



# Bangladeshi Contenance Project

A Report on a Scoping Project Undertaken by the Contenance and Stoma  
(Bladder and Bowel Care) Services,  
the Bengali Women's Health Project and the Advocacy Service.  
ISLINGTON PCT AND CAMDEN PCT

## Contenance & Stoma Services

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## Aim

The aims of this project are to carry out a scoping exercise evaluating the needs and requirements for continence care provision within the Bangladeshi community in Camden PCT and Islington PCT areas.

## Objectives

The Bangladeshi population continence project will :-

- Undertake focus groups and meetings with the local Bangladeshi community to assess the needs for continence care provision.
- Undertake questionnaires with local GP's to assess the current position.
- Identify appropriate models for provision of care following the scoping exercise.
- Provide a framework for continence care provision for the Bangladeshi community.

## Introduction

The Continence and Stoma (Bladder and Bowel Care) Service provides care for people with bladder and bowel problems across both Camden and Islington PCTs. According to the Department of Health good practice guidelines for continence care (2000), services need to be developed to meet the needs of all the population. Currently the Service does not pro-actively reach one particular ethnic group, the Bangladeshi community although this group has been targeted previously with little uptake in services.

Bangladeshis, with a total population of 12,569, are the largest group among Black and Ethnic Minority communities in Camden. The proportion of the Bangladeshi population rose from 3.5% of the total Camden 1991 census to 6.3% of the 2001 Census population.

In order to meet the needs of the Bangladeshi community, there was an attempt during 1997-1998 to run specific continence clinics targeted at local Bangladeshi women. Unfortunately these clinics were not well attended and they were therefore not cost effective and thus were discontinued. However, this may be due to the way they were delivered and the Continence and Stoma (Bladder and Bowel Care) Services wanted to consult with the local community in order to evaluate the need for re-establishing service. This is especially relevant due to the high increase in the local population since the service last ran Bangladeshi specific clinics.

## Literature Review

During the course of this research 14 studies were reviewed into Bangladeshi health issues which of interest only contained one other study into continence issues in Bangladeshi women and was linked to mother and baby clinics.

A study investigating the connection between ethnicity and variations in the nation's health (Balarajan, 1995) showed coronary heart disease among persons under 65 years was highest in those born in the Indian Subcontinent, 55% above the normal rate in England and Wales, Caribbeans and African groups experienced the lowest rates. Stroke mortality under 65 years of age was highest in Bangladeshis, followed by other Commonwealth Africans, and then Caribbeans. Patterns of cancer deaths also varied, with breast cancer mortality rates being lower in all ethnic groups, and lowest in those born in the Indian Subcontinent. Lung cancer was shown to be higher in Irish men and women, whilst lung cancer mortality among Bangladeshi men was significantly higher than in Indians and Pakistanis, being only 15% less than that of the rates in England and Wales. Suicides were lowest in Bangladeshis and Pakistanis and highest among Indians and the Irish. Accidental deaths in children were highest in Pakistanis followed by the Irish, who also experienced higher rates among young persons (Balarajan, 1995).

Balarajan (1995) suggests that the Health of the Nation (HoN) Strategy should set appropriate and achievable targets including ones in new areas of relevance for ethnic groups and that the NHS should set objectives to respond to the needs of ethnic minority communities. The HoN white paper clearly explained the needs of black and ethnic minority people in health strategy. This requires measures to assess their health needs, institute a strategy to address these needs and be able to monitor them.

The collection of ethnicity data in the 1991 Census has assisted in a better understanding of the composition of the population (National Institute for Ethnic Studies in Health and Social Policy, 1991) Camden and Islington PCTs have recently begun the collection of ethnic origin and first language data to allow for an accurate appraisal of the local population.

A further study into the ethnic and socio-economic influences on recording of preventative care in general practice was undertaken by Atri et al (1996) in Tower Hamlets in East London, who have a Bangladeshi population comprising 23% of the whole population. It showed that minority ethnic groups were considerably more disadvantaged than white people and five times more likely to be overcrowded, three times less likely to own their own home, twice as likely to be in social classes IV and V and less likely to be employed, however it was concluded that despite these major socio-economic inequalities it is possible to maintain equitable records of preventative activity for the major causes of death.

