



The Foundation of Nursing Studies  
Developing Practice • Improving Care

Foundation of Nursing Studies Dissemination Series 2005 Supplement 2

# Reports from Winners of Foundation of Nursing Studies Awards 2004

## Access All Areas: Improving Primary Care Services for Patients with Learning Disabilities

### Project team:

Scott Harrison – Primary Care Nurse Specialist  
Liz Bery – Health Co-ordinator

### Location:

Warrington Primary Care Trust and 5 Boroughs Partnership  
NHS Trust

### Contact details:

Scott.Harrison@warrington-pct.nhs.uk

### Background

The health of people with a learning disability continues to be significantly poorer than that of the general population with a much higher incidence of physical health and mental health problems and greatly increased likelihood of sensory impairment, epilepsy and preventable malignancy. Despite the many reports and policy recommendations about how to improve this situation, little has been done in mainstream health services to address the social exclusion of this group, and, as a result, their health and wellbeing continue to decline.

The White Paper, Valuing People, published in 2001, provides the health service with key goals for engaging people with a learning disability in mainstream health services and ensuring they have equal access to high quality care. To address the needs of people with learning disabilities in Warrington, the project team have developed a programme for delivering primary health care that has its roots firmly in the principles of social justice and public health. By incorporating the specialist input of the learning disabilities team with mainstream primary care services, a joint effort to challenge exclusion and address the agenda of Valuing People has been made.

### Aim of project

"Access All Areas" – an innovative approach to health needs assessment for adults with learning disabilities was born in 2001. In recognition that the principles of Valuing People were perfectly suited to the principles of health visiting, the specialist learning disabilities team in Warrington in partnership with the community public health nursing team and service users worked to develop this comprehensive programme.

The focus of Access All Areas, in line with the guidance in Valuing People, is to facilitate access to mainstream primary care services, avoiding 'two tier' systems of health care that research shows to be ineffective and often of poor quality, thus, the project fully embraces the principle of 'nothing for me without me' and demands full partnership working with clients.

Using a public health model of health care, people with learning disabilities are supported to make healthy choices and often, for

the first time, given information in accessible formats to support those choices.

### Identifying patients

By spring 2005, 270 clients with learning disabilities had been identified through an audit of GP electronic patient records and the cross referencing of people accessing the specialist learning disabilities team. Each GP practice is being 'health mapped' by the team, who help the GP identify the clients' current use of primary care services in order to prioritise future health contact. Whilst some clients have relatively frequent access to primary care, many have lengthy gaps in accessing services with some clients receiving regular repeat prescriptions without being seen by a primary care professional for up to 14 years.

### Health needs assessments

Each client identified by the project is considered individually and their specific communication and individual needs identified wherever possible in a team approach with community learning disability nurses and specialist speech and language therapists. Primary care based nursing staff are encouraged and assisted to assess the current health status of each patient, considering their current access to primary care services.

Clients are then invited to have a comprehensive health needs assessment and, if they want one, a Health Action Plan. Clients are contacted by letter, which has been designed in collaboration with specialist speech and language therapists, and are offered a choice of attending their GP surgery or, if they have complex needs and are unable to access surgeries, being visited at home by a primary care nurse specialist.

### Developing health profiles

An essential part of the project has been providing clients with access to, and ownership of, their health information and health history. The historical provision of institutional care has left a legacy of stolen histories – clients who were cared for in the large institutions prior to the reorganisation of community care have often incomplete or vague medical and social histories and essential information failed to follow the clients into their new social settings. The present organisation of community care through provider agencies means that different providers have different methods for recording health and personal information, often in ways which meet organisational rather than personal needs. As a result, patient held Health Profiles have been implemented to ensure that clients have ownership of personal information and are included in their care. These profiles are very similar to the National Personal Child Health Record in that they contain the client's main health information and provide an active record for staff to make notes in. They are extremely useful at focusing clients and staff on health history and health needs and fully including the client in identifying needs and planning to improve their health.

The Health Action Plan contained in the profile is explained to the client in understandable terms and, together with the

# FOCUS

nurse/health visitor, the client is facilitated in identifying their health needs and formulating a simple plan to meet those needs, identifying who in the client's life can support this plan (Department of Health, 2002). The core of this process is providing clients with choices about their health and lifestyle and facilitating healthy choices where possible.

