

Evaluating the nursing, midwifery and health visiting contribution to chronic disease management: An integration of three reviews

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Research Report

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Executive Summary

Background

This report integrates the evidence from three related, but independent, reviews commissioned by the National Institute for Health Research (NIHR) Service Delivery Organisation (SDO) to evaluate the nursing, midwifery and health visiting (NMHV) contribution to models of chronic disease management (CDM). The three reviews were the first phase of work of three larger projects specifically commissioned to add to the understanding of the contribution of nurses, midwives and health visitors to chronic disease management.

1. Bunn et al 2007. Evaluating the nursing, midwifery and health visiting contribution to chronic disease management: a mapping of the literature. *University of Hertfordshire & City University, London*

2. Forbes et al 2007. Defining and evaluating the contribution of nurses to chronic disease management: an integrated review of the literature in diabetes mellitus, multiple sclerosis and chronic obstructive pulmonary disease. *King's College London*

3. Scott et al 2007. Evaluating the contribution of nurses, midwives and health visitors to the care of people affected by long-term conditions: a literature review. *Royal College of Nursing Institute, London, St. Georges, University of London, University College London, University of Hertfordshire, University of Surrey, King's College London*

These research projects were commissioned in the context of recognition of the growing prevalence of people with chronic diseases and the associated costs to them, their families, the health and social care services and the economy. Approximately two thirds of emergency hospital admissions are related to chronic diseases and the costs for managing patients with multiple chronic conditions are high. Nurses make up a large part of the health workforce in the UK and Government policies have suggested that nurses play a greater role than before in the health service response to people with chronic diseases¹⁰. The impetus for this integrated review came from the NIHR SDO representatives.

Aims and Objectives

Principal research questions

Each review had its own focus, but all were guided by the principal research questions derived from the NIHR SDO commissioning brief:

¹⁰ *The terms chronic diseases and long term conditions have been used in this review to reflect the terminology used by the three reviews*

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- What are the different models of chronic disease management that involve nurses, midwives, health visitors, how have they developed and why?
- What are the ways that they involve service users and carers?
- What are the roles and responsibilities of nurses, midwives and health visitors in current models of chronic disease management?
- What is the impact of nurses' contribution to the experiences of patients, service users, professionals and carers?
- What enables nurses to contribute most effectively to successful outcomes of care?
- What is the impact of the nurses' contribution upon the cost, quality, effectiveness and organisation of the care provided?

Aims and Objectives of the integrated review

Aim

To synthesise the findings of the three reviews on the contribution of NMHV to CDM

Objectives

- To integrate the three reviews using appropriate methodologies and to provide an overall review of NMHV contribution to CDM
- To summarise the different approaches of the three reviews, their theoretical assumptions and methods
- To synthesise the findings and highlight methodological challenges
- To demonstrate the synergy, commonality and consensus between the three reviews
- To describe the process and outcomes for NMHV contribution and evidence of its impact
- To establish the types of NMHV activity and the contextual settings that have the strongest evidence base for practice
- To identify gaps in the evidence about effectiveness and appropriateness of specified interventions/models of care
- To make recommendations for practice and research

Methods

The process of integrating the three reviews

An iterative, consensus based approach was adopted through joint meetings and workshops with all three teams involved in planning and discussing the integration. Initially this process involved exploring methodologies for integrating evidence, developing a protocol and establishing a framework to support the synthesis of the findings. Latterly, it was employed to validate the synthesis and develop a consensus on the presentation of the final report. The ways in which the work was shaped through the workshops and editorial group meetings included:

1. Appraisal of the three reviews by DT
2. Development, compilation and circulation of all materials (by DT) to the three teams prior to meetings

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3. Consensus building through editorial group meetings with the three reviewers. Specific issues included methods of summarising and organising data, and synthesis of evidence from the three reviews
4. Further discussions on the draft report with the three teams at joint workshops to reach a consensus on the final review.

