ABC of psychological medicine

Organising care for chronic illness

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A major and increasing task for health services is the management of chronic illness. Although the details of chronic illness management will depend on the illness in question, many of the principles are common to all chronic conditions.

Principles of effective management

Whatever health services may offer, most of the day to day responsibilities for the care of chronic illness fall on patients and their families. Planners and organisers of medical care must therefore recognise that health care will be most effective if it is delivered in collaboration with patients and their families. To enable patients to play an active role in their care, health services must not only provide good medical treatment but also improve patients' knowledge and self management skills. This can be done by supplementing medical care with educational and cognitive behavioural interventions. Chronic disease treatment programmes have tended to underestimate the need for this aspect of care, and, consequently, many treatment programmes have been psychologically naive and, as a result, less effective than they could have been.

Services also need to be not merely reactive to patients' requests but proactive with planned follow up. Finally, to be most efficient, interventions are best organised in a stepped fashion—that is, the more complex and expensive interventions are given only when simpler and cheaper ones have been shown to be inadequate or inappropriate.

Collaboration with patients and families

To win the collaboration of patients and their families, those providing care need to negotiate and agree on a definition of the problem they are working on with each patient. They must then agree on the targets and goals for management and develop an individualised collaborative self management plan. This plan should be based on established cognitive behavioural principles and on the evidence relating to the management of the chronic condition.

In order to implement collaborative care, patients and their families require access to the necessary information and services to enable them to play a full and informed role. The need for collaborative care in which patients play an active role has been highlighted in Britain with the development of the concept of the "expert patient."

Encouraging self care

Active self care is critical to the optimal management of chronic illness. Interventions to optimise self care are based on cognitive behavioural principles.

They start with an assessment of patients' attitudes and beliefs about their illness and their chosen coping behaviours. This assessment then guides the provision of information, the resolution of misunderstandings and misinterpretations, and collaborative goal setting. These are agreed between patient and members of the healthcare team.

The outcome of this initial assessment takes the form of a personal action plan, a written agreement between those delivering care and the patient. The patient keeps a copy of the plan, and the healthcare team keeps another. The plan can be written on brief, standardised forms. The plan is not static but is

Treating chronic conditions must involve the family

Common elements of effective chronic illness management

- Collaboration between service providers and patients
- A personalised written care plan
- Tailored education in self management
- Planned follow up
- Monitoring of outcome and adherence to treatment
- Targeted use of specialist consultation of referral
- Protocols for stepped care

Principles of collaboration

- Understanding of patients' beliefs, wishes, and circumstances
- Understanding of family beliefs and needs
- Identification of a single person to be main link with each patient
- Collaborative definition of problems and goals
- Negotiated agreed plans regularly reviewed
- Active follow up with patients
- Regular team review

The UK "expert patient" programme*

- Encouragement of self care protocols, nationally and locally
- Development of electronic and written self care material
- Training programmes, national and local
- Integrating self care into local health planning
- Nurse led telephone service (NHS Direct)

* From; Department of Health. *The expert patient: a new approach to chronic disease management for the 21st century* (www.ohn.gov.uk/ohn/people/expert)

developed over time: the initial goals and the care plan designed to achieve them are refined in view of the patient's progress and the identification of factors that are either helpful or unhelpful in achieving the desired outcome.

Active follow up

The personal action plan guides the patient's follow up contacts. Active planned follow up ensures that the plan is carried out and that modifications to it are made as needed. These steps are repeated in an iterative, ongoing, and flexible way rather than all at once in a single visit. Because the care of chronic illness is a long term process, the work of supporting self care does not need to be done all at once but can be spread over many contacts.

Individualised stepped care

Stepped care provides a framework for using limited resources to greatest effect. Professional care is stepped in intensity—that is, it starts with limited professional input and systematic monitoring and is then augmented for patients who do not achieve an acceptable outcome. Initial and subsequent treatments are selected according to evidence based guidelines in light of a patient's progress.

The principle of increasing intensity of professional input for those who do not respond to initial management is familiar in primary care. However, organised stepped care requires the systematic monitoring of progress and higher levels of coordination between specialist care, care management, and primary care than generally exist. The primary care team, a specialist consultant (when needed), and a care manager (when needed) work together to provide the level of professional support needed to achieve a favourable outcome. Stepped care is individualised according to each patient's preferences and progress.

Skills required by those delivering care

The team providing care must not only be familiar with a patient's condition but must also possess the psychological skills to help the patient achieve self care. They also need access to specialists in psychological and psychiatric management to provide supervision and consultation in selected cases. The necessary psychological skills include

- Anxiety management
- Recognition and treatment of depression
- Cognitive behavioural analysis
- Cognitive behavioural principles of step by step change
- Ability to monitor patient's progress.

Changes in the organisation of care

Achieving collaboration between healthcare providers and chronically ill patients requires organisational changes in six related areas.

Organisation of care—Clinical leadership should encourage efforts to improve quality, including development of incentives for improved care and reorganisation of acute care to encourage self care.