The key messages arising from this study were :-

- Major socio-economic inequalities exist between ethnic groups and disadvantaged communities
- Despite these socio-economic disparities, selected general practitioners equitably deliver preventative services for the major causes of premature death
- Recording of mammography and cervical cytology were important exceptions and these programmes require additional support at practice level.

(Atri et al, 1996)

It is of interest that Greenhalgh et al (1998) concluded that whole populations should be studied, not samples, in order to ensure accuracy of results as it is important to understand how one group influences another.

Greenhalgh et al (1998) also identified the influence of structural and material barriers to improving health care, such as poor housing, unsafe streets and financial hardship, but equally important were religious restrictions and ethnic customs. It was noted that health education needs to work together with communities 'lay epidemiology' and folk models to be most effective. Educators must centralise the cultural experiences of those who have been marginalized. It was noted that Bangladeshis in the study indicated a high regard for oral explanations from information sources such as friends and relatives and that the potential for high degrees of learning from oral sources within the Bangladeshi communities is high.

The study undertaken by Balarajan suggests that it is essential to effectively monitor the health of ethnic minority groups and that specific programmes of health improvement must be instituted for different ethnic groups as there is a wide variation in disease patterns. Variations in ethnic groups, due perhaps to biological, cultural, religious, socio-economic or other environmental factors cannot be expected to respond on all occasions to a universal approach.

One study by Hennink et al (1998) investigating the use of family planning services by Asian women showed that professional married women and unmarried women are able to meet their family planning needs by utilising existing family planning services. However, married non-professional women experience significant difficulties in using family planning services largely due to communication problems with health professionals and their low levels of personal autonomy. Most Asian women in the study showed a strong preference for a female GP and a non-Asian GP for sexual health and contraceptive services.

A further study (Scott, 1999) investigating general practice screening for Bangladeshi families aimed to establish a specific screening clinic for Bangladeshi families in inner city London, the clinic showed very successful results with 58% of Bangladeshi families who were registered to the surgery attending the clinic. The study concluded that this clinic could provide a model which could be adapted for other hard to reach communities as an effective way of screening.

Two studies undertaken in Bangladesh (Afsana & Rahid, 2001) (Hemmings, 1993) one on maternity care and one on a Bangladeshi health care project show valuable lessons about how health care is received by Bangladeshi communities. The Bangladeshi health care project trains local people to deliver paramedic-type care to local villages and also undertake health promotion. These local 'paramedics' are well received and the infant mortality rate has significantly dropped in the areas where this service is available.

The outcome of the maternity care study in Bangladesh has been the initiative of the Bangladesh Rural Advancement Committee organising a series of workshops for their health workers focusing on gender and health across the life cycle; reproductive health and rights; women's rights; human rights; gender roles and power dynamics; quality of care behaviour and communication; women's rights to health care and social change. The study concluded that in Bangladesh, despite the importance of skilled delivery and emergency obstetric care in reducing maternal mortality, acceptance of delivery in a health facility by rural women is still minimal. The research demonstrated the need and scope for improving quality of services and care at primary care clinics as well as at district hospitals. The study noted that long term commitment will be required to address women's rights to quality health care and in bringing about social change (Afsana & Rahid, 2001).

Of particular significance to our study, a project was undertaken at Sandwell Healthcare NHS Trust in the West Midlands to address the continence needs of the 2000 plus Bangladeshi women in the area few of whom were accessing the continence service (Scott, 1999). Views of the local population, community leaders and health and social care workers were sought to identify contact patterns and barriers to access. The service employed a bilingual health care worker trained in continence issues to build trust and understanding with the local Bangladeshi women. It was noted that it was important to provide information in a language that the community would understand and a series of audiotapes were produced as not all the women were able to read. The service set up drop in clinics at local GP practices which ran alongside the health visitors baby clinic.

This project has proved so successful that a national project has been instituted to advise other providers on continence services to Bangladeshi communities.

