

# A community outreach service for people with COPD

CHRONIC illness is increasingly recognised as one of the most important health issues facing western society (*British Medical Journal*, 2002; McWilliam et al, 1996; Newby, 1996). Chronic obstructive pulmonary disease (COPD) is a classic example of a chronic illness. Like other chronic conditions it requires ongoing input and support from a range of health care services.

Although there are considerable physiological differences in the presentation of chronic conditions, it is acknowledged that each illness confronts patients and their families with the same range of demands:

- To alter their behaviour;
- To deal with the social and emotional impacts of symptoms, disabilities and approaching death;
- To take medicines;
- To interact with medical care over time.

Patients must receive the best treatment regimens to control the disease and mitigate any symptoms, but they also need information and support so that they are able to self-manage their health and, in many instances, their death (*BMJ*, 2002). Consequently, the nursing care for these patients includes teaching them and their families how to manage the disease proactively, as well as assessing the response to interventions in terms of improvements in each patient's ability to manage their daily life (McAllister, 2002). In addition nurses need to identify the needs of carers and facilitate access to appropriate support (Newby, 1996).

Government policy has highlighted the importance of interagency collaboration to support people in the community. Nurses are well placed to coordinate access to a range of non-NHS services based on an assessment of individual patient/carer need (Procter, 2000).

In order to address the above aspects of nursing care, a nurse-led, interagency community outreach service has been set up in the North East of England for people with COPD. This article describes the development of the service and its evaluation.

## Readmission linked to social factors

A service development group was established, comprising nurse and GP researchers from the two local universities, representatives from local NHS trusts, primary care and local authorities. The group looked at local patterns of service use by patients with COPD and found that hospital readmission was more closely related to the patients' perceived quality of life than to physiological measures of disease severity. This mirrored research carried out elsewhere. Increasing social stressors, low levels of social support and low self-esteem have all been associated with decreasing functional status in patients with chronic lung disease regardless of the se-

verity of the disease (Osman et al, 1997; Blake, 1991). Similarly, poor quality-of-life scores are associated with higher hospital readmission rates for patients with COPD irrespective of physiological measures of disease severity. It was thought that the holistic care and support provided by a nurse-led community outreach service would improve the quality of life of people with COPD.

## Developing the service

The COPD outreach service specification was developed by nurse academics working closely with service providers. The respiratory consultant, nurse, physiotherapy respiratory specialists and medical social worker were also involved in developing the service.

The service was specifically targeted at people with COPD who live in their own or in sheltered homes. It was funded by the local authority, managed by a social work team leader and led by a hospital respiratory specialist nurse (RNS) who had been seconded to the local authority from a local NHS trust. A team of six outreach workers delivered the service.

Before the introduction of this service, local provision for patients with COPD relied heavily on hospital and GP services. Every patient admitted to hospital with COPD was assessed by an RNS. A hospital-based district nurse worked with the respiratory team to provide support for early discharge. Access to home-based physiotherapy was limited, as was hospital-based pulmonary rehabilitation. At the time the service was being developed, the respiratory consultant was working with Healthy Living Centres to expand local capacity and improve access to exercise facilities for respiratory patients.

The RNS took up her position in March 2000, and the six outreach workers were recruited between June and October 2000. Referrals to the service were taken from June 2000, and administrative support was made available in September 2000. Between June 2000 and January 2001 (the period of the evaluation) there were 115 referrals from hospital practitioners.

## The COPD patients

Patients referred to the service were severely disabled by COPD. The mean exercise tolerance was 20 yards and the maximum was 50 yards. Some 81 per cent scored 5 (get out of breath dressing/undressing or can't leave the house) – the maximum score – on the Medical Research Council (MRC) dyspnoea scale. Of the 115 referrals to the service, 15 were assessed as not eligible, mainly because they were not resident in the catchment area.

Of the 100 people assessed, 45 were managed solely by the RNS. Predominantly, these required either information about other available services or direct



Mike Polloway

## AUTHORS

**Bill Watson, MSc, RGN**, is senior lecturer, Northumbria University; **Alisa Mylotte, MSc, RGN**, is respiratory nurse specialist, Northumbria Healthcare Trust; **Susan Procter, BSc, PhD, CertEd, RGN**, is associate nursing director, Gwent Healthcare NHS Trust.