## Training

The project has highlighted important training issues for primary care staff around the adaptation of mainstream services to meet individual needs and the importance of preparation, non-treatment visits to primary care facilities and meeting staff prior to care being carried out.

Challenging negative attitudes towards people with a learning disability has been a central part of the project. Consultation with clients uncovered a shameful history of second rate care, unprofessional staff attitudes and behaviours and a wealth of serious and unmet health needs. It was identified that primary care staff often do not have the necessary training and skills to deal sensitively with those of a different intellectual ability, or have the equipment and motivation to organise their services to ensure that people with learning disabilities are fully included (Fitzsimmons and Barr, 1997).

A comprehensive joint training programme to address these concerns has been devised by both the specialist team and the primary care nurse specialist and is now underway, with excellent feedback. A full day of training is being offered to all primary care staff regardless of their position in the organisation and covers the main areas of concern – roles, responsibilities, the core difficulties of learning disabilities, the problems in accessing health care and the potential solutions to these problems.

## Outcomes

The initial pilot project included a total of 70 clients who were identified through an audit of electronic patient record searches and the cross referencing of people accessing the Specialist Learning Disabilities team. The final client group included in the audit was made up of 62 patients - 40 men (64.5%) and 22 women (35.5%) with a mean age of 38.4 years (range = 18 – 81).

Since rolling out the project in November 2004, an uptake of 280 clients has been achieved, 32% of whom now have an active Health Action Plan following a comprehensive health needs assessment. 28 GP practices are now included in the project, across the Warrington area.

The key areas of health where Health Action Plans, advice and support are required reflect national standards (Mencap 2004) and include:

- Oral health and treatment of dental caries
- Weight management and access to both healthy food choices and adequate levels of exercise
- Sexual/Reproductive health and access to national screening programmes
- Self-examination and self-awareness of the body
- Management of chronic health conditions including epilepsy, diabetes and asthma
- The promotion of continence
- Effective medicines management

## Cultural change

Access All Areas has identified some barriers to collaborative practice that require dismantling. In the context of health action planning, it seems that primary care and specialist teams do not share the same 'language' of disability. Primary care nurses often work within the individual/medical model of disability which sees people as disabled by their impairments and places the 'problem' of disability with the individual. Specialist learning disability teams and social care organisations, however, work within the social model of disability which asserts that people with impairments are prevented from participation due to barriers that exist in society.

Working to a shared agenda requires an ability to see the other's perspective from both the specialist and primary care teams involved in health action planning, with the mutual goal of producing outcomes which successfully merges multiple and new insights and develops a shared view of disability as a social phenomena that can be negated by removing the barriers that exist in mainstream health services and allowing people with different abilities to fully take part in their health care. Nurses of both disciplines should place more concern on the expertise of their own role and focus more on the needs of the individual and how their skills can be shared with colleagues to effect positive change and deliver expert care. All mainstream health providers should examine the culture that presently exists within their organisation, with a critical eye, to determine where and how systems disable clients or de-value people in marginalised groups.

## Conclusions

The success of primary care providers in delivering the health care guidelines of Valuing People is dependent on both the motivation of primary care staff and the ability of both primary care and specialist learning disability teams to work collaboratively towards the common goal of improving access to mainstream health services. Access All Areas has demonstrated that, in order for social exclusion to be tackled fully, a joined up approach is required across agencies that recognises how current practices may inadvertently assist exclusion and the importance of joined up solutions that prioritise health and wellbeing as the basis for inclusion in community, work and family life.

## References

- Department of Health (2002) *Action for health, health action plans and health facilitation: detailed good practice on implementation for learning disability partnership boards*. London: HMSO.
- Fitzsimmons, J. and Barr, O. (1997) A review of the reported attitudes of health and social care professionals towards people with learning disabilities: implications for education and further research. *Journal of Learning Disabilities for Nursing, Health and Social Care*. Vol. 2. pp 57-64.
- Mencap (2004) *Treat Me Right: Better healthcare for people with a learning disability*. London: Mencap.

