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Evaluation of a pilot study for breast and cervical cancer screening with Bradford's minority ethnic women; a community development approach, 1991-93.

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Abstract The objectives were: to provide information about breast and cervical cancer and related screening services to minority ethnic women, to enable them to make well informed decisions and choices; to adopt a health education strategy based on a community development approach, augmented by a local publicity campaign; and to evaluate both the direct and indirect effects of this project. To this end a community development intervention study was made over 18 months from October 1991 to March 1993 in Bradford, a multicultural city with 87,000 residents from minority ethnic groups. The subjects of the study were 1,628 women from minority ethnic groups in three geographical areas of Bradford. A stratified sample of 1,000 women (670 South Asian, 163 African-Caribbean, 96 Eastern European and 71 other) was interviewed at the beginning of the project and six months after the health promotion intervention.

Two specifically trained Health Promotion Facilitators from minority ethnic groups undertook community development work within three neighbourhoods in Bradford with the largest minority ethnic populations. There were group sessions in both formal and informal settings, which included health education about breast and cervical cancer and the associated screening programmes. These sessions were in the women's preferred languages and audio-visual material and a specially designed teaching pack were used.

There were significant differences in the baseline levels of knowledge about cervical cancer and breast cancer across the different minority ethnic groups. The South Asian women had the lowest levels of knowledge and also showed the most significant improvements. Significant increases in attendance for cervical smear and breast cancer screening were self-reported. These were confirmed by anecdotal views of local health professionals. In addition, a local self-help group for South Asian women was established; also the contacts with other related organisations and professionals has helped to raise the issues of ethnically sensitive services within the voluntary and statutory sectors.

A community development approach to health promotion is particularly valuable in communities with low levels of knowledge about a disease/s or health service provision. Community development approaches often produce outcomes that had not been predicted. There is a need to conduct a definitive study in this area of health promotion for minority ethnic populations with emphasis on evaluation, cost-benefit analysis and opportunity costs.

Introduction

In response to concerns about the low uptake of breast and cervical screening amongst minority ethnic women, the Department of Health selected the former Yorkshire Regional Health Authority to manage and co-ordinate a health promotion project to address this issue. The former Region in turn chose Bradford Health District in West Yorkshire. Yorkshire and Bradford were selected for a number of reasons, including:

- the Region had one of the largest ethnic minority populations outside London
- there was already an ethnic minority breast screening initiative in the Region from which this project could learn and build on
- there was a Regional Development Officer whose brief was to co-ordinate services for minority ethnic groups
- Bradford also had a Service Quality Advisor in each of the acute and community Trusts with a responsibility for developing services for ethnic minorities
- Staff recruitment for this project would be facilitated by the above two items
- the Public Health Department which had carried out some work on the epidemiology of cancer in Bradford, had expressed an interest in having an input into developing this initiative

Bradford Metropolitan District is an inner-city area, with high levels of socio-economic deprivation characterised by poor housing, high unemployment and high levels of sickness and death.[1] Table I shows the multi-cultural nature of the city; 18% (1 in 6) of Bradford's population is non-white as defined by the 1991 Census.

The South Asian[a] origin population is large, 75,050, and is primarily from Pakistan. In the 1960s a large number of people came to Bradford to work in the textile industry, particularly from the Mirpur district of Azad Kashmir in Pakistan.[2] Bradford now has the largest number of people of Pakistani origin of any district in the country.

Table I Bradford Metropolitan District Council's population by ethnic group, 1995.

Ethnic Group	Population
White	396,470
Indian	13,250
Pakistani	57,250
Bangladeshi	4,550
Black	5,940
Other	6,180
Total	**483,640**

[Source: BMDC-1991 Census-based, uplifted for the 3.8% of people not counted and projected for mid-1995].

The age and sex breakdown of the population in Bradford is shown in Table II. This demonstrates the classic pillar-box distribution of the non-Asian population and the population pyramid of the South Asian population. The proportions of women eligible for cervical screening (age 20-64) are 48% and 55% for Asian origin and non-Asian origin women, and for breast cancer (age 50-64) 8% and 15% respectively.