## Method

This project is a first line pilot study carried out via a partnership approach involving the

- Health Promotion Service
- Advocacy Service
- Bengali Women's Health Project
- Continence and Stoma Services.

The Bengali Women's Health Project, through its own network with frontline community workers, facilitated the running of sessions at five community centres. An additional session was organised by the health advocates at Crowndale health centres. The input from the project's health advisors, community workers was most useful in the facilitation of useful discussion with members of the community on continence issues which are still considered as a sensitive/very personal issue in the community.

Due to language barriers faced by many of the community members, we used questionnaires as a prompt to initiate discussion and detailed notes were taken of all the issues, barriers, and recommendations that were discussed in the focus group sessions.

We adopted a questionnaire method of study. Two sets of questionnaires were devised for our scoping exercise. This project was financed for two days per week over 3-4 months. For such a short period of time the questionnaire method was felt to be the most appropriate in order to collect the relevant information. The questionnaires were developed by Suchrita Ghosh and Mandy Wells (Senior Specialist Nurse, Continence and Stoma Service, St Pancras Hospital). The questionnaire was sent out with an explanatory letter from Mandy Wells introducing Suchrita as a new Bangladeshi Continence Project Worker.

The questionnaires were sent to 20 GP practices selected randomly from the Camden and Islington GP lists.

The second set of questionnaires were devised with the help of Kawser Zannath (Senior Health Promotion Specialist, St Pancras Hospital) and were only used for the Bengali Focus Group (User group) and Bangladeshi Community Groups.

Both sets of questionnaires consisted only of the issues related to accessing services for bowel and bladder problems regardless of age and sex. At the same time, we asked people's views and suggestions on improving our service accessibility.

From previous experience it was clear that there was a degree of reluctance by the Bangladeshi community to access the service. It was hoped that this pilot study would identify barriers and ways to overcome these thus improving the quality of life of those members of the population requiring care.

## Results

Two separate sets of data were collected. One from Primary Care and one from the Community groups.

A response rate of 50% was received from GP's in the Camden and Islington area, therefore 10 questionnaires were completed and returned. Attempts were made to visit those surgeries that had failed to return the completed questionnaire but this proved extremely difficult as GPs were reluctant to make an appointment. I therefore managed to visit only 5 surgeries (these visits took 7-8 weeks to arrange).

The information collected from returned questionnaires showed :-

- South Camden GPs do not routinely check up on bowel and bladder problems unless they have concerns
- South Camden GP's are keen to see the Bangladeshi community group to be run locally where lots of health promotion discussion should take place for bowel and bladder problems.
- GP's do not feel the Bangladeshi community require different treatment from other communities.
- GP's find it time consuming to use an interpreter
- GP's agree that Bangladeshi women are more reluctant to discuss bowel/bladder problems
- GP's find Bangladeshi people are very willing to access services if they are needed for their children
- GP's think more health promotion discussion needed to encourage the Bangladeshi community to raise awareness of their own health needs
- Most GP's have information only in English about the Continence Service
- Most GP's do not know about specialist clinical services
- GP's tend to refer patients to acute sites
- Very few GP's refer patients to St Pancras Hospital
- Some GP's requested flier translated into Bengali for bowel and bladder problems

- Most GP's think that more female health professionals are required.
- All GP's agree that there need to be specialist clinics running in community
- Some GP's agree that the Bangladeshi community have problems with bowel and bladder problems

The data collected from the Bangladeshi community however showed very different results from that collected from GP's.

Six community groups were visited in North Camden which totalled 129 women. 6 professionals from the focus groups also joined in the scoping exercise. A specially designed questionnaire was used.

The majority of the women considered bladder weakness as their personal problem of not being able to control themselves. They didn't think of it as a medical condition for which you can seek help from health services. Even when some women felt that they should discuss their condition with the GP, they have usually some other health problems which they discuss with the GP and leave out the bladder problem as a non-urgent issue.

Many women consider bladder problems as something you develop when you give birth to children. Few consider it as an old age problem and one which the sufferer should put up with.