# IBDS

## Development of a Rapid Access Service for Patients with Exacerbating Inflammatory Bowel Disease

### Project leader:

Cath Pearson, Inflammatory Bowel Disease Nurse Specialist

### Location:

Royal Bolton Hospital

### Contact details:

cath.pearson@boltonh-tr.nwest.nhs.uk

### Background

Inflammatory Bowel Disease (IBD) is a life long condition which occurs at a young age and has the potential to cause life long ill health. In any year, an estimated 50% of patients with IBD experience frequent relapses or continuous disease (Travis, 1998). Symptoms of the condition include increased frequency in bowel movements, rectal bleeding, abdominal pain and malnutrition. The impact upon the individual is immense physically, psychologically and socially. Therefore a key feature of effective management of IBD is rapid access to expert advice and clinic appointments in the event of a relapse (Carter et al, 2004).

### Aim of the project

The aim of the project was to implement a nurse-led service which would improve access to the health care team for patients with exacerbating IBD. By achieving this, it was anticipated that the outcomes of this project would be to:

- Develop a patient centred service for patients with IBD
- Improve access for patients with IBD to the gastroenterology team
- Facilitate earlier review for patients with IBD, adopting a proactive approach to management
- Improve communication between patients, primary care and the gastroenterology team
- Develop an outline of the process

### Method

#### Step 1. Identifying the problem

Review of the evidence provided little guidance in the establishment of rapid access services within IBD. However, the effectiveness of rapid access facilities in other areas is well documented e.g. day surgery (Knowles and King, 1995); incontinence care (Brown and Thomas, 1995) and primary care settings (Marklund et al, 1991). The key themes from the evidence suggested that rapid access services facilitated an improvement in decision making and information giving, and reduced emotional stress on a day-to-day basis. These themes provided the key areas for initial exploration.

#### Patient questionnaires

Following the completion of the literature review, a questionnaire was devised. This was undertaken in May 2002. One hundred questionnaires were distributed to patients and eighty returned. The overall conclusion drawn from the questionnaire was that patients with IBD generally believed that access to the gastroenterology team during episodes of exacerbation was poor. Further examination of the data revealed that during an

exacerbation the effect of ill health affected patients' home lives, sexual relationships and ability to work. This in turn resulted in feelings of isolation and depression. In an attempt to improve their symptoms, patients often adjusted medications themselves to treat their symptoms, in some cases immunosuppression therapy had been doubled and steroids commenced at sub-therapeutic doses.

The questionnaire also revealed dissatisfaction with care received in primary care with 56 (70%) of respondents believing that they did not receive appropriate care from their GP. Themes included perceptions of delayed management and reluctance for referral to secondary care. Of the 56 patients, 28 contacted their consultant directly and of these 20 were happy with the outcomes of their contact. 24 patients (30%) sought no help from either primary or secondary care, and waited up to 3 months for their next clinic appointment.

#### Patient focus groups

A patient focus group had previously been established to support service development. A discussion was facilitated with this group around the findings of the questionnaire. Themes from the group supported the questionnaire findings.

#### Process mapping

Process mapping (Department of Health, 2003) was undertaken to track the journey of 10 patients, examining the route to secondary care following a relapse of their IBD. Many inconsistencies were identified. Patients were waiting on average eight weeks for review in secondary care. This resulted in patients changing medication themselves in an attempt to resolve symptoms, prolonged periods off work and interruptions in family life.

#### Step 2. Planning change

After discussion with the Consultant Gastroenterologists, the IBD nurse outlined a number of measures to resolve access issues and implement a rapid access service. Protocols were established to support the nurse specialists' practice, and further academic development in the form of level 3 modules in inflammatory bowel disease, clinical examination and nurse prescribing were undertaken.

#### Step 3. Implementing change

In August 2002 a telephone helpline was set up to enable rapid referral from GPs and patients. Three dedicated clinic sessions were established during which patients could attend, either by turning up unappointed or by prior arrangement with the IBD Nurse. During the clinic appointment, patients had a full nursing history taken, clinical examination performed and treatment prescribed. Onward referral for radiological, pathology or endoscopic investigations could be arranged, along with referral to the surgical team, dieticians, psychology or stoma care. All interventions were recorded in the medical notes and the GP and patient sent copies of clinic letters within two working days.