Through this approach, the review benefited from discussion and guidance from the three teams and was therefore subject to ongoing internal peer review.

Data extraction and synthesis of the three reviews

Data were extracted using the framework to map and integrate the content of the three reviews. The areas examined included: the underpinning research questions and focus of the reviews; the type of material included in the reviews (methods, settings, country of origin); the range of disease conditions examined; nursing roles, specific nursing interventions; models of nurse-led services; the nursing contribution to care and organisations; the impact of nursing on structure, process and outcome; barriers and facilitators to the contribution of nurses; and the main implications for practice and recommendations for research identified by the reviews.

A flexible framework, driven by current models for CDM, was developed and used to organise data extraction and synthesise the findings from the three reviews. It incorporated key distinguishing features/domains of NMHV contribution to CDM, with specific questions for drawing out the required information from the evidence presented in the three reviews. Thematic findings from the reviews were mapped on to the key NMHV contribution concepts identified in this framework.

Methodologies employed by the three reviews

All three reviews differed in their theoretical approach, focus and the way the data were organised, categorised, synthesised and discussed. This made it difficult to extract comparative data.

Conceptual frameworks

Bunn et al (2007) used a cyclical 'whole systems' approach based on a framework for implementing evidence-based, protocol-driven care. They focused on most chronic conditions (except cancer) and all ages. Forbes et al (2007) conceptualised the nursing contribution according to assessment, health promotion, clinical care, and health care organisations. They focused on three tracer conditions (Chronic Obstructive Pulmonary Disease (COPD), Diabetes, Multiple Sclerosis (MS)). Scott et al (2007) developed a framework based on current policy themes and focussed on case management for older people and organisational interventions for five target conditions: COPD, asthma, epilepsy, Parkinson's disease and rheumatoid arthritis.

Searching, retrieval and categorisation of items¹¹

Search strategies described by Bunn et al (2007) and Scott et al (2007) were similar and systematic with searches conducted from 1996-2006 using a range of electronic databases. Forbes et al (2007) conducted systematic and consistent searches for each disorder; from 1980 – 2006 for COPD and diabetes and 2002-6 for MS (they had already undertaken a review of earlier literature). Independent screening of abstracts was conducted by Bunn et al (2007) and Forbes et al (2007). Scott et al (2007) developed included items through the data extraction process, refining the inclusion criteria iteratively, rather than through systematic screening and selection. All reviews sought grey literature and expert opinion and searched reference lists.

All three reviews included key data on study types, designs, disease condition, nursing roles, interventions or service models, process and outcome measures and each used its own structured tool according to the review's organising framework.

Evidence synthesis

The reviews used different approaches, mainly descriptive and narrative, using their initial frameworks or theoretical assumptions to guide the synthesis. Bunn et al (2007) mapped findings on nursing roles, interventions and effectiveness according to disease categories and Forbes et al (2007) conceptualised the nursing contribution using an overall theoretical interpretation of the content of three reviews (COPD, Diabetes, MS). This included interventions, nursing roles and their effects on care structures, processes, outcomes and cost effectiveness. Scott et al (2007) applied realist synthesis to the evidence on 'organisational interventions' of nurse-led services for five conditions according to the types of settings.

Results

Descriptive Mapping

The majority of the material included in the reviews was from the UK. The exception was studies on case management which were largely from the USA. Collectively the reviews examined 477 research papers. Scott et al (2007) also included 78 non-research items (articles such as policy documents, book chapters, etc). Bunn et al (2007) identified 203 items, Forbes et al (2007) identified 160 items, and Scott et al (2007) identified 192, of which 114 were research-based papers.

Diabetes was the most common item, followed by COPD, asthma and cardiovascular disease (CVD) although there was considerable variation between the reviews in the proportions of items by disease categories. There was some overlap of included items for disease conditions common to one or more reviews although this was fairly minimal. This reflected the differing foci, inclusion criteria and methodologies of the three reviews for screening and retrieving items for inclusion. Most items were evaluative in

¹¹ *Refers to articles or papers*

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nature and also included systematic reviews, descriptive and qualitative papers; there was considerable variation in the proportion of study types and designs.

