (tape\$ or taping).tw. 36 exp videorecording/ 37 (recording\$ or video\$).tw. 38 (patient adj summar\$).tw. 39 (written or letter\$).tw. 40 or/33-39 41 (consultation\$ or interview\$ or discuss\$ or advise\$ or disclos\$ or visit\$).tw. 42 (bad adj new\$).tw. 43 exp truth disclosure/ 44 or/41-43 45 exp office visits/ 46 exp referral/ and consultation/ 47 or/45-46 48 exp patient education/mt 49 exp consumer participation/ 50 exp patient participation/ 51 ((patient\$ or consumer\$ or famil\$ or parent\$ or sibling\$) adj3 (education or participation)).tw. 52 or/48-51 53 40 or 43 or 52 54 21 and 53 55 54 and 32

Appendix 4. Search strategy -Embase (Ovid) (1980 to March 2006)

1. exp breast cancer/ 2. exp neoplasm/ and medullary.mp. 3. exp fibrocystic breast disease/ 4. or/1-3 5. exp breast/ 6. breast.tw. 7.5 or 6 8. (breast adj milk).ti,ab,sh. 9. (breast adj tender\$).ti,ab,sh. 10. or/8-9 11. 7 not 10 12. exp neoplasm/ 13. 11 and 12 14. exp lymphedema/ 15. 14 and 11 16. 4 or 13 or 15 17. exp mastectomy/ 18. exp mammary neoplasms/ 19. exp breast examination/ 20. exp mammography/ 21. or/17-20 22. 16 or 21 23. exp clinical trial/ 24. comparative study/ 25. drug comparison/ 26. major clinical study/ 27. randomization/ 28. crossover procedure/ 29. double blind procedure/ 30. single blind procedure/ 31. placebo/ 32. prospective study/ 33. ((clinical or controlled or comparative or placebo or prospective or randomi#ed) adj3 (trial or study)).ti,ab. 34. (random\$ adj7 (allocat\$ or allot\$ or assign\$ or basis\$ or divid\$ or order\$)).ti,ab. 35. ((singl\$ or doubl\$ or trebl\$ or tripl\$) adj7 (blind\$ or mask\$)).ti,ab. 36. (cross?over\$ or (cross adj1 over\$)).ti,ab. 37. or/23-36 38. audio\$.tw. 39. exp tape recorder/ 40. (tape\$ or taping).tw. 41. exp videorecording/ 42. (recording\$ or video\$).tw. 43. (patient adj summar\$).tw. 44. (written or letter\$).tw. 45. or/38-44 46. (consultation\$ or interview\$ or discuss\$ or advise\$ or disclos\$ or visit\$).tw. 47. (bad adj new\$).tw. 48. exp truth disclosure/ 49. or/46-48 50. exp office visits/ 51. exp referral/ and consultation/

52. or/50-51
53. exp patient education/
54. exp consumer participation/
55. exp patient participation/
56. ((patient\$ or consumer\$ or famil\$ or parent\$ or sibling\$) adj3 (education or participation)).tw.
57. or/53-56
58. 45 or 48 or 57
59. 22 and 58
60. 59 and 37

Appendix 5. Search strategy - British Nursing Index (Ovid) (Jan 1984 to February 2006)

1 exp breast cancer/ 2 ((cancer or neoplasm\$) and medullary).ti. 3 or/1-2 4 breast.ti. (5 (breast adj milk).ti,ab. 6 (breast adj tender\$).ti,ab. 7 or/5-6 84 not 7 9 exp neoplasms/ 10 8 and 9 11 exp lymphoedema/ 12 11 and 8 13 3 or 10 or 12 14 mastectom\$.ti,ab. 15 (breast cancer prevention and screening).mp. [mp=heading words, title] 16 mammograph\$.ti,ab. 17 or/14-16 18 13 or 17 19 exp clinical trials/ 20 (comparative adj stud\$).ti,ab. 21 (double-blind adj stud\$).ti,ab. 22 (single-blind adj stud\$).ti,ab. 23 placebo\$.ti,ab. 24 (prospective adj stud\$).ti,ab. 25 ((clinical or controlled or comparative or placebo or prospective or randomi#ed) adj3 (trial\$ or stud\$)).ti,ab. 26 (random\$ adj7 (allocat\$ or allot\$ or assign\$ or basis\$ or divid\$ or order\$)).ti,ab. 27 ((singl\$ or doubl\$ or trebl\$ or tripl\$) adj7 (blind\$ or mask\$)).ti,ab. 28 (cross?over\$ or (cross adj1 over\$)).ti,ab. 29 or/19-28 30 audio\$.ti. 31 (tape\$ or taping).ti. 32 (recording\$ or video\$).ti. 33 (patient adj summar\$).ti. 34 (written or letter\$).ti. 35 or/30-34 36 (consultation\$ or interview\$ or discuss\$ or advise\$ or disclos\$ or visit\$).ti. 37 (bad adj new\$).ti. 38 truth.ti. 39 or/36-38