All activity from the telephone helpline and clinic attendance was recorded on a database to monitor and record use of the service

# F O I S

## Evaluation

The project was evaluated through the data collected through the database, further patient questionnaires, focus groups and process mapping.

### Analysis of data

An audit was completed between August 2002 and August 2004. A total of 1448 patients contacted the telephone help line, of which 280 patients had a new episode of exacerbation, 368 patients had unstable disease and had become symptomatic on reduction of steroids and 800 patients contacted for general advice.

Of the 648 patients with new exacerbation or unstable disease, 93% were referred to the clinic (the remainder had an appointment within 10 days):

- 29% of new episodes of exacerbation, and 12% of patients with unstable disease were seen in clinic within 1 day
- 54% of new episodes of exacerbation, and 49% of patients with unstable disease were seen in clinic within 3 days
- 17% of new episodes of exacerbation, and 39% of patients with unstable disease were seen in clinic within 5 days
- A further 60 patients used the 'drop in' facilities for management of exacerbating disease
- In clinic all patients required rapid assessment by the gastroenterology team

### Patient questionnaires

Patient questionnaires were repeated in May 2004 and 50 questionnaires were completed. The questionnaire revealed that 80% of patients felt that they received rapid and appropriate access to secondary care review. Of the 50 questionnaires completed, 80% of respondents had been reviewed by IBD Nurse Specialist at some point over the past twelve months. All patients reviewed by the IBD Nurse felt that the care she provided was appropriate and supportive. The main themes to emerge were that patients felt that:

- The IBD Nurse was easy to talk to
- Management and investigations were explained in an easy to understand manner
- Treatment was agreed with the patient and the patient included in the decision making process
- As a result of longer clinic times they had a better understanding of their condition, its management and long term treatment options

### Focus groups

Further, focus groups were held in April 2003 reinforcing that the rapid access service had improved access to the gastroenterology team. Overall, the groups had a more positive outlook regarding the care they received by the gastroenterology team. They perceived that a nurse-led service improved emotional and physical support, resulting in greater feelings of empowerment. Patients felt that they had received more information about facilitating self management and raising self awareness of their symptoms, they identified that this reduced the amount of time they were off work or unable to socialise with their families.

Process mapping further supported this belief, identifying that the average time to consultation in secondary care had reduced from eight weeks to ten days from referral, facilitating earlier therapeutic management of symptoms and improving the effectiveness of care the patients received.

## Conclusion

The establishment of a rapid access service for patients with IBD has enabled easier access to the secondary care team. Evaluation of the project has demonstrated that with appropriate support and preparation a nurse specialist is ideally placed to undertake rapid assessment of patients with relapsing disease.

Those involved with the management of patients with IBD will acknowledge the recent advances in patient care. The development of rapid access service is essential. However this should not replace education and support of both medical and nursing colleagues in primary care, and the facilitation of self management strategies in this patient group. It is on this belief that the project will go on and provide support for patients in primary care, with care pathways being established and planned education programmes for primary care. The ongoing aim of the IBD service will be to facilitate access to expert advice and management within primary care.

## References

- Brown, J. and Thomas, E. (1995) Hotlines. *Nursing Times*. Vol.15. No.91. pp 61-62.
- Carter, M.J., Lobo, A.J. and Travis, S.P.L. (2004) Guidelines for the management of IBD in adults. *Gut*. Vol. 53 (supp): V1-V16.
- Department of Health (2003) *Improvement leaders guide to process mapping, analysis and redesign*. Modernisation Agency [www.modern.nhs.uk/improvementguides/process/](http://www.modern.nhs.uk/improvementguides/process/)
- Knowles, L. and King, T.A. (1995) A note on a day care pre operative day care telephone helpline. *Nursing*. Autumn. No 20.
- Marklund, B. et al. (1991) How well do nurse run telephone consultations compare with consultations in the surgery agree? A Swedish experience. *British Journal of General Practice*. Vol. 41. pp. 462-465.
- Travis, S. (1998) *Ulcerative colitis*. *Medicine*. London: The Medicine Publishing Group.