There was local concern in Bradford amongst health professionals that, as elsewhere, the response rates for cervical and breast cancer screening were significantly lower than in the 'white' population. This is tempered by the lower mortality from these two cancers in women of South Asian origin;[3] but the view was taken that as these cancers have a significant preventable component, then the service should be offered on an equitable basis. In addition, it was predicted that the incidence is likely to rise as these women and subsequent generations become more westernised.

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[a] South Asian/Asian refers to the population from India, Pakistan and Bangladesh

Table II Age and sex breakdown of the Bradford MDC population, mid-1995 population*

Total population

	0-4	5-14	15-24	25-44	45-64	65-74	75-84	85+	Total
Males	18,900	36,100	34,000	73,500	47,800	17,800	7,900	1,800	237,800
Females	18,700	34,300	32,800	69,200	49,300	21,300	14,000	6,300	245,800
Total	37,500	70,400	66,800	142,800	97,100	39,100	21,900	8,100	483,600

South Asian-origin population

	0-4	5-14	15-24	25-44	45-64	65-74	75-84	85+	Total
Males	5,300	9,400	7,900	10,300	4,400	1,100	200	0	38,600
Females	5,200	9,000	7,700	9,500	4,100	700	200	100	36,500
Total	10,500	18,400	15,600	19,800	8,500	1,800	400	100	75,100

[Source: BMDC]. * South-Asian/Asian refers to the population from India, Pakistan and Bangladesh.

There are three main issues relevant to this pilot study: use of other appropriate health services by minority ethnic women; uptake of breast and cervical screening services by minority ethnic women; and interventions to improve screening for breast and cervical cancer and their impact.

The use of primary care services by black and minority ethnic groups has been reviewed recently by Rudat[5] and by Blakemore[6] Access to general practitioners was reported as more difficult amongst South Asians, particularly Bangladeshis (17% compared with 5% for the 'white' population).[5] For women aged 30-74, covering the majority of the target population for screening, the standardised percentage with 'difficulties with access to GP' are similar for Pakistani and Bangladeshi women, at 18% and 19% respectively. This compares with 15% for Indian women and 7% for the UK population. The main reasons given by the South Asian adults (men and women) were that the surgery was too far away (70% compared with 51% for the 'white' population) and difficulty with walking (16% compared with 14% among whites). Another finding of relevance to women's screening programmes is the ethnicity of the GP. For the South Asian population groups, the ethnic identity of their GP is the mirror image of that of the 'white' population. So, over four in five South Asians attend surgeries with an Asian GP and less than one in five attend surgeries with a white GP. This pattern is the same amongst the younger South Asians.[5]

Language of communication between doctor (or health professional) and patient is important for health promotion messages, and Rudat's work shows that for those who do not describe English as their main language, which is the situation for the majority of Bradford's South Asian population, 50% of Pakistanis, 59% Bangladeshis and 40% of Indians communicate in the mother tongue or another South Asian language. The gender preference for their GP is stronger amongst South Asian women, with 50% overall preferring a female.

With regard to uptake of cervical or breast cancer screening in the South Asian origin populations, there are two studies of particular relevance. McAvoy and Reza[7] assessed the effects of three different methods of health education for cervical cytology among 737 Asian women in Leicester. The selected women were Asian, aged 18 to 52 and were not recorded on the laboratory system as ever having had a cervical smear. The three study groups were: visited and shown a video; visited and shown a leaflet and factsheet; and posted a leaflet and factsheet; a fourth group was the control, who were not contacted. Four months after the final interview, the first two study groups both showed a significant increase in attending for a cervical smear, 30% in the video groups and 26% in the leaflet (visited) group. These figures increased to 47% and 37% for those who actually watched the video or read the leaflet respectively. Their findings are consistent with the view of health promotion and health education staff, that personal instruction is the best form of education.[8] The most notable changes were with the Urdu speaking, Pakistani Moslem women who, in another of McAvoy and Reza's studies, had the lowest uptake of cervical smears.[9]

Hoare and Johnson in 1991[10] outlined the results of a study for breast cancer screening amongst Asian and non-Asian women. The Asian women were easier to gain access to (87 versus 93) than non-Asian women (77 versus 103). The outcomes of personal visits were also different, with 70% of Asian women but only 36% of non-Asian women subsequently attending for mammography. The overall effectiveness in this study was quoted as follows: 'In terms of the effectiveness of personal visits on the overall uptake of screening, attendance for breast screening by Asian women increased by 9%'.