Care Context: Health care delivery

Interventions by nurses

The reviews reported considerable heterogeneity and overlap in intervention types. Common areas of intervention were:

- Educational interventions to promote self management skills
- Case management and care co-ordination
- Interventions to support continuous disease management (monitoring and therapy adjustment)
- The management of health technology (assessing, prescribing, implementation and safety)
- Psychological support (varying from communication to applied psychological methods)
- The management of the care system (access, onward referral, discharge planning)
- The provision of outreach nursing and home-based support

The use of protocols and evidence based guidelines seemed to be more common for some conditions, such as diabetes, than others (Bunn et al 2007). Classification according to Kaiser Permanente (KP)¹² levels of care showed that nursing interventions were active at all levels of this vertical model. However, there was variation within and between disorders in the contribution of nurses at and across the different levels of this model. There was a preponderance of items relating to the specialist disease management levels. Health promotion and self care interventions providing patient education were mostly reported for secondary or tertiary prevention, employed different approaches and varied between disorders. The evidence for interventions of more recently legislated authority by nurses in the UK, such as nurse prescribing, is embryonic.

Case management, which in the US is sometimes regarded as a component of disease management, was described in various ways and was often poorly defined. The reported interventions carried out by nurses are complex and involve inter-related components that do not easily identify 'active' elements. The levels and types of intervention may reflect the degree of complexities and chronic disability in conditions.

The types and roles of nurses in chronic disease management

Specialist nurses, practice nurses and designated nurse case managers (from a variety of professional nursing backgrounds) were the most commonly identified providers of care for CDM in this literature. They deliver interventions in a variety of settings mostly in the community (for example the patient's own home), primary care or hospital outpatient clinics with limited examples in inpatient settings. They also work across

¹² Department of Health. 2005b. *Supporting People with Long Term Conditions. An NHS and Social care Model to support local innovation and integration.* DH: London

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primary/secondary sectors (cross boundary) with the aim to improve the interface between primary and secondary care (i.e. specialist hospital-based nurses working in primary care).

There is an intrinsic heterogeneity in the nurses described with diverse roles and functions, reflecting a lack of standardisation. The contribution of nurses is influenced by funding, infrastructure, location, education, clinical expertise and other contextual factors.

Nursing roles are described as expanding hierarchically, for example clinical specialist and nurse consultant roles, as well as laterally (across boundaries or settings). This includes substitution for doctors, for example through nurse-run clinics, expansion through cross boundary working and advanced practice such as leading new service developments. Training pathways for taking on new roles are diverse and unclear and, in many cases, nurse specialists work with widely different levels of responsibility and professional autonomy.

Intra-professional relationships are increasingly important. With the shift towards primary care, practice nurses are taking a lead in the day-to-day management of some disorders such as diabetes and COPD. However, there were many examples showing that these roles are dependent on the provision of ongoing clinical support and education from specialist nurses. In some disorders, such as MS, there is little evidence of a primary care focus with specialist nurses providing most support. There was also some evidence of sub-specialisation with nurses with other problem specific roles providing intermittent input in areas such as continence, pain and tissue viability

The case management function of nurses was an emerging area with some evidence showing that the nursing workforce was being redesigned to expand this function. A key driver for this has been the Government's target for reducing emergency admissions in England. However, this function was poorly defined, as reflected in the multiple titles applied to the role (such as community matrons, advance primary nurses, case or care managers, care co-ordinators) and in the varying foci of case management between disorder specific and generic case management.

The reviews identified very little literature on the role of midwives and health visitors in CDM and there are very few accounts of general nursing care.