# FOCUS

## Patient Stories: A Tool for Evaluating Practice

### Project leaders:

Jill Down, Trust Lead for Practice Development  
Alison Sorley, Practice Development Nurse

### Location:

Addenbrooke's Hospital, Cambridge University Hospitals Foundation Trust

### Contact details:

jill.down@addenbrookes.nhs.uk

### Background

Evaluating practice and ensuring patients are at the centre of care are central to healthcare delivery today (Department of Health, 2000,2001,2004). To support the delivery and evaluation of patient centred care and monitor progress towards achieving it, a Trust vision for Practice Development was developed:

*To work in partnership with patients ensuring they are the focus of effective care'*

In order to achieve the vision, five strategic aims were developed:

1. To improve the patient experience and outcomes
2. To develop an effective workplace culture
3. To develop new ways of working
4. To implement evidence based practice
5. To engage stakeholders, disseminate information and enable action planning

The work undertaken in this project formed part of the first aim, to improve the patient experience and outcomes. A practical tool has been developed by nurses for use in clinical areas to enable a coordinated approach across the Trust to the taking of patient stories to help staff to understand and learn from the patient experience. In addition it provides a process for analysis of the information across the Trust thus providing a mechanism for feedback and action planning.

### Aims of the project

The focus of this project was:

- To understand the patient experience by taking patient stories and asking, 'what is it like to be a patient at this hospital?'
- To provide feedback to clinical areas, using patients' own words
- For each area to use the information to make improvements and share good practices
- To work with all staff who are at the interface with patients, using the evidence from patient stories to help them change the way they work in practice to directly impact on patient care
- To work with individuals and teams to develop a learning culture and achieve sustainable change

### Methodology

This work received approval from the Local Research Ethics Committee and was led by the Trust Practice Development Group working with Ward Managers, Senior Clinical Nurses, a patient and supported by Kim Manley, Head of Practice

Development, Royal College of Nursing Institute. It utilised an action research approach to deliver and evaluate the work as a robust, systematic, and continuous process in which nurses are researching their own work and actions.

One complete cycle of taking patient stories has been completed to date. Six patient stories were taken in each of 15 clinical areas within the Trust including parent stories from those under 18 and carer stories from those in critical areas. A total of 96 stories were taken in the first cycle. The learning from the initial cycle of taking stories has been incorporated into the next cycle that is currently in progress.

### Methods

A review of information collected across the Trust such as audits, surveys, and complaints, indicated that much of the information gained was in response to specific questions asked of patients. This review highlighted that the use of patient stories would provide an opportunity to explore, understand and learn from the patient experience more fully by collecting stories of their experience and whatever was important to them, in their own words. This would provide direct feedback from patients and provide an opportunity to develop and use a practical tool to evaluate care delivered in clinical areas.

'Patient satisfaction consists of both a cognitive evaluation and an emotional reaction to the care received and services delivered. An individual subjective perception is thus closely tied to expectations. For this reason there is a growing consensus that asking patients what they experienced is more informative than simply asking whether they were satisfied.' (Lygon and Hittinger, 2003).

### Outline of the process

Initial planning identified several steps in the process of taking stories and using them in practice:

- Developing a protocol for taking stories
- Preparation of staff to take stories
- Taking the stories
- Analysis of the stories
- Feedback to clinical teams
- Feedback to the Trust and across the Trust
- Action planning with teams
- Sharing good practices
- Monitoring and evaluation of action plans

#### Developing a protocol and training staff

There was no protocol available in the public domain to guide the process of taking stories. A facilitated dramatisation process involving clinical staff and a patient representative was used to develop one (Down, 2004). This had the effect of actively involving staff and using an approach that was inductive and practical whilst highlighting the practical, ethical and moral issues that might be encountered in clinical areas when taking stories. A set of 'Frequently Asked Questions' was developed in addition to the protocol to further support practitioners. Staff were trained to take stories using the knowledge gained from developing the protocol and the pilot process.

#### Taking the story

The stories were tape-recorded and notes taken. The interview starts by asking the question 'What is it like to be a patient here?'



