Evaluating the effectiveness of innovations involving nurses for people in the community with chronic obstructive airways disease

Report for the National Co-ordinating Centre for NHS Service Delivery and Organisation R & D (NCCSDO)

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Executive Summary

This report describes an ‘extended’ systematic review of nurse innovations for patients with COPD normally living in the community and a survey of the current provision of respiratory nurse specialists (RNS) services for patients with Chronic Obstructive Pulmonary Disease (COPD) in England and Wales in April 2003.

The aim of the literature review was to locate and review systematically relevant quantitative and qualitative studies involving nurse services for people with COPD who normally live in the community. The aims of the survey were to map the current provision of specialist nurse service for patients living in the community with COPD in England and Wales, and to identify the type of provision.

We conducted a comprehensive literature search for English and Dutch language published articles including 19 electronic bibliographic databases. The methodological quality of the published reports of the included randomised controlled trials (RCTs) was assessed in two different ways, both of which record risk of bias, and these assessments were used to allocate a level of evidence score to each outcome reported by the individual studies.

The literature search identified nearly 7,000 citations including 168 potentially relevant articles. Following full text retrieval 40 papers remained eligible; of these 13 were randomised controlled trials and two were systematic reviews. For data extraction and synthesis we divided the studies into two distinct groups: chronic disease management type interventions for patients with COPD and interventions for acute exacerbations of COPD. No evaluations of specialist nurse led clinic interventions were identified.

We identified one Cochrane systematic review and seven published randomised controlled trials (RCTs) of chronic disease management nursing interventions for patients with COPD. All the RCT studies of chronic disease management nursing interventions had some methodological limitations. The chronic disease management interventions could be divided into brief (one month) and long term (one year). Most involved home visits by a respiratory nurse but in two studies it was not clear where follow up was carried out. The content of the home visits varied.

There is some evidence that for patients with moderate to severe COPD chronic disease management nursing interventions may not: reduce mortality; improve health related quality of life as determined by disease specific instruments; improve psychological well-being; reduce impairment and disability as determined by total Sickness Impact Profile scores; improve pulmonary function; or reduce all cause hospital admissions.

However, there is limited evidence arising from a single RCT that a nurse led home care programme involving quarterly home visits and monthly telephone calls may reduce hospital admissions and hospital costs at 12 months follow up among patients on long term oxygen therapy.

We identified several potential outcomes of the chronic disease management nurse interventions on which there is currently no, or very little, evidence; including patient self management skills, and coping with their disease.

We identified one Cochrane systematic review and six RCTs of nursing interventions for acute exacerbations of COPD. The aim of these studies was generally to explore the feasibility and safety of transferring hospital care to the community. All the RCTs had some methodological limitations, most of the studies had small sample sizes and none were designed to show true equivalence between the intervention and control groups. No study involved more than two centres so it is not certain that the benefits seen can be rolled out to the whole population. Some of the interventions for acute exacerbations involved early supported hospital discharge while in others patients could avoid hospital admission altogether. For all studies only around a quarter of patients presenting with an acute exacerbation of COPD were eligible and consented to participate. Generally the components and the intensity of the different interventions for acute exacerbations were similar. In all the interventions a respiratory nurse was the main health care provider. Most services operated on weekdays only and the number of whole time equivalent nurses in the team when reported was two or three.

There is reasonable evidence that among the selective patient populations that have been included in trials to date domiciliary interventions for acute care in COPD do not influence: mortality; pulmonary function; or hospital readmissions within the following three months.

There is very little, or no, evidence available on the effect on patients or their carers of domiciliary interventions for acute care in COPD around: health related quality of life; satisfaction with care; and psychological well-being.

Other non RCT quantitative studies were scarce and contributed very little to the review's findings. Only two qualitative studies were identified, both around chronic disease management, these appeared to be of poor quality and their results could not be confidently transferred to other situations. The additional search of Dutch language literature yielded only one relevant, published paper although we did identify three studies from The Netherlands which were in progress or awaiting publication. Some of which were evaluating interventions that have not previously been evaluated – clinic interventions

There is very little information in the published, 'grey' and unpublished literature on how to implement nurse innovations for COPD in the community.

We identified 234 specialist nurse led services in England and Wales for patients with COPD in the community from the survey. Current provision of specialist respiratory nurse services is scattered over England and Wales. There appears to be inequality in the provision of these services and many Primary Care Trusts do not have a nurse led service for patients with COPD in the community.

Most existing services are based in secondary care and are funded by recurrent monies form primary and/or secondary care. 14 per cent of services have some funding from non-recurrent or charitable monies.

The current provision of respiratory nurse specialist services for patients with COPD in the community in England and Wales appears to be dynamic with new services developing or changing while others are discontinued.

The type and content of the services identified in the survey varied greatly, but the majority involved chronic disease management schemes. It was notable that the types of service provided, and their components, were often very different from the services evaluated in the research literature. In particular there were many hybrid schemes (schemes providing both acute interventions and chronic disease management) and many schemes providing clinic care only.