In the light of these findings, this pilot study aimed to assess the effectiveness of community-based intervention to improve knowledge and uptake of breast and cervical screening among minority ethnic women in Bradford.

Method

Training of Health Promotion Facilitators

The training of the Health Promotion Facilitators was designed and implemented by a team of external consultants, consisting of a principal lecturer in Health Education, a Health and Ethnicity Consultant and a Health Promotion Officer. The advisor to the Department of Health on Ethnic Minority Health (Ms Veena Bahl) was also involved, demonstrating the degree of commitment from the Department to this pilot project.

The training programme, which was of a few weeks' duration, drew heavily on the principles outlined in the Department of Health's training manual for the employment and training of Link-workers. Six core areas were covered: breast cancer; cervical cancer; general women's health issues; health education/promotion; professional and personal development and preparation for practice.

The tutors for the training programme were from minority ethnic communities - African-Caribbean, South Asian and Chinese. This ensured that cultural and religious aspects were understood, as well as the effects of racial disadvantage and discrimination. Emphasis was placed on skills development of the health promotion facilitators with regard to communicating health promotion messages to the target groups. Practice sessions were conducted in appropriate languages for the staff and minority ethnic women.

Health Education Strategy

The health education strategy adopted was based on a community development approach augmented by a local publicity campaign. The community development work was carried out within the three neighbourhoods in Bradford with the largest minority ethnic populations. The Health Promotion Facilitators held group sessions in both formal and informal settings, including community centres, women's groups, clinics, health centres, factories, schools, mothers' and toddlers' groups and general practitioners' surgeries. These were all places where women attend or meet naturally. The aims of the health education sessions were to:

- Respond to the women's general concerns, as well as about breast or cervical cancer or the screening programmes;
- Raise awareness by informing women about the value of breast and cervical screening;
- Explain the procedure if abnormalities were detected;

- Advise the women about how to access these services.

These sessions were incorporated within a wider community development programme, which involved Bradford Health Authority's Health Promotion staff and other health professionals. So, in keeping with community development principles the agenda was set by the women who were invited to identify their priorities. As anticipated, a wide range of issues were of concern;

Cystitis
Arthritis
Healthy eating
Drugs
Weaning
Dental Health
Sickle Cell Anaemia & Thalassaemia
Thrush
Aches & Pains
HIV / AIDS
Asthma
Home Safety
Back problems
Depression
Food Hygiene
Diet & Nutrition
Diabetes
First Aid Course
Childhood illness
Breast & cervical cancer

The health promotion around breast and cervical cancer was carried out in formal and informal workshops and discussions over a period of weeks. This was in the women's own languages and audio-visual materials and teaching packs were developed by the Health Promotion Facilitators with the support of the Health Promotion Unit. A video - Mrs Khan Goes for Breast Screening (developed by the NHS Breast Screening Programme) - was also used in the sessions with the women; one-to-one counselling was available if required.

The local publicity campaign involved displaying posters in the facilities where the health education was conducted. In addition, leaflets and posters were used, available in the local community languages. The local press and radio was used; the project co-ordinator was involved in feature interviews. This publicity campaign ran for the full course of the project's life (18 months).