# FOCUS

Start wherever you'd like to start and tell me whatever you'd like to'. Interviews lasted from 10 minutes to 2 hours and the patient was asked to make any additions or retractions before the interview finished.

## Analysis

The stories were all analysed using a system to capture key themes and descriptors and retaining the patients' words. The themes for each story were reviewed by another practitioner and again by the patient if at all possible. This participant and independent validation is necessary in action research methodology to ensure robustness and improve validity. Following analysis of several stories a template was built that would help provide a framework for providing feedback of all stories across the Trust. A total of 38 themes emerged from all the stories taken across the Trust with each clinical area having a different emphasis of responses. The themes included those within the Essence of Care standards (Department of Health, 2001) as well as additional areas such as waiting, drug administration, estates and facilities and personal televisions, all in both positive and less positive responses. Table 1 demonstrates how the themes were presented when feeding back to clinical teams.

**Table 1.**

Theme: Physical Environment	+ve comments	-ve comments
<p>4 of 6 patients made comments 3 +ve and 4 -ve comments</p> <p><b>Descriptors:</b> <b>+ve</b> clean ward nice day room relaxed atmosphere positive environment quiet</p> <p><b>-ve</b> claustrophobic cold loss of control sharing toilet facilities noisy</p>	<p>'Quite enjoyed it - relaxed atmosphere, no rushing-like a weeks holiday' (pt 2)</p> <p>'They come and move my bed every day to clean underneath it' (pt 3)</p> <p>'Quiet and peaceful, especially at night'</p>	<p>'Felt frustrated at loss of control in some areas such as temperature of ward and sharing of toilets with patients with diarrhoea' (pt 1)</p> <p>'Couldn't shave in the bathroom as there was not enough light' (pt 4)</p> <p>'Ward daunting because of monitors' (pt 6)</p> <p>'More toilets on the ward would be useful' (pt 2)</p>

## Feedback

The information from stories was fed back to the area where they were taken and to as many of the team as possible. In conjunction with critical incidents, complaints and risk information, this information was used by clinical teams to develop action plans. Additional reports and personal feedback was given to every department and individual mentioned in the stories across the Trust.

## Outcomes

The outcomes of the project can be put into 3 categories

1. Direct impact on patient care – some examples include
  - Review of self-medication following feedback of pain issue and self medication audit
  - Doors in bays now have springs and are closed at night
  - Patient rest period implemented
  - Floor repairs
2. Skills development of staff
  - Gaining informed consent
  - Actively listening to patients
  - Using evidence from practice to influence practice
  - Guidelines developed for giving and receiving feedback

- Guidelines developed for action planning
3. Organisational impact
    - Trust wide actions
    - For example, mealtimes have been put onto the personal televisions
    - Feedback to other departments mentioned in all stories
    - Sharing of good practices across the Trust
    - Informing the Patient and Public Involvement strategy
    - Protocol for taking stories developed for use across the Trust by all staff
    - Informing training and education programmes for all staff groups e.g. customer care
    - Informing Essence of Care work
    - Promoting and developing a culture of team working

## Discussion

The whole process of taking patient stories has proved to be a very powerful tool. Evaluation has taken place at each stage of the process and the learning has been fed back to inform the next stage. This has resulted in refinements to the protocol to include more detail about such things as protecting patients' privacy, practical issues around the use of tape recorders, randomly selecting patients and the mechanisms for using the feedback and facilitating change with clinical teams

The need to give and receive effective feedback was highlighted as crucial to the work and identified as an area that required development. Work is currently focusing on developing effective facilitation skills in clinical staff. Guidelines were developed, again using an inductive approach that would support practitioners to be more effective in providing feedback. Additionally, work was undertaken to facilitate the development of action plans with ward teams and identifying mechanisms within the governance structure for reviewing and evaluating the impact.

## Conclusion

This work has highlighted the benefits of a 'joined up' Trust approach to collecting stories that provides rich information about what is important to patients. It is acknowledged that it is a labour intensive process but has the additional benefits of developing the skills of staff and provides a tool for use as part of the Performance Management and Clinical Governance process in clinical areas. Most importantly the initiative generates and uses evidence from patients and integrates it within everyday practice and provides a practical tool for evaluation of practice.