## ABSTRACT

**Watson, B. et al (2003)**

**A community outreach service for people with COPD. *Nursing Times*; 99: 17, 33–36.**

This paper describes the development and evaluation of a nurse-led interagency community outreach service for patients with chronic obstructive pulmonary disease. The service improved the quality of life of the patients who accessed it. However, difficulties in maintaining the service arose from the historical structure of care delivery and policy frameworks.

per cent (standard deviation = 2.82) of patients reported experiencing at least some difficulty.

The patients were asked to rate the service in terms of how it affected their quality of life, as well as their perceived importance of the service (Fig 1). Most respondents gave a rating of 'A great deal' (55.7 and 64.3 per cent respectively).

Patients also assessed the impact of the service on different aspects of their lives (Fig 2), with 77.4 per cent indicating that the service had helped them in multiple (>2) ways. People who felt that the service helped to improve their breathing made up the largest group, while the smallest group comprised those who felt that the service had helped to get them to go out more. There was evidence here that patients felt the service had enabled them to avoid admission to hospital.

**The qualitative interviews**

Information supplied by the qualitative interviews indicated how the service achieved the above results. Some of the comments follow:

'Well I get agitated you know, frightened with the breathlessness... but with the lass coming and taking me out and even just sitting talking to me I'm starting to do things. The other day the sun was shining so I went out into the back garden... just on my own you know... and I pulled a few bushes out. I was only out about 10 minutes and then I had to come back in to the oxygen mask, but I'm trying things now.'

'I've got one of these stair-lifts you know, and the other day I thought, "I'm going to try and walk up the stairs"... Oh I was really exhausted when I got to the top... but that lad's helpful and he'll say "try this and try that".'

'I know a couple of times it has stopped me going in [to hospital]... I could ring [the administrator] and tell them how bad I was and she would get somebody to me every day for a while... just to help you through while you're bad.'

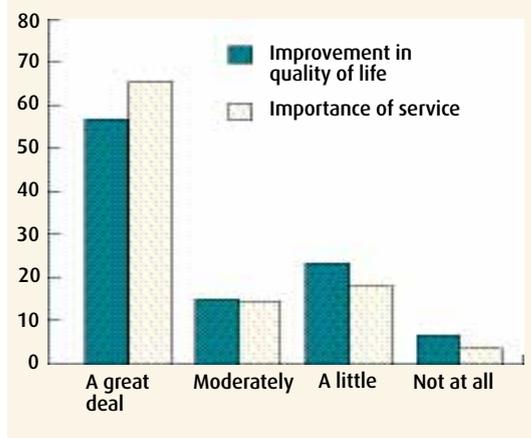
From a health management perspective the avoidance of hospital admission indicated by these comments was an interesting finding worthy of further investigation.

**Discussion**

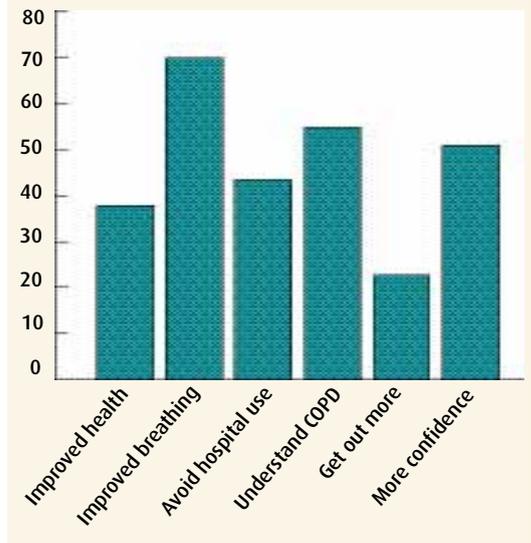
The service was designed to address key care issues of promoting a better quality of life and functional independence of a group of patients known to be vulnerable to poor outcomes. Given the assertion that nurses looking after COPD patients should be assessing their response in terms of their ability to manage their daily lives (McAllister, 2002), the evidence described above is important because it indicates that the patients thought the service improved their quality of life and may have reduced hospital admission.

The limitations of this evaluation must, however, be recognised. The evaluation was cross-sectional and occurred at one point in time. Therefore, patients completing the evaluation had been accessing the service for variable lengths of time. No baseline or comparative data was collected so it is not possible to attribute reported improvements in quality of life to the service. Data was

**FIG 1. PATIENT RESPONSES TO EFFECT OF COPD SERVICE ON QUALITY OF LIFE AND THEIR RATING OF THE IMPORTANCE OF THE SERVICE**



**FIG 2. PATIENT ASSESSMENT OF THE IMPACT THAT THE SERVICE HAS HAD ON DIFFERENT ASPECTS OF THEIR LIFE**



not collected on hospital use by these patients therefore this finding is indicative only.

