Self-care and Case Management in Long-term Conditions: The Effective Management of Critical Interfaces

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

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Executive summary

Background

It has been estimated that a large number of people suffer from a long-term condition and many of these are older people and significant users of health and social care resources. Three levels of care are specified in long-term conditions policy guidance: supported self-care for the majority of the chronic care population; disease/care management for patients who have multiple long-term conditions; and case management for those patients who are very high intensity users of unplanned secondary care. Additionally, self-care has been identified as integral to the maintenance of health and well-being for people with long-term conditions. The role of community matron was developed within the NHS and social care model for long-term conditions to undertake the case management role and within this assess the extent to which self-care support services might contribute to patient welfare.

Aims

This research had three aims. The first was to map current provision of NHS case management services in primary care for people with long-term conditions. A second aim was to classify programmes on observable features of case management implementation with particular focus upon the integration of care between primary and secondary care and between health and social care. Third, the research sought to identify the extent and nature of self-care initiatives within this service and to investigate the role of self-care initiatives as determinants of entry and, particularly, exit to the case management services.

Methods

A mixed method approach to data collection was undertaken. First, an extensive review of the literature was completed to provide a critical appraisal of the evidence relating to: case management by nurses for adults with long-term conditions; interventions supporting self-care typical of the potential case-managed population; and how case management might support self-care services. Second, a national postal survey of case management for people with long-term conditions and self-care services was undertaken. Third, findings from the survey were compared with previous studies of local authority care management arrangements for adults. Fourth, case studies of long-term conditions services in four primary care trusts were undertaken by means of a semi-structured interview with the service manager and a focus group of practitioners within each. Finally, a user consultation exercise was undertaken comprising four focus groups with the purpose of involving participants in analysing and interpreting the results of the research.

Findings

Literature review

Nurse case management for people with long-term conditions was variably implemented. Case managers usually undertook key tasks such as assessment, care planning and implementation of the care plan and sometimes also monitoring and reviews. Implementation could also vary in terms of therapeutic interventions, illness management and care co-ordination, in addition to target client groups and available services. The variability between studies reflected different models of care, in addition to local implementation issues such as target client groups and the range of services at the disposal of the case manager.

Self-care interventions are often delivered using patient education, consisting of a combination of written materials and teaching sessions. Typically this is through a multi-disciplinary approach or by use of trained volunteers with experiential knowledge and can be condition specific or general, for example the Expert Patient Programme. Only modest evidence of benefit from these self-care interventions was identified with improved outcomes most likely in self efficacy, knowledge of illness and physical functioning. Self-care support within the nurse case management interventions tended to be less formalised, more individualised and delivered one-to-one in the home. Evidence relating to the impact of case management upon self-care related outcomes was inconclusive although an improvement in treatment adherence and reduced health service use was noted.

Survey

The national survey revealed considerable similarity between the objectives of the case management services and that self-care services were available in most areas, primarily accessible advice and information, generic self-care support training and disease specific self-care support training, although rarely used by case managed patients. Most case managers were nurses based in single discipline teams in primary care. Few were based in integrated health and social care settings although about half of the case management services reported formal links with local authority adult social care services. Case management services were more likely to have formal links with other primary care services such as community nursing and intermediate care. Links with secondary care services were mainly with specialist disease nursing and were rarely formalised with old age psychiatry and hospital pharmacy services. Most services reported an average active caseload per worker of fewer than fifty with referral criteria agreed locally incorporating the number of hospital admissions, age and disease. About half targeted their service on specific diseases or conditions. Assessment, implementation and monitoring of the care plan and providing patient education were almost universally reported as being part of the case manager role but it rarely incorporated financial assessments or budget management incorporating costed elements of the care plan.

A comparison of case and care management in different settings

Similarities in the goals and objectives of primary care trust case management and local authority care management arrangements were noted. The principal

differences reflected policy guidance with the latter emphasising inappropriate care home admission and a care management approach to the majority of users and the former a greater focus on improved health outcomes for patients and a more differentiated response to need apparent in the levels and qualifications of staff providing assistance and the intensity of the support provided.

Case studies

The four sites were selected to reflect different approaches to case management. They were categorised as either high or low on four domains: self-care services the presence of which was common to all; integration with social care services, a differentiated approach within the service and the performance of higher level case management tasks. The assessment of health needs and implementation, monitoring and review of care plans was undertaken in all sites. Three also reported care planning and arranging services. All provided hands on care and clinical oversight with three out of the four also providing patient advocacy, emotional support and medications review. Variation was, however, reported in terms of caseload size and the extent of integration with local authority adult social care services. All provided generic self-care support and self help groups, three provided advice and information and two provided technology and equipment to support self-care and self-care training, most of these being disease specific. Some self-care support was provided by case managers: all services provided patient education by this means and two contributed to self-care service provision and one to self-care programme development. All case managers referred on to self-care support services, most frequently for accessible advice and condition specific self-care support training.

Service user consultation

The user consultation exercise revealed priorities for service development not reflected in current policy guidance and service provision. In consideration of the range of self-care support services alternative therapies were a popular option and where group support was involved there was a preference for groups of people with the same condition rather than the generic Expert Patient Programme. Furthermore, users considered the provision of practical assistance should be a core element of a case management service.

Conclusions

The findings suggest that the local arrangements for the provision of case management and self-care services within the NHS and social care model for long-term conditions are more complex and less clearly defined than envisaged in policy guidance. Moreover there is considerable variation despite some similarities in arrangements across the country. This relates both to case management practice and its interface with self-care services which are often both at an early and partial stage of development. Furthermore, from the limited evidence available it would appear that for patients in receipt of case management, self-care support, if appropriate, is more likely to be part of the care plan provided by a nurse practitioner and not as a single response provided by other means. These

conclusions from primary data collection reflect those from the extensive literature review.

The development of case management in primary care trusts replicates earlier findings relating to the development of care management arrangements in local authority adult social care services although the former appear to be more targeted on people with complex needs. Furthermore, there is little evidence of integration between the two services, a pre-requisite to improving the patient experience.

Recommendations

Three broad areas for further research are identified. The first relates to the interface between self-care services and case management embracing the nature of self-care support, target groups and appropriate time frame for service receipt; patient pathways within the long-term conditions service; and the potential of self-care services to support carers. A second relates to programme fidelity within case management services and particularly the role of care plans and outcomes for patients and carers of different approaches. The third is more speculative, anticipating future service developments, specifically policy guidance relating to personal health budgets and the requirement for a single professional to promote access to all services identified in a care and support plan.

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

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