## References

- Department of Health (2000) *The NHS Plan: a plan for investment, a plan for reform*. London: Department of Health.
- Department of Health (2001) *Essence of Care: patient focussed benchmarking for healthcare professionals*. London: Stationary Office.
- Department of Health (2004) *Standards for Better Health: Healthcare Standards for Services under the NHS*. London: Department of Health.
- Down, J. (2004) *From Deception to Delivery: A Journey Towards a Trust-wide Strategy to Develop a Culture of Person-centredness*. Chp 12 in McCormack, B., Manley, K. and Garbett, R. *Practice Development in Nursing*. Oxford: Blackwell Publishing.
- Lygon, M and Hittinger, R. (2003) Editorial: Patient and Public Involvement. *Clinical Governance Bulletin*. Vol.4. No.1. pp 1.

# FOCUS

## 'How are you Feeling?' – Multicultural Resources to Inform Women and their Relatives about Postnatal Depression

### Project leader:

Abi Sobowale, Health Visitor

### Location:

Sheffield South West PCT

### Contact:

abs50@nhs.net

### Background:

Depression has recently been rated as the most common mental health disorder presented in the primary care and community setting. It is a major cause of disability worldwide and will move from the fourth most common cause of disability to become the second most common cause of disability by 2020 (National Depression Campaign, 1999).

Whilst common in men and women, the young and the old, the prevalence of depression varies and is influenced by gender, ethnicity, and other social and economic factors. Pregnancy and childbirth may increase a woman's vulnerability to depression with an increased risk of depression occurring in the early postnatal period (Cox et al. 1993). As an aspect of mental health, depression in pregnancy and following childbirth can be associated with stigma in many cultures especially non-Western cultures. Consequently, the rate of recognition and report of symptoms by sufferers may be affected.

### Postnatal depression (PND) in ethnic minority women

PND is a real illness that can be treated successfully. For ethnic minority women who can experience isolation, lack of emotional and practical support, dislocation caused by migration, cultural incongruence, unemployment and financial difficulties, PND is a significant health issue. Although ethnic minority women experience depressed moods like other women, their cultural values and expectations may inhibit the expression of such feelings and moods that may help the recognition and management of depression. Consequently this group of women may suffer in silence and adopt coping mechanisms instead of seeking help. This may also make it difficult for health workers to recognise PND in this group of women and to provide appropriate support.

Screening and detecting PND in women of non-Western cultures, particularly those with English as a second language, has been challenging for primary health care workers. This is due to the limitations of the screening tool commonly used in primary care settings in the UK. Additionally, the cultural differences, traditions and rituals surrounding pregnancy and childbirth

amongst some minority groups, and a lack of cross-cultural equivalence in concepts of depression may affect detection rate. For effective detection and management of PND, health providers have to understand the differences and the women themselves have to have a certain level of understanding of depression, hence the need to develop multicultural resources. Such an approach is supported by the National Service Framework for Mental Health (Department of Health, 1999) and the NICE guideline (NICE, 2004) for depression which recommends that screening, diagnosis and management of mild to moderate depression should happen in primary care and that good information to promote understanding for patients, their families and carers should be available.

### Involving users

The need to develop the multicultural resources was jointly identified by users who emphasised the need to be able to talk. Local women became interested in the project following their involvement in a previous Health Action Zone project which had set out to identify a PND assessment tool for Asian women. This initial work, a collaborative project between Sheffield and Bradford, focused on one language group. This target group gained an improved understanding of PND and initiated the development of the multicultural resources during the evaluation of their work.

Local women were enthused and readily volunteered to work with the project leader. A community development approach was adopted that involved working with women and other members of the target population through existing community groups and organisations (see Box 1) and by the women engaging others themselves. Establishing a relationship with one community group often paved the way for reaching and working with others.