The service has not been without its difficulties. These are briefly discussed below.

■ Funding streams: health and social care do not currently have shared funding. Tensions have arisen over the relative contributions each sector makes to the service budget.

■ Genericism vs specialisation: policies founded upon a generic social care model may not recognise the scope of professional practice issues that arise from a clinical specialist model of practice. The *Code of Professional Conduct* specifically states that nurses must acknowledge the limits of their professional competence and only undertake practice and accept responsibilities for those activities in which they are competent (Nursing and

referral to other services (such as social care, the housing department, the community disability service and other health services such as pulmonary rehabilitation and gastroenterology).

During the period of evaluation, the outreach workers took on 55 of the 100 referrals. Of these, 33 remained on the active caseload at the end of the evaluation period. Eight people died and 14 were discharged, nine (64 per cent) of whom were self-caring at the point of discharge.

### Outreach workers' input

During the evaluation period there was a total active caseload of 33 patients. This gave each outreach worker an average caseload of 6.5 patients, or an average of 4.5 hours' input per patient, per week. The input included:

- Promotion of activity – such as taking patients out for short walks on flat ground;
- Promotion of independence – actively encouraging patients to undertake activities of daily living (self-care, shopping, climbing stairs and gardening) with decreasing support and assistance over time;
- Increase of socialisation – such as taking patients out to the library or organising social activities for groups of users;
- Maintenance of physical health – such as promoting and supervising nutritional intake;
- Carer support – providing respite care so that the main carer could take time out.

The outreach workers negotiated their time with patients to fit in with their own family commitments. They were not expected to assess the physical condition of their patients. Without this service these patients would be self-assessing their disease and seeking help from their GP or A&E department if they had reason to be concerned. If there was concern about a patient's physical condition the outreach worker was able to contact the RNS who would provide advice and refer on if necessary. The outreach workers adopted the role of lay carers rather than professional providers. This approach builds on current evidence in the management of chronic disease (McWilliam et al, 1996).

The people in the active caseload can be divided into three categories in terms of the input they require from the service:

- Provision of short-term input – where the service is being accessed for specific, time-limited reasons, such as following hospital discharge or temporary absence of the main carer;
- Provision of ongoing input – where disease severity, level of personal or family resources, or the patient's concurrent medical or social situation requires a constant level of input from the service. A small number of people in this category were referred on to other services, such as residential care, when it became apparent that their needs could be met more efficiently elsewhere;
- Fluctuating provision – where patients determine their own level of access. This may mean that they effectively

discharge and re-refer themselves over time, or that they receive a 'baseline' level of input, which is increased at times of greater need;

Discharge from the outreach service also fell into three categories. The first category was made up of those discharged by the RNS following recovery from an acute episode. Here professional judgement was used to assess each patient's clinical progress, level of self-care ability and the support that would be available after discharge.

The second category comprised those who would receive ongoing, intermittent input from the service. Here the patients decided when they started and when they stopped receiving care. Discharge was very much patient-led. Patients in the third category were those who were discharged into more intensive care settings such as nursing homes.

### Evaluation of the service

The evaluation used descriptive methods. All current and discharged patients (n=100) were sent a self-completion postal questionnaire to record:

- Their current level of functioning;
- The types of input they had received from the service;
- The ways they felt the service had helped them;
- Their general perceptions of the service in terms of its impact on their quality of life and its importance to them.

Additionally, each patient's functional ability was assessed using the Multidimensional Health Assessment Questionnaire (MHAQ). This measures the difficulty experienced by an individual in undertaking a number of activities of daily living. A four-point scoring mechanism is used with 1 equalling 'no difficulty', 2 equalling 'some difficulty', 3 equalling 'much difficulty' and 4 equalling 'unable to do'.

The response rate was high (74.7 per cent). There were marked differences in the return rate of people on the current caseload compared with those who had been discharged from the service, with responses of 83.9 and 69.2 per cent respectively.

In addition to the questionnaire, six patients took part in a semi-structured telephone interview to explore their experiences of the outreach service. The interviews lasted only 15 minutes because these patients suffer from breathlessness. The conversations were recorded on audio tape with the person's consent. Thematic content analysis was then carried out.