Study sample

The work was carried out within the three neighbourhoods in Bradford with the largest minority ethnic populations. The Health Promotion Facilitators conducted group sessions in both formal and informal settings, as described above. The majority of women were involved with a wider programme of health promotion which was being run in the areas by the Asian Health Promotion Officers from Bradford Health Authority. Others were informed via the local publicity campaign or by word of mouth. A total of 1,628 women from four minority ethnic groups (African-Caribbean, Asian, Eastern European and other classification which included Chinese) were in direct contact with the Health Promotion Facilitators.

A stratified sample of 1,000 women (670 Asian, 163 African-Caribbean, 96 Eastern European and 71 other) was interviewed and given a questionnaire at the beginning of the project to ascertain the levels of knowledge about breast and cervical cancers and the screening services. The sample was weighted to include women from all ethnic groups and to ensure that half of the sample were aged 50-65. In addition, qualitative information was provided through the discussion and focus groups with the women.

Six months after the health promotion intervention, these women were again interviewed to measure any change in knowledge.

Results

Of the 1,000 women sampled from the total 1,628 women from four ethnic groups who were actively involved in the project, 670 were Asian, 163 African-Caribbean, 96 Eastern European and 71 were of other ethnic groups including Chinese.

Most of the African-Caribbean women (63%) had heard of cervical cancer prior to the intervention, whereas just over a third of the South Asian women said that they had heard of cervical cancer. Six months after the intervention, nearly all the groups showed a significant change in their knowledge about cervical cancer. The biggest change was in South Asian women (Table III).

Table III Women who had heard of cervical cancer

	Before intervention	**After intervention**
African-Caribbean (n=163)	63.1% (103)	79.8% (130)*
Asian (n=670)	35.8% (240)	68.7% (460)*
East European (n=96)	37.5% (36)	45.8% (44)
Other (n=71)	71.8% (51)	78.9% (56)
All women (n=1000)	43% (430)	69% (690)*

[*$p < 0.05$)]

Table IV Women who had heard of a cervical smear

	Before intervention	**After intervention**
African-Caribbean (n=163)	97.5% (159)	98.1% (160)
Asian (n=670)	41.8% (248)	60.1% (403)*
Eastern European (n=96)	65.6% (63)	76% (73)*
Other (n=71)	85.9% (61)	90.1% (64)
All women (n = 1000)	53.1% (531)	70% (700)*

[*$p < 0.05$]

Most of the women (66%-98%) in each of the groups, except the South Asian women, had heard of cervical smears. The lowest level of knowledge was again reported by Asian women (41.8%). The post-intervention responses do not therefore show a great deal of change except for this group of women. It was also noted that almost all of the African-Caribbean women questioned had heard of a cervical smear and therefore the post-intervention score did not show any significance (Table IV).

The highest "yes" score from women before the intervention on whether they had heard of breast cancer was from Eastern European women (31.3%). Less than 1 in 5 women from "other ethnic groups" claimed that they had heard of breast cancer. In this area of work, the intervention appears to have been most effective, with all groups recording a significant increase in the level of knowledge (Table V). The responses to awareness of mammography were surprising in that they did not seem to correlate with awareness of breast cancer, perhaps indicating that women from these groups were not linking mammography with breast cancer. The most significant increase was among South Asian women (Table VI).

Table V Women who had heard of breast cancer

	Before intervention	**After intervention**
African-Caribbean (n=163)	24.5% (40)	87.7%(143)*
Asian (n=670)	21.3% (143)	95.5 (640)*
East European (n=96)	31.3 (30)	84.3 (81)*
Other (n=71)	19.7% (14)	78.9 (56)*
All women (n=1000)	22.7% (227)	92% (920)*

[*$p < 0.05$]

Table VI Women who had heard of mammography

	Before intervention	**After intervention**
African-Caribbean (n=163)	88.3% (141)	92.6% (151)*
Asian (n = 670)	19.5% (130)	56.6% (379)*
East European (n=96)	30.2% (29)	79.1 (76)*
Other (n=71)	49.3% (35)	61.8% (44)*
All women (n=1000)	33.51% (335)	65% (650)*

[*$p < 0.05$]

Table VII Reported uptake of breast cancer screening before and after the intervention.