#### Box 1 Groups and organisations involved in the development of the multicultural resources

- Sheffield women
- Roshni Asian Women Resource Centre
- Sheffield Somali Mental Health Project
- Somali Hope
- SAVTE – Women's Health Project
- Kin-Hon Project
- Sharrow Sure Start
- National Sure Start
- Sheffield PCTs (City wide)
- Professional colleagues in the 4 countries
- The Community Practitioners' and Health Visitors' Association (CPHVA)
- Postnatal Depression Network
- Sharrow Community Forum
- Sheffield University
- Department of Health – HAZ, NIMHE

# FOCUS

## Developing the resources

To help health workers address the very real problems facing mothers from communities which can be very isolated from health services if they don't speak English, it was decided to develop a set of picture booklets. These emphasise the social, cultural and emotional expressions and physical symptoms of PND with the aim of promoting a discussion about moods and feelings between the clients and their health workers to help the early recognition of PND.

The 'How are you feeling?' booklets have been deliberately compiled with simple engaging illustrations and non-wordy captions for professional and non-clinical health workers to use with women who are literate or illiterate. They have been produced in six different languages – Bengali, Arabic, Somali, Chinese, Urdu and English.

The nature of the picture content was partially determined by women from each language group working with an artist and the project leader and then piloted with their relatives and friends. Local women modelled for the photographs and also chose suitable words to form the simple texts. Community consumer groups acted as expert resources and helped with checking the translations.

Supported by health visitors from around the country, the booklets were piloted by focus groups, community groups and individual women in Sheffield and across the UK.

The 'picture booklets' are accompanied by a set of multicultural posters, designed to be displayed in doctors' surgeries/clinics, and community organisation premises so that they can encourage mothers with symptoms of depression to seek professional help. Furthermore, a training and resource pack has been produced jointly by Sheffield South West PCT and the Community Practitioner and Health Visitor Association (CPHVA) to support the use of the booklets.

## Challenges

Developing resources in six different languages simultaneously presented many challenges as the project workers were constantly communicating with people using different languages and with different literacy skills. It helped to respect and value the contribution of everyone. Whilst some of the women who were involved could neither read nor write English and/or their own language, they had excellent language and cultural skills and were therefore able to make a valuable contribution to the project.

Choosing the appropriate words to use in the resources presented some challenges, particularly relating to the different use of language across the generation gaps. This was overcome by adopting a robust translating system to ensure common understanding.

It was also difficult, on occasions to keep the project on the top of stakeholders' agendas, however, frequent communication with all involved ensured that this happened.

## Future developments

The missing piece of the jigsaw is an information leaflet to provide much needed information for women and their families to encourage early recognition of PND and self-referral for support.

Building on the extensive work that has already taken place in Sheffield, a project is currently underway to develop leaflets based on the 'How are you feeling?' booklet and posters that will be aimed at pregnant women and new mothers. Once again they will be produced in six languages. The leaflets will have an illustration of a pregnant woman and a mother and baby on the front. The inside page will have the simple but engaging illustrations depicting social, physical and emotional symptoms and the back page will provide information on the available local support systems and local contact details e.g. midwife, health visitor, GP and local support groups.

The users, community groups and practitioners that helped with the production of the other resources have been approached to develop and pilot the information leaflets. The feedback obtained from the different groups will influence the final leaflets.

## Conclusion

By adopting an inclusive approach, it has been possible to develop a series of multicultural resources that aim to raise awareness about PND and promote the early detection of PND. A wide group of women, community groups, professionals and other organisations have worked together in a way that has ensured that every member's contribution has been equally valued. From the beginning there has been a sense of ownership among the women, the community groups and the project workers. People have been committed, given their time freely, supported one another when the going was tough and shared in the final glory.

The resources are now being used widely across the UK and have created international interest from the USA, Australia and New Zealand.

## References

- Cox, J.L., Murray, D. Chapman, G.A. (1993) A controlled study of the onset, duration and prevalence of postnatal depression. *British Journal of Psychiatry*. Vol. 163. pp 27-31.
- Department of Health (1999) *National Service Framework for Mental Health: Modern Standards and Service Models*. London: Department of Health.
- National Depression Campaign (1999) *National Depression Campaign Survey: London. Cited in Guidelines in Practice* (2005) Effective recognition in primary care is the first stage in a structured approach to depression management. Vol.8. pp 25-32.
- National Institute of Clinical Excellence (2004) *Depression: The management of depression in primary and secondary care. NICE Clinical Guideline 23*. London: NICE.