Service context: Health care organisation

Nurses contribute to the management of care systems at all levels. They are involved in the organisation of care as well as at the 'micro' level of interaction between nurses, patients and other professionals. They have a role in workforce and service development through improving access and developing new interfaces/systems between services. Nurses' roles in health technology include managing and monitoring care performance although the level of their involvement is unclear. Service configurations, structures and resources appear to influence the continuity of care. The regulation of care systems for each type of disease and the nursing contribution to different levels of this system is unclear (Forbes et al 2007).

Evidence of impact

Overall the level of evidence examining the impact of nursing is of poor quality (reflecting a low investment in nursing research). There is little standardisation of interventions with often little explicit linkage to the outcome measures adopted. The problem is compounded by a lack of clarity, in many studies comparing nurses with other health care professionals, as to whether the desired outcome is equivalence (e.g. nurses are as safe and effective as doctors) or evidence of increased effectiveness. In addition, although many studies have shown that nurses can provide safe and effective care, they often do not examine the contribution of nursing activities specifically. Nevertheless, the reviews identified examples showing how nurses contribute to care structures, processes and clinical outcomes. Economic benefits were also reported particularly in relation to the minimisation of acute care use (hospital stay and emergency care). In addition the reviews identified evidence indicating that the contribution of nurses is likely to have benefits in terms of quality of care, such as patient satisfaction, care experience and continuous support.

There is evidence that nurses can safely and effectively run out-patient clinics (for example anticoagulant and cardiovascular clinics). In primary care, specialist nurses and practice nurses qualified in asthma care appear to improve process of care, clinical outcomes and reduce costs. Hospital at home schemes appeared to be safe for people with mild COPD, although their effects on people with severe COPD are unknown, and nursing outreach programmes may reduce hospital admissions in people with severe disability. The contribution of nurses may be effective in improving clinical outcomes and produce benefits for people with diabetes, which has modifiable factors and a clear care management process compared with COPD or MS.

The nursing contribution appeared to improve access, especially for vulnerable or hard to reach groups, and service infrastructure/care systems by responding to gaps and quality of services (Forbes et al 2007). Nursing focused service models designed to improve the interface between primary and secondary care through 'shared care' appeared to improve communication between health professionals (Bunn et al 2007; Scott et al 2007).

Barriers and facilitators to the contribution of nurses in CDM

The evidence on barriers and facilitators to the nursing contribution reflects common factors previously identified as influencing innovation and change in organisations¹³. The issue identified in these reviews, which is, perhaps, specific to nursing, is that of autonomy. Overall the reviews identified the following key factors that facilitated the contribution of nurses to CDM:

¹³ Isles V and Sutherland K. 2002. *Change management - Review of existing research evidence on change management and quality improvement*. Available at <http://www.sdo.lshtm.ac.uk/files/adhoc/4-review.pdf>

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- Organisational preparation for new roles
- Good communication and collaboration between health professionals and primary/secondary interface
- Responsive doctors providing high levels of professional autonomy for nurses
- Adequate resources
- Continuous professional development
- Role clarity
- User involvement (few examples of nurses involving users in their care are given by Forbes et al (2007) with little material describing nurses' consultations with service users in a formal way to promote better care)

The barriers identified reflect the converse of the facilitating factors plus some other contextual features and inter professional issues:

- Constant reconfiguration of services and roles
- Instability in resources
- Lack of opportunities for training to expand nurses' roles
- Work force changes
- Lack of autonomy and recognition of expertise
- Poor interface between primary and secondary care
- Lack of managerial support
- Inappropriate use of nurses' time
- Professional concerns when new roles are not understood

Patient perspectives

The literature suggests that, when asked, patients report general satisfaction with the care provided by nurses, in particular patients view nurses as more approachable and accessible than doctors and value their consultation styles. However, the evidence also suggests that patients do not see nurses as currently able to provide all their chronic disease management needs particularly in relation to medication, although this perception does not come from studies specifically examining patient perspectives on nurse prescribing. Patients also value the appropriateness and timeliness of educational support from nurses although the reviews found that patients sometimes receive conflicting information or advice from different health care professionals. In addition, patients may have a differing view to professionals on what their own responsibility is in managing their condition.