	Before intervention	After intervention
African-Caribbean	20	87
Asian	66	176
East European	12	15
Other	12	18
All women(n=500)	110 (22%)	296 (59%)

Table VIII Reported uptake of cervical smears before and after the intervention.

	Before intervention	After intervention
African-Caribbean	132	159
Asian	430	587
East European	61	65
Other	43	61
All women(n = 1000)	666 (67%)	872 (87%)

Five hundred women aged between 50 and 65 from the sample of 1,000 women were asked if they had attended for breast cancer screening. Six months later, these women were again asked and the results are shown in Table VII.

Although the reported uptake of mammograms about trebled, it was only 59% of all those who were invited, which is still a low figure.

Similarly, the sample of 1000 women were asked if they had attended for a cervical smear. The results are as shown in Table VIII. Reported uptake of screening after the intervention shows that, of the 1000 women questioned, 872 reported having attended for a smear. While this reported uptake was not checked by follow-up with GPs, anecdotal evidence and communication with practice managers showed that there had been an increase in the uptake.

Reasons for non-compliance

Of the women who reported not attending for a smear, 62% reported they did not need to go; a further 22% said that as they were well they declined the test and 16% could not find the time for the test.

Similarly, a sample of 100 women who had not attended for breast cancer screening were asked why they had not attended: 28% reported that they did not attend because of the possibility of the test being carried out by a male doctor; a further 25% said they did not understand the letter and 15% were unable to speak English.

In addition to the harder data, a number of other important areas were raised by the women, specifically concerning the women of South Asian origin. Responses from the women revealed a number of organisational and administrative factors which contributed to non-uptake of services. These related specifically to Asian women and include mis-spelt names; letters sent to the wrong women; and letters incorrectly addressed. One woman who had previously had a mastectomy and another who had died were referred to the Health Promotion Facilitators as defaulters.

In following up non-attenders for mammography, a number of other issues which again relate specifically to South Asian women were identified. First, compared to the rest of the population they appeared to be more geographically mobile. For example: a quarter of the women had changed address and 15% were out of the country at the time they were sent the invitation for mammography. It was not uncommon for women to visit Pakistan for long periods. Several had returned permanently to the Indian subcontinent and some had only ever been visitors to the UK. Second, in some cases other members of the family, including men, needed to be approached in order to gain access to the women. Third, although modesty is an important issue for all women, in the case of Asian women, religious requirements make it inappropriate and improper for them to be examined by men, particularly in relation to such a sensitive area of service.

Discussion

This pilot study shows some similarities and some differences to previously published studies of this type. The Bradford minority ethnic women showed a similar pattern to Rudat's study,[5] in that there is a poor correlation between knowledge and awareness of cervical cancer and cervical smear testing. So, more women were aware of cervical smears at the outset of the study; their knowledge about both cervical smears and cervical cancer improved as a result of the intervention. There was also an apparent mis-match between knowledge concerning breast cancer and the corresponding screening test mammography.

There were significant differences in the baseline levels of awareness about cervical cancer and breast cancer across the different ethnic groups. The South Asian women had the lowest levels of knowledge and also showed the most significant improvements. This is consistent with some other published work,[7] but contradictory to another study.[12] There were significant differences in knowledge concerning the two cancers being studied, cervical and breast cancer. Forty three percent of minority ethnic women were aware of cervical cancer, compared with 23% for breast cancer. Although breast cancer is the commonest cancer in women, less than 1 in 4 of the minority ethnic women in the study were aware of it at the outset. After the health promotion intervention, the level of awareness had risen to 92%.

