The nursing contribution to chronic disease management: a whole systems approach

Executive summary for the National Institute for Health Research Service Delivery and Organisation programme

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Executive Summary

Background

Transforming the delivery of care for people with Long Term Conditions (LTCs) requires understanding about how health care policies in England and historical patterns of service delivery have led to different models of chronic disease management (CDM). It is also essential in this transformation to analyse and critique the models that have emerged to provide a more detailed evidence base for future decision making and better patient care. Nurses have made, and continue to make, a particular contribution to the management of chronic diseases. In the context of this study, there is a particular focus on the origins of each CDM model examined, the processes by which nursing care is developed, sustained and mainstreamed, and the outcomes of each case study as experienced by service users and carers.

Aims

To explore, identify and characterise the origins, processes and outcomes of effective CDM models and the nursing contribution to such models using a whole systems approach

Methods

The study was divided into three phases:

Phase 1: Systematic mapping of published and web-based literature.

Phase 2: A consensus conference of nurses working within CDM. Sampling criteria were derived from the conference and selected nurses attended a follow up workshop where case study sites were identified.

Phase 3: Multiple case study evaluation

Sample: 7 case studies representing 4 CDM models. These were: i) public health nursing model; ii) primary care nursing model; iii) condition specific nurse specialist model; iv) community matron model.

Methods: Evaluative case study design with the unit of analysis the CDM model (Yin, 2003):

- semi-structured interviews with practitioners, patients, their carers, managers and commissioners
- documentary analysis
- psycho-social and clinical outcome data from specific conditions
- children and young people: focus groups, age-specific survey tools.

Benchmarking outcomes: Adults benchmarked against the Health Outcomes Data Repository (HODaR) dataset (Currie *et al,* 2005). Young people were benchmarked against the Health Behaviour of School aged Children Survey (Currie *et al,* 2008).

Cost analysis: Due to limitations in the available data, a simple costing exercise was undertaken to ascertain the per patient cost of the nurse contribution to CDM in each of the models, and to explore patterns of health and social care utilisation.

Analysis: A whole system methodology was used to establish the principles of CDM. **i) The causal system** is a "network of causal relationships" and focuses on long term trends and processes. **ii) The data system** recognises that for many important areas there is very little data. Where a particular explanatory factor is important but precise data are lacking, a range of methods should be employed to illuminate each factor as much as possible. **iii) The organisational whole system** emphasises how various parts of the health and social care system function together as a single system rather than as parallel systems. **iv) The patient experience** recognises that the whole system comes together and is embodied in the experience of each patient.

Key findings

While all the models strove to be patient centred in their implementation, all were linked at a causal level to disease centric principles of care which dominated the patient experience.

Public Health Model

- The users (both parents and children) experienced a well organised and coordinated service that is crossing health and education sectors.
- The lead school nurse has provided a vision for asthma management in school-aged children. This has led to the implementation of the school asthma strategy, and the ensuing impacts including growing awareness, prevention of hospital admissions, confidence in schools about asthma management and healthier children.

Primary Care Model

- GP practices are providing planned and routine management of chronic disease, tending to focus on single diseases treated in isolation. Care is geared to the needs of the uncomplicated stable patient.
- More complex cases tend to be escalated to secondary care where they may remain even after the patient has stabilised.
- Patients with multiple diagnoses continue to experience difficulty in accessing services or practice that is designed to provide a coherent response to the idiosyncratic range of diseases with which they present. This is as true for secondary care as for primary care.
- While the QOF system has clearly been instrumental in developing and sustaining a primary care nursing model of CDM, it has also limited the scope of the model to single diseases recordable on a register, rather than focus on patient centred care needs.

Nurse Specialist Model

- The model works under a disease focused system underpinned by evidence based medicine exemplified by NICE guidelines and NSF's.
- The model follows a template drawn from medicine and sustainability is significantly dependent on the championship and protectionism offered by senior medical clinicians.
- A focus on self-management in LTCs gives particular impetus to nurse-led enablement of self-management.
- The shift of LTC services from secondary care to primary care has often not been accompanied by a shift in expertise.

Community Matron Model

- The community matron model was distinctive in that it had been implemented as a top down initiative.
- The model has been championed by the community matrons themselves, and the pressure to deliver observable results such as hospital admission reductions has been significant.
- This model was the only one that consistently resulted in open access (albeit not 24 hours) and first point of contact for patients for the management of their ongoing condition.

Survey Findings

Compared to patients from our case studies those within HODaR visited the GP, practice nurse or NHS walk-in centres more, but had less home visits from nurses or social services within the six weeks prior to survey. HODaR

patients also took significantly more time off work and away from normal activities, and needed more care from friends/ relatives than patients from our study within the last six weeks. The differences between the HODaR and case study patients in service use cannot easily be explained but it could be speculated when referring to the qualitative data that the case study patients are benefiting from nurse-led care.

Cost analysis –

The nurse costs per patient are at least ten times higher for community matrons conducting CDM than for nurses working in other CDM models. The pattern of service utilisation is consistent with the focus of the community matron role to provide intensive input to vulnerable patients.

Conclusions

Nurses are spearheading the kind of approaches at the heart of current health policies (Department of Health, 2008a). However, tensions in health policy and inherent contradictions in the context of health care delivery are hampering the implementation of CDM models and limiting the contribution nurses are able to make to CDM. These include:

- data systems that were incompatible and recorded patients as a disease entity
- QOF reinforced a disease centric approach
- practice based commissioning was resulting in increasing difficulties in cross health sector working in some sites
- the value of the public health model may not be captured in evaluation tools which focus on the individual patient experience.

Recommendations

Commissioners and providers

1. Disseminate new roles and innovations and articulate how the role or service fits and enhances existing provision.

2. Promote the role of the nurses in LTC management to patients and the wider community.

3. Actively engage with service users in shaping LTC services to meet patients' needs.

4. Improve the support and supervision for nurses working within new roles.

5. Develop training and skills of nurses working in the community to enable them to take a more central role in LTC management.

6. Develop organisations that are enabling of innovation and actively seek funding for initiatives that provide an environment where nurses can reach their potential in improving LTC services.

7. Work towards data systems that are compatible between sectors and groups of professionals. Explore ways of enabling patients to access data and information systems for test results and latest information.

8. Promote horizontal as well as vertical integration of LTC services.

Practitioners

1. Increase awareness of patient identified needs through active engagement with the service user.

2. Work to develop appropriate measures of nursing outcomes in LTC management including not only bureaucratic and physiological outcomes, but patient-identified outcomes.

Implications of research findings

1. Investment should be made into changing patient perceptions about the traditional division of labour, the nurses' role and skills, and the expertise available in primary care for CDM.

2. Development and evaluation of patient accessible websites where patients can access a range of information, their latest test results and ways of interpreting these.

3. Long-term funding of prospective evaluations to enable identification of CDM outcomes.

4. Mapping of patient experience and patient satisfaction so that the conceptual differences between these two related ideas can be demonstrated.

5. Development of appropriate measures of patient experience that can be used as part of the quality outcome measures.

6. Cost evaluation/effectiveness studies carried out over time that includes national quality outcome indicators and valid measures of patient experience.

7. The importance of whole system working needs to be identified in the planning of services.

8. Research into the role of the health visitor in chronic disease management within a public health model.

Disclaimer

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Addendum

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