Policy context

All three reviews focused on the English policy (which adopted the Kaiser Permanente Model and community matrons) in line with SDO conventions. Scott et al's review of the policy literature was part of the evidence review and was based on assumptions underlying English policy, rather than the UK.

Healthcare services internationally are seeking new ways to cope with the challenges posed by the growing number of people who are living with long-term conditions. A common policy goal is to reduce the number and length of hospital attendances and admissions that these people have historically experienced. The literature reflected this, and provided examples of how nurses are helping to increase the capacity and capability of the primary

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care sector through nurse-led clinics, role expansion and the provision of new and innovative ways of working to meet complex needs (such as outreach services and 'hospital at home' provision). The nurse is identified as a key provider in English policy and the community matron was identified as the key worker in supporting people with complex and long-term problems.¹⁴ This was influenced by research and practice on case management in the United States. There were also some examples of primary care based nurses taking greater responsibility for referrals and managing case loads across organisational boundaries, in line with government policy on the care of people affected by long-term conditions. Department of Health policy is aimed at promoting new and innovative roles for nurses, accompanied by a drive to modernise nursing careers which addresses the identified need for nurses to receive appropriate training and support. Current policy also emphasises the importance of user involvement in service developments, but there were few accounts of this in the literature.

Limitations and methodological challenges

A number of methodological limitations were reported by the three reviews including poor quality studies, heterogeneity of interventions and short-term outcomes. The studies demonstrated a lack of clarity about whether interventions aimed to demonstrate equivalence or benefit or what elements of the complex interventions were being compared. There is also minimal empirical work that distinguishes between different approaches to providing nursing care. Information on a theoretical basis, content and intensity of interventions which are likely to influence effectiveness were not often available. There were few cost effectiveness evaluations or full economic appraisals. In addition to the limitations identified by each review, there were methodological challenges integrating the three reviews. The reviews each had a different theoretical approach and focus, different conceptual frameworks and adopted different methodologies for the conduct and synthesis of their reviews. This presented challenges for integration and made the identification of unifying concepts problematic. Moreover, the variations in the proportions of study types and how they relate to the impact of nursing contributions evaluated is unknown. The literature is restricted to the evidence base drawn from the three reviews with their individual distinct focus and other relevant studies on CDM may therefore have been excluded.

Conclusions

The evidence from the three reviews suggests that the nursing contribution to chronic disease management may improve quality of care, such as

¹⁴ *Department of Health. Liberating the talents. Helping primary care trusts and nurses to deliver the NHS Plan.* London: Department of Health; 2002. www.dh.gov.uk/assetRoot/04/07/62/50/04076250.pdf

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patient satisfaction, care experience and continuous support. There is also evidence to show that nurses are integral to the structure and process of CDM and that they help implement care with proven clinical outcomes. It has also been shown that in some circumstances nurses provide care that is at least as safe and effective as that provided by doctors, although the cost effectiveness of many interventions is unproven.

Implications for policy, organisation and service delivery

The implications for policy, organisation and service delivery are that whilst nurses make a positive contribution to chronic disease management, several key issues need to be addressed. For policy makers, practitioners and managers, areas of policy, organisation and service delivery relevant to nursing contribution and supported by review evidence include:

1. Standardising nursing roles and functions through a consensus dialogue involving patients and other professionals. It will be important to recognise that different disorders and care contexts have different requirements. There will not be a 'one role fits all' solution. It is particularly clear from the reviews that both generic and specialist roles are required and while primary care can manage much of the care of people with long-term conditions they will require the support of specialist roles if they are to maintain care standards and incorporate new technologies and practices. Furthermore, it must be recognised that different disorders, specifically degenerative disorders, require a different approach as they may be less sensitive to target models based on disease outcomes
2. Appropriate training
3. Improving levels of professional autonomy for nurses
4. Identifying the types of 'professionals' suitable for a case management role, preparing and supporting nurses for a case management role in complex organisational infrastructures
5. Development and evaluation of new roles in joint practice based services of specialist nurse and practice nurse
6. Involving patients and users in the design of interventions, particularly patient reported outcome measures
7. Preparing and empowering GPs and relevant stakeholders for new developing roles, ensuring adequate support for nurses through collaborative working
8. Change management to address the barriers and facilitators for the development of effective models of nursing contribution