### Results

Table 1 shows the respondents' abilities to carry out a range of activities of daily living as assessed using the MHAQ. The highest mean scores occurred for shopping (3.42), climbing stairs (3.16) and driving a car (3.16), indicating that, on average, patients had most difficulty carrying out these activities.

The scale also shows that patients had difficulties in a number of other areas. The only areas where the majority of patients indicated that they had no difficulty was, lifting a full cup or glass to mouth and turning taps on and off. Even with low-exertion activities, such as dressing, washing, bending and sleeping, an average of 81.5

For related articles on this subject and links to relevant websites see [www.nursingtimes.net](http://www.nursingtimes.net)

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TABLE 1. RESPONDENTS' ABILITY TO CARRY OUT A RANGE OF ACTIVITIES OF DAILY LIVING

Activity of daily living	No difficulty	Some difficulty	Much difficulty	Unable to do	Mean (95% CI) score
Dress yourself including shoelaces and buttons	22.6%	48.4%	21.0%	8.1%	2.15 (1.93-2.36)
Get in and out of bed	41.9%	45.2%	11.3%	1.6%	1.73 (1.54-1.91)
Lift a full cup or glass to mouth	77.4%	19.4%	1.6%	1.6%	1.27 (1.13-1.42)
Walk outside on flat ground	14.5%	24.2%	38.7%	22.6%	2.69 (2.44-2.94)
Wash and dry entire body	17.7%	32.3%	24.2%	25.8%	2.58 (2.31-2.85)
Bend down to pick up clothing	17.7%	46.8%	25.8%	9.7%	2.27 (2.05-2.50)
Turn taps on and off	67.7%	17.7%	14.5%	0%	1.47 (1.28-1.66)
Get in and out of a car or bus	21.0%	46.8%	24.2%	8.1%	2.19 (1.97-2.41)
Do your own shopping	8.1%	8.1%	17.7%	66.1%	3.42 (3.18-3.66)
Climb a flight of stairs	6.5%	14.5%	35.5%	43.5%	3.16 (2.93-3.39)
Drive a car five miles from home	12.9%	12.9%	19.4%	54.8%	3.16 (2.88-3.44)
Get a good night's sleep	16.1%	37.1%	30.6%	16.1%	2.47 (2.23-2.71)

Midwifery Council, 2002). The RNS has been asked by her social service manager to assess non-respiratory clients. She considers this outside her professional scope of practice and feels compromised by the request. Social services do not have the budgets required to recruit nurse specialists to cover every chronic disease and therefore the replication of this model of service provision to other chronic diseases is doubtful.

■ **Liability:** an organisation's policies provide safeguards for its 'native' forms of practice. They may not provide appropriate legal safeguards for the realities of multi-agency practice exemplified in the secondment described in this article.

■ **Outcomes:** establishing this service within local authority community care effectively set up a two-tier local authority system with patients diagnosed with COPD receiving a highly individualised and responsive service known locally as the 'deluxe' service. This service replicates the principles of universal access based on need that characterises NHS provision.

In contrast, social service provision has historically been based on selectivity and means testing. Differences reflecting historical access policies are built into each practitioner's mode of practice, making it difficult for both health and social care practitioners to adjust to different organisational expectations. Over time the differences between the service for COPD patients based on NHS principles of access and those based on social service access policies became apparent and created tension. The tension was severe enough to jeopardise the continued provision of the COPD

outreach service based on the principles of care management outlined above.

These difficulties arose primarily from the secondment of the RNS into a social service department, which was necessary, because this was the source of the funding. Contemporary government policy is increasingly calling for partnership working and multi-agency service developments, as set out in *The NHS Plan*. The problems described above illustrate some of the issues health and social care providers may need to address if these plans are to become a reality. These problems arise primarily from the systems of care delivery rather than the practice of individuals. They reinforce the conclusion of the *BMJ's* editorial (*BMJ*, 2002), which emphasised that systemic change is necessary to meet future health care needs.

Conclusion

We hope that our experiences will alert nurses who may be embarking on the development of new multi-agency services to the problems that can arise. This will enable them to anticipate and perhaps address some of the issues before they threaten the success of service developments or compromise the professional practice of individual nurses. It is worth noting that some of the difficulties encountered in establishing this type of service may be more to do with historical structures of service provision and policy frameworks than with the behaviour of the individuals involved. ■