



Success and failure in integrated models of nursing for long term conditions: Multiple case studies of whole systems

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ABSTRACT

Background: Current projections indicate that the UK faces a 252% increase in people aged over 65 with one or more long term conditions (LTC) by 2050. Nurses, managing their own caseloads and clinics, working across sectors and organisational boundaries and as part of a wider multi-disciplinary team, are frequently seen as key to managing this growing demand. However, the evidence base informing the nursing role in managing LTC, the most effective configuration of the multi-disciplinary team and the policy evidence relating to the infrastructure required to support cross organisational working, remains weak.

Objectives: To explore, identify and characterise the origins, processes and outcomes of effective chronic disease management models and the nursing contributions to such models.

Design: Case study whole systems analysis using qualitative interview methods.

Settings: Two community matron services, two primary care (GP) practice nursing services, two hospital based specialist nursing services were purposefully sampled from across England and Wales.

Participants: Selection criteria were derived using a consensus conference. The nurses in the service, all patients and carers on the caseload, members of the multi-disciplinary team and stakeholders were invited to participate.

Methods: Semi-structured interviews with all participants, thematic analysis within a whole system framework.

Results: The study found high levels of clinical nursing expertise which in the case of the community matrons was meeting the aim of reducing hospital admissions. Both the primary care and hospital nurse specialist indicate similar levels of clinical expertise which was highly valued by medical colleagues and patients. Patients continued to experience fragmented care determined by diagnostic categories rather than patient need and by the specific remit of the clinic or service the patient was using. Patient data systems are still organised around the impact on services and prevalence of disease at an individual level and not around the patient experience of disease.

Conclusion: Nurses are making a major contribution to meeting the policy objectives for long term conditions. Primary care nurses and hospital nurse specialists do broadly similar roles. The scope of the nursing roles and services studied were idiosyncratic, opportunistic and reactive, rather than planned and commissioned on an analysis of local population need.

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What is already known about the topic?

- Reducing mortality from chronic illness and maintaining health among those experiencing long term conditions requires health care professional engagement with lifestyle factors, interventions to support self-care and the acquisition of genuine patient expertise encompassed in the long term conditions model of care.
- The majority of people with long term conditions are able to self-care with carefully targeted professional input.
- There is evidence of improved outcomes from enhancing nurse leadership and nurse led case management.
- The transfer of nurse-led models of care developed in different health policy contexts, particularly the US, into the UK setting, has not replicated the patient outcomes demonstrated elsewhere.
- The evidence base informing the nursing role in managing long term conditions, the most effective configuration of the multi-disciplinary team and the policy evidence relating to the infrastructure required to implement the long term conditions model of care, remains weak.

What this paper adds

- The study identifies shared features of the expertise and behaviours of primary care nurses, hospital based nurse specialists and community matrons in enabling effective self-management support for patients with long term conditions.
- Hospital nurse specialist and primary care nursing service models evolved organically interfacing locally with disease orientated systems underpinned by evidence based medicine as exemplified in nationally endorsed guidelines, service frameworks and the Quality Outcomes Framework (which governs the quality and funding of primary care services in the UK). Collectively these create a web of structural relationships which hamper the development of nursing roles to respond effectively to the needs of patients with long term conditions.
- The structural determinants of the community matron role are rooted in the principles of long term condition care models derived from a predominately US evidence base using principles of population stratification. Community matrons demonstrated many of the behaviours identified to be supportive of the long term conditions model of care. However, community matrons had to work hard to establish their legitimacy in the local health community and lacked championship by powerful professional colleagues.
- Despite exemplary clinical expertise on the part of the nursing services, the experience of patients with a range of different conditions was remarkably similar and remains rooted in a disease orientated, fragmented model of care. Changing care models to meet the needs of patients with long term conditions requires a systemic rather than individualistic approach to service development.

1. Introduction

This paper provides an analysis of the contribution nurses make to the implementation of the aims of the UK

Department of Health Long Term Conditions (LTC) strategy (Department of Health, 2005a). Current projections indicate that the UK faces a 252% increase in people aged over 65 with one or more LTCs by 2050 (Department of Health, 2011). Effective management of LTCs challenges many of the assumptions that underpin a disease orientated model of care dominant in western health care delivery systems (Department of Health, 2004a; Harwood et al., 2004; Ham and Oldham, 2009; World Health Organization, 2002). Reducing mortality from chronic illness and maintaining health among those experiencing LTCs requires engagement with lifestyle factors (Wanless, 2002) and the acquisition of genuine patient expertise (Thorne, 2008). This is difficult to address in acute care settings which are characterised by disease orientated, episodic and time limited engagement with the patient, focused on early discharge back into the community.

Evidence indicates improved outcomes from enhancing nurse leadership (Bodenheimer et al., 2005) and nurse led case management (Sargent et al., 2007). There is evidence that people with LTCs are able to self-care with carefully targeted professional input (Berzins et al., 2009). A range of US models piloted within the UK such as Kaiser Permanente and Pursuing Perfection (Department of Health, 2004b) and the Expert Patient Programme (Rogers et al., 2006; Wilson, 2008) have the facilitation of patient self-management as a key aim (Department of Health, 2001, 2005b). Many of the UK initiatives build on evidence of the effective management of LTCs pioneered in the US (Wagner, 1998; Boaden et al., 2006; Wagner and Groves, 2002; Department of Health, 2005b, 2008). Nurses, managing their own caseloads and clinics, working across sectors and organisational boundaries and as part of a wider multi-disciplinary team, are frequently seen as key to managing increasing demand (Bodenheimer et al., 2005; Department of Health, 2005a, 2008). However, the transfer of nurse-led models developed in different health policy contexts, particularly the US, into the UK setting has not replicated the patient outcomes demonstrated elsewhere (Boaden et al., 2006; Wilson et al., 2006; Gravelle et al., 2007). The evidence base informing the nursing role in managing LTC, the most effective configuration of the multi-disciplinary team and the policy evidence relating to the infrastructure required to support cross organisational working, remains weak (McHugh et al., 2009).

2. Aim of study

The PEARLE study (Prevention, Enabling Self Care and cARe in Long Term Conditions Evaluation) aimed to explore, identify and characterise the origins, processes and outcomes of effective chronic disease management models and the nursing contributions to such models.

3. Methodology

Results from the PEARLE study specifically relating to public perception of the nurse's role in long term conditions are reported elsewhere (Wilson et al., 2012). The findings presented here are taken from an analysis of six case study sites (see Table 1) representing three of the

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