Gaps in evidence and recommendations for research

This synthesis of the three reviews shows that while there are many nursing activities in CDM, very few of these have been properly developed or evaluated. If the nursing contribution is to be properly developed and understood an ongoing programme of research is required to develop and test specific activities. The tendency has been for whole role evaluations or comparisons that provide little enduring knowledge to help nurses, policy makers or health care commissioners determine cost-effective approaches to care. The following recommendations are made for future research and will be particularly useful for practitioners, educators and researchers:

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1. The need to assess the effectiveness of specific nursing activities and interventions in relation to patient centred outcomes that have a proven relationship to those activities (this may require proof of concept studies). The activities should be clustered to reflect the main areas of activity identified in the reviews (health promotion; self-care support; case management; interventions to support continuous disease management; health technologies; psychological interventions; system level initiatives; and interface interventions like outreach nursing and home-based support.
2. The need to identify and test the efficiency and patient experience of different assessment systems for identifying needs and factors that are important in meeting those needs.
3. The need for user involvement in the development of nursing interventions and tools for measuring patient reported outcomes.
4. The need to develop methods appropriate for assessing nursing interventions and tools for measuring patient (and carer) outcomes.
5. The need to develop, compare and evaluate standardised core components for case management to be deployed in different care contexts (disorder specific, generic and older frail).

These initiatives would best flourish in integrated, ongoing, collaborative (inter-professional and inter organisational) research programmes located in diverse settings with facilitated access to patients and carers.

New insights of nursing contribution in CDM

Two reviews proposed evolving models of nursing contribution based on their evidence base. Forbes et al (2007) suggested an evolving model of nursing contribution to continuing care management with the nurse functioning in her relationship with the patient as an educator; interpreter; monitor; modulator and referrer. Scott et al (2007) acknowledged the inherent difficulties in integrating the medical, psychological and social models for evaluating the nursing contribution in chronic disease management and suggested a trajectory framework. It involves 'supportive assistance', an ongoing process that takes into account of the whole trajectory, shifting in accordance with changes in the patient's illness and circumstances. Such models may be useful in placing nursing services appropriately to increase the benefits of their contributions.

Despite the limitations, our review involved extensive coverage and provides an understanding, from different perspectives, of the current evidence on the nursing contribution to chronic disease management. It generates insights into the importance of process and context to outcome and also gives due weight to the perspectives of research participants. An overview such as this review provides a sense of 'added value' to the overall approaches and messages from reviews that all explore the nursing contribution to CDM in very different ways. Summaries of reviews are designed to be accessed by a variety of users⁶ and those requiring detailed syntheses, can refer to the original reviews and their primary studies. The process of drawing together, mapping and synthesising evidence from the reviews enabled us to pull together common findings and to reach an overall consensus on key issues. Further findings from their current empirical work examining existing models and determining future nursing service requirements may provide more insights into future models for nursing in England.

Disclaimer:

This report presents independent research commissioned by the National Institute for Health Research (NIHR). The views and opinions expressed therein are those of the authors and do not necessarily reflect those of the NHS, the NIHR, the SDO programme or the Department of Health

Addendum:

This document is an output from a research project that was commissioned by the Service Delivery and Organisation (SDO) programme, and managed by the National Coordinating Centre for the Service Delivery and Organisation (NCCSDO), based at the London School of Hygiene & Tropical Medicine.

The management of the 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. Although NETSCC, SDO has conducted the editorial review of this document, we had no involvement in the commissioning, and therefore may not be able to comment on the background of this document. Should you have any queries please contact sdo@southampton.ac.uk.