Many of the chronic disease management type services currently available in England and Wales offer models of care which have not been robustly evaluated in COPD (i.e. have not been the subject of RCTs). However, unlike the chronic disease management type models which have been the subject of RCTs, many current services contain components which are evidence based such as the provision of pulmonary rehabilitation.

Consumers who gave feedback on an interim report of the review were generally supportive of the research reported in the RCTs. Most respondents felt that the studies were evaluating appropriate outcomes but several felt that it was also important to look at;

- the psychological benefits of treatment
- the effect on self management
- the effect on quality of life and
- the effect on carers.

Many of the consumers who responded were not happy about basing decisions on service provision on this sort of research. Among other things some felt that each individual patient's needs should be taken into account and that they needed better information and education about their disease.

Recommendations

Recommendations for service providers

Nurse led hospital at home or early discharge schemes for patients with COPD living in the community should be prioritised over the type of nurse led chronic disease management models that have been studied to date.

Hospital at home or early discharge schemes should include the following components common to most of the interventions which have been subjected to evaluation in RCTs;

- a package of care on discharge home including drugs, nebulisers and oxygen concentrators, as indicated
- patients to be seen at home within 24 hours of discharge
- home visits to include assessment of the patient
- the use of explicit care pathways
- arrangements for out-of-hours care (usually provided by existing services) and
- follow up under the scheme lasting at least seven days and probably longer.

Service providers should be aware that five of the six hospital at home or early discharge schemes that have been subjected to evaluation in randomised controlled trials only operated on weekdays. Hospital at home or early discharge schemes that operate over weekends must be robustly evaluated.

There is very little evidence available at present to support the continuation of the *type* of chronic disease management models *that have been evaluated to date*. Existing services providing this sort of care should be robustly evaluated against the aims of the particular service. Alternatively, these services should consider adopting the characteristics of generic disease management programmes, or disease management programmes for other chronic conditions, which have been shown to be effective in well designed evaluations.

If any new, nurse led chronic disease management services for COPD patients living in the community are established they should be robustly evaluated against the aims of the particular service.

Novel service developments should be explored for the type of patients presenting with an acute exacerbation of COPD who were not considered eligible for, or did not wish to participate in, the early discharge or hospital at home schemes evaluated to date. (From our national survey we identified two, at present, unevaluated schemes for such patients.

1)supported discharge schemes that discharge patients home to nurse support later than a conventional ‘early discharge’ but discharge earlier than a conventional hospital stay for an acute exacerbation

2) community nurse unit schemes where a patient is admitted whose exacerbation does not require hospital admission but requires more monitoring than domiciliary nurse visits.)

Information on the successful implementation of new services for patients with COPD in the community should be disseminated. Keeping details on the implementation of new services for patients with COPD in the community should be standard practice and this information should be made easily available and actively disseminated to other health professionals and policy makers.

Recommendations for future research around COPD care

Multi-centre implementation research rolling out hospital at home/early discharge schemes to see if the benefits demonstrated in single centres can be seen across many centres and in different populations is required.

The potential benefits in terms of reduced hospital admissions and emergency department visits with chronic disease management schemes in COPD patients receiving long term oxygen therapy should be explored further.

Studies should look at the effect of domiciliary interventions on other community health care services and on social services.

Health economic studies of hospital at home/early discharge schemes which include the costs carried by patients and carers are needed.

Researchers should consider including patients’ health related quality of life and carers’ quality of life as outcomes and should explore the effects of interventions on patients’ and carers’ psychological well being and coping. Wherever possible validated instruments suitable for patients with COPD and their carers should be used.

Researchers should use robust techniques to explore patient and carer satisfaction with services.

There is a need for qualitative research of high quality around these interventions.

For the benefit of future readers, researchers should document the components of interventions clearly in published reports on their work or in linked documents stored on the world wide web.

Recommendations for systematic reviewers

Conducting a survey of the existing provision of services in tandem with a systematic review of the effectiveness of different service models can be a very useful exercise and, where appropriate, should always be considered.

Methods need to be developed to identify the best ways of involving consumers in systematic reviews and consulting them about the findings. In particular, techniques should be developed to explain systematic reviews and communicate their findings to consumers or other lay audiences.

This review demonstrated the potential benefits of drawing on a broader range of evidence than conventional systematic reviews, however in practice in extending the review this way contributed little to our overall findings. Further work should be undertaken to determine whether the benefits of this approach outweigh the resources required to extend the scope of a review in this way.

Recommendations for research funders

Research comparing the effectiveness of generic verses single condition interventions in chronic disease management should be commissioned.

Research which unpicks whether generic interventions and/ or interventions which have been found to be effective in one chronic disease can be transferred with similar benefit to another chronic disease should be commissioned.

Disclaimer

Addendum

This document was published by the National Coordinating Centre for the Service Delivery and Organisation (NCCSDO) research programme, managed by the London School of Hygiene and Tropical Medicine.

The management of the Service Delivery and Organisation (SDO) programme has now transferred to the National Institute for Health Research Evaluations, Trials and Studies Coordinating Centre (NETSCC) based at the University of Southampton. Prior to April 2009, NETSCC had no involvement in the commissioning or production of this document and therefore we may not be able to comment on the background or technical detail of this document. Should you have any queries please contact sdo@southampton.ac.uk