The women of South Asian origin had the lowest baseline levels of knowledge about breast and cervical cancer and the associated screening tests. This study has confirmed the anecdotal views of health professionals working in these areas and supports the need for a community development approach. It is interesting that there were significant increases in uptake of both cervical smear and breast cancer screening as a result of this study; although these were not validated fully, the finding was supported by follow-up with the relevant GPs and practice nurses and is consistent with McAvoy's and Reza's work referred to earlier.[7]

These findings contrast with some other studies of the effectiveness of community level interventions. A Liverpool report[11] compared ability to follow-up a younger group of women, aged 20-64, who had not attended for cervical cytology. This target population is not specified by ethnic group, only by non-attendance for a smear. They found that 58-68% of visits by community nurses resulted in no access, and a further 12-13% of addresses were probably incorrect. The authors concluded that 'only 3-5% of first visits resulted in women attending for smears', and that even when contact was made with the right woman 'only 23-26% of such visits resulted in them attending for a smear'. These results were probably a true reflection of inner city FHSA register accuracy; also, there is no reference to minority ethnic women, whose main difficulties are about knowledge and communication (as discussed above), and whose needs differ from those of non-Asian women.

Another study by Hoare *et al* from Manchester,[12] probably the most controversial, was a randomized controlled trial of a 'Link-worker intervention' for breast cancer screening in Asian women. Of the 247 Asian women in the intervention group, contact could not be established with 40%. Similar information is not given in the paper for the control group (e.g. validity of address), but as it was a randomised controlled study it should be similar to the intervention group. The conclusions were mixed, so that although 'a Link-worker intervention was not a successful strategy for increasing the uptake by Asian women' (49% compared with 47% in the control group), it was acknowledged that 'it could be surmised, although it cannot be demonstrated, that contamination of the control group occurred, in that information about breast screening was spread throughout this close-knit community, with the result that attendance for screening may have been raised generally in the population'. This could have been addressed by looking at historical data for that geographic area, or by having a second control group in another locality.

Further concerns about the Manchester study were expressed in two published letters,[13,14] which question the basic methodology about the ethnic background of the researchers and validation of the method used. More seriously, the description of the intervention is 'to say the least, skimpy':[14] apparently a semi-structured questionnaire followed by 'a short explanation about breast screening'. It is also not clear if the interviewers were appropriate health promoters, and Bhopal concludes 'one wonders whether the term Link-worker is appropriate here'.[14]

Two other positive outcomes have been identified as a result of this project, although not directly relating to cervical and breast cancer screening. Through their networking, the Health Promotion Facilitators came into contact with a number of minority ethnic women who already had cancer. This subsequently enabled the setting up of a local cancer self-help group for South-Asian women (Umeed project). In addition, subsequent liaison with other related organisations and professionals (such as the Breast Care Nurse and Bradford Cancer Support Centre) helped to raise the issues of ethnically sensitive services within the voluntary and statutory sectors.[2] The confidence and skills of women involved in this project have developed significantly and will continue to influence the provision and delivery of cancer services. Bradford Health Authority has now appointed several full-time health promotion staff from minority ethnic backgrounds to continue to provide a specialised ethnic-specific service for Bradford's minority ethnic groups. This will ensure that the longer term benefits of raising awareness and levels of knowledge will be addressed.

Evaluation of this type of community development project needs to cover both quantitative and qualitative methods. The women acted as their own controls in this study, which prevented the possibility of contamination or Hawthorne effect. A control group could have been constructed in another part of the city, but this was not feasible within existing resources. It was also more relevant to the aims of the study to concentrate on changes in knowledge for each individual woman. Another difficulty concerned the diversity of women studied, with very different cultural, religious and communication needs. In future work of this type, an early decision would need to be made about the minority ethnic groups to be included. The appropriate sample size would then need to be studied. Flexibility is also needed to ensure that unpredicted outcomes are also included in the evaluation, as with the two additional positive outcomes found in this study. Community development projects are more likely to throw up these type of outcomes, which in themselves are a measure of success. An evaluation structure which is too rigid would hide such important outcomes of this type of work.

The old maxim that 'good research should always ask as many questions as it answers' is relevant to this work. Although this pilot study clearly adds weight to the benefit of this type of intervention for minority ethnic women, there is still room for a definitive study, perhaps multi-centre, and with strong emphasis on evaluation and cost-benefit analysis. This would sit happily with the Health of the Nation target setting exercise and the Central R&D initiative.

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