Comments received from the groups were :-

- There is very little understanding or knowledge about the continence services in the Bangladeshi community. Many even do not know that such a specialist service exists.
- Some of the groups had never had this kind of discussion prior to the focus groups
- The group discussion assisted some women to identify bowel and bladder problems as a health issue

- 50% of the women realised for the first time that they could improve their quality of life
- The group would like specialist clinical services in the community health clinics
- They would prefer female health professionals
- They would prefer female nurses with an interpreter
- They require more health promotion, discussion and information of this kind
- They felt that group discussion would also be useful for the male members of the community as men also suffer with continence problems
- The majority of the women in the Bangladeshi community do not know how to access this service
- Many women feel the stigma that surrounds the condition and silently suffer and feel embarrassed to discuss their problem
- The religious practice of prayer five times a day requires Muslims to be cleaned of any trace of urine or stool in their body or clothes. So the people who suffer from bowel and bladder problems face the extra pressure of cleaning themselves every time they prepare for prayer.
- They felt that open discussion with specialist health professionals would break the barriers and people would then come forward to get help
- They would like to see well woman clinics running again in the community where women of all ages can be looked after, such as pre-menopausal, post menopausal, neo-natal and post natal groups for Bangladeshi women
- They would prefer female GP's and nurses
- They would appreciate some home visits from health professionals
- There is a need for more health promotion discussion prior to setting up any specialist clinics so that community members are aware of their own health needs and are encouraged/feel confident to take up the services.
- Bowel and bladder problems are not life threatening
- GP's seem very busy. They do not have time to listen

- There is a need for Bengali fliers and booklets about bowel/bladder problems in GP's surgeries and community health clinics
- To improve their quality of life and have some dignity, they wish their GP to be more caring and sympathetic
- GP's only send them to hospitals for urine culture, if this is normal they do not send them for further investigation
- GP's sometimes fail to take children's continence problems seriously, saying it is an excuse to miss school and sometimes give advice that is not practical

## Discussion

This study has been very worthwhile and revealing, however with the limited time it has been difficult to obtain adequate information. A follow-up study would be required to provide more information.

There was a degree of lack of cooperation from GP's and due to time constraints it was difficult to follow up appointments if GP's were unavailable. There was, however, great support from both the local Bangladeshi community and from focus groups. The Bangladeshi community would benefit from a female Bengali health worker who can spend time with them at least once per month. They are in need of more health promotion and discussion to build confidence and trust as well as leaflets and written information translated into Bengali for the Continence Service.

The Bangladeshi women who took part in this study felt very strongly that continence issues were not taken seriously by GP's and referral was not made to the Continence Service. They would very much like to be able to access this service and it would make it easier to access if there were clinics run at local health centres.

The women also had problems filling out the clinical questionnaires sent out with the first appointment and therefore missed appointments due to the confusion this created. They requested that these questionnaires be filled out with the aid of an interpreter at the continence clinic on the day of their first appointment.

## Conclusion

This is a first line pilot study and was most effective in providing two-way information with the local Bangladeshi community, however this study had severe time limitations and as such was inconclusive from the GP point of view as so few were accessed.

The project unearthed a number of points for future provision of continence services and these need to be addressed through a more detailed project.

Other studies carried out in the Bangladeshi community have found that culturally Bangladeshi people are very rigid and hard to reach, however this study has shown this to be untrue and the groups visited were very open and receptive to information and advice.

## Recommendations

It is recommended that:-

- Monies are identified from either the HAZ scheme, the Neighbourhood Renewal Fund or other funding sources to support a continuation of this project.
- A continuation to include investigating prevalence of urinary and/or faecal incontinence in the local population.
- More G.P's are visited as ascertain their values and beliefs and practices.
- A Bengali Advocate is financed for 0.2 wte a week for 2 years to provide education and training and support to specialist clinics.
- Bangladeshi specific continence clinics are set up with additional funding to support an extra 01.wte continence nurse for the specialist continence services.
- The Bangladeshi specific continence clinic also provides a holistic approach to assessment and links to the work being carried out by the Breast and Cervical Screening group in order to identify if women have had breast and/or cervical screening. It will also scope if there are any other conditions that this community are not discussing with their primary care practitioners.

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## Bangladeshi Continenence Project



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