40 exp general practice/
41 (referral\$ or consultation\$).ti.
42 (patient\$ adj educat\$).ti.
43 (consumer\$ adj participat\$).ti.
44 (patient\$ adj participat\$).ti.
45 exp Patients- Empowerment/
46 ((patient\$ or consumer\$ or famil\$ or parent\$ or sibling\$) adj3 (education or participation)).ti.
47 or/40-46
48 35 or 39 or 47
49 18 and 48
50 49 and 29

Appendix 6. Search strategy - PsycInfo (Ovid) (1967 to May 2006)

1 exp breast cancer/ 2 exp neoplasms/ and medullary.mp. 3 (fibrocystic adj25 disease\$).ti,ab,sh. 4 or/1-3 5 exp breast/ 6 breast.ti,ab,sh. 7 5 or 6 8 (breast adj milk).ti,ab,sh. 9 (breast adj tender\$).ti,ab,sh. 10 or/8-9 11 7 not 10 12 exp neoplasms/ 13 11 and 12 14 lymphedema\$.ti,ab,sh. 15 14 and 11 16 4 or 13 or 15 17 exp mastectomy/ 18 exp mammary neoplasms/ 19 (breast adj25 (self adj examination\$)).ti,ab,sh. 20 exp mammography/ 21 or/17-20 22 16 or 21 23 exp clinical trials/ 24 exp empirical methods/ 25 (comparative adj stud\$).ti,ab,sh. 26 (drug adj comparison\$).ti,ab,sh. 27 (major adj (clinical adj stud\$)).ti,ab,sh. 28 placebo/ 29 prospective studies/ 30 ((clinical or controlled or comparative or placebo or prospective or randomi#ed) adj3 (trial or study)).ti,ab. 31 (random\$ adj7 (allocat\$ or allot\$ or assign\$ or basis\$ or divid\$ or order\$)).ti,ab. 32 ((singl\$ or doubl\$ or trebl\$ or tripl\$) adj7 (blind\$ or mask\$)).ti,ab. 33 (cross?over\$ or (cross adj1 over\$)).ti,ab. 34 or/23-33 35 audio\$.tw. 36 exp tape recorders/ 37 (tape\$ or taping).tw.

38 exp videotape recorders/ 39 (recording\$ or video\$).tw. 40 (patient adj summar\$).tw. 41 (written or letter\$).tw. 42 or/35-41 43 (consultation\$ or interview\$ or discuss\$ or advise\$ or disclos\$ or visit\$).tw. 44 (bad adj new\$).tw. 45 truth\$.tw. 46 or/43-45 47 exp professional referral/ 48 (referral\$ or consult\$).tw. 49 or/47-48 50 exp client education/ 51 exp client participation/ 52 ((patient\$ or consumer\$ or famil\$ or parent\$ or sibling\$) adj3 (education or participation)).tw. 53 or/50-52 54 42 or 49 or 53 55 22 and 54 56 55 and 34

Appendix 7. Search strategy -Library and Information Science Abstracts (Ovid) (1969 to May 2006)

((DE="breast cancer") or (neoplasm* and medullary*) or (fibrocystic near disease*)) or (((((DE="breast cancer") or (neoplasm* and medullary*) or (fibrocystic near disease*)) or (breast)) or (breast near milk) or (breast near tender))) and (neoplasm\$)) or ((lymphedema\$) and ((((DE="breast cancer") or (neoplasm* and medullary*) or (fibrocystic near disease*)) or (breast\$)) not ((breast near milk) or (breast near disease*)) or (breast near milk) or (breast near tender)))) or ((mastectom*) or (mammary near neoplasm*) or (breast near (self and examination)) or (mammography))

WHAT'S NEW

Last assessed as up-to-date: 6 September 2006.

Date	Event	Description
13 May 2008	Amended	Converted to new review format.

HISTORY

Protocol first published: Issue 2, 2006 Review first published: Issue 3, 2007

Date	Event	Description
10 May 2007	New citation required and conclusions have changed	First review publication

CONTRIBUTIONS OF AUTHORS

Karen Lockhart (Lead author): Developed the protocol, searched the databases, reviewed abstracts and wrote the final review.

Isabel Dosser (Co-author): Developed the protocol, searched the databases, reviewed abstracts and co-authored the final review.

Catriona Kennedy (Co-author): Developed the protocol and made comments on the final review.

Susanne Cruickshank (Co-author): Developed the protocol and made comments on the final review.

Shonagh Bertram (Consumer Representative): Gave consumer oriented view on final review to ensure that it is orientated towards women with breast cancer.

DECLARATIONS OF INTEREST

None

SOURCES OF SUPPORT

Internal sources

• Napier University, UK.

External sources

• Centre for Integrated Healthcare Research, UK.

INDEX TERMS

Medical Subject Headings (MeSH)

*Communication; Breast Neoplasms [*diagnosis; psychology]; Mental Recall; Patient Satisfaction; Truth Disclosure

MeSH check words

Female; Humans