Clinical information systems—A disease (or disorder) registry should be set up that identifies the population to be served and includes information on the performance of guideline based care, including self care tasks. The registry should permit identification of patients with specific needs, reminder systems, and tailored treatment planning.

Plan for collaborative self care

1 Assessment
- Assess patient's self management beliefs, attitudes, and knowledge
- Identify personal barriers and supports
- Collaborate in setting goals
- Develop individually tailored strategies and problem solving

2 Goal setting and personal action plan
- List goals in behavioural terms
- Identify barriers to implementation
- Make plans that address barriers to progress
- Provide a follow up plan
- Share the plan with all members of the healthcare team

3 Active follow up to monitor progress and support patient

Levels of stepped care

1 Systematic routine assessment and preventive maintenance
2 Self care with low intensity support
3 Care management in primary care
4 Intensive care management with specialist advice
5 Specialist care

Assumptions of stepped care

- Different individuals require different levels of care
- The optimal level of care is determined by monitoring outcomes
- Moving from lower to higher levels of care based on patient outcomes can increases effectiveness and lower costs

Example of changes in organisation of care for patients with diabetes

Organisation of care
- Primary care clinic initiates year long effort to reorganise diabetes care
- Team is set up and meets regularly to make changes, monitor progress, and address obstacles

Clinical information systems
- Team develops a register of all patients with diabetes in the clinic, with records of HbA_{1c} values, eye and foot examinations, and goals and key elements of patients' personal action plans

Delivery system design
- Clinic nurses assigned responsibility for diabetes case management
- Doctors agree to provide planned visits for all diabetic patients at least once a year, including preventive services (such as eye and foot examinations, ordering HbA_{1c} tests, screening for depression)
- Clinic support staff maintain the register and print out a status report before each visit

Decision support
- Team agrees on standard evidence based guidelines and adapts them to clinic and liaison with the specialist diabetic clinic
- Team agrees a standard form for planned visits

Community resources
- Nurse case managers plan training in diabetes self management. The nurses are trained to co-lead the course at regular intervals

Self care support
- Nurse case managers decide that every diabetic patient will have a personal action plan developed within a year
- Each nurse sees one patient a week until this goal is accomplished
- Nurses telephone patients who have not been seen for six months and those who need extra support to achieve their goals

Delivery system design—Practice team roles should be changed in the organisation of visits and in follow up care. Useful innovations include group visits, planned visits, and telephone delivered care.

Decision support—Evidence based practice guidelines and protocols should be made effective by integrating information and reminders into visits. There should be collaborative support from relevant medical specialties.

Community resources—Links should be established with community resources, especially for vulnerable populations such as elderly, low income, and deprived populations.

Self care support—Tailored educational resources, skills training, and psychosocial support are effective. Successful self care programmes rely on collaboration; patient centred interventions for managing illness are especially beneficial.

Is this approach feasible for the large numbers of patients seen in busy primary and secondary care settings? There is growing experience with integrating support for self care to the delivery of routine medical care. Specific techniques such as cognitive behavioural interventions and the use of nurses and other staff as care managers have been found to be both feasible and effective. However, the full implementation of this approach in primary care requires substantial organisational changes. These enable medical and other expertise to be used more effectively and efficiently. They also enable doctors to obtain greater satisfaction in being responsible for higher quality care.

Evidence that it works

Collaborative self care has been used to guide efforts to improve the quality of chronic illness care in many different healthcare settings and for many different chronic conditions including diabetes, heart failure, geriatric care, depression, and asthma. This approach gives patients the confidence and skills for self care and for getting what they need from the healthcare system (that is, becoming active, informed patients). Such effective support of patients is more likely to occur when the providers of care themselves have the information, training, resources, and time to deliver effective interventions (that is, are a well prepared, proactive practice team).

There is now considerable evidence and practical experience that supports fundamental changes in the way we organise and deliver health care to better support patients who are living with a chronic condition. Consequently, we need to include psychological and behavioural expertise as essential supplements to basic medical treatment.

Patient centred care is more than a respectful attitude or a style of clinical interviewing. It means that healthcare systems are organised to maximise the effectiveness of patients to manage their chronic illness themselves.

Psychological medicine will make its full contribution only when an awareness of the importance of psychological and behavioural factors is fully integrated into general medical care.

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The ABC of psychological medicine is edited by Richard Mayou, professor of psychiatry, University of Oxford; Michael Sharpe; and Alan Carson, consultant neuropsychiatrist, NHS Lothian, and honorary senior lecturer, University of Edinburgh. The series will be published as a book in Winter 2002.

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Making evidence based care time and cost effective

Problems
- Time for patient care
- Time for assessing evidence
- Unrealistic patient expectations and demands
- Lack of patient understanding of behavioural basis of self care
- Lack of involvement of patients in clinical decisions
- Lack of professional skills
- Access to disparate community and medical services

Solutions
- Treatment protocols
- Involvement of healthcare team
- Use of self help procedures
- Formalising links with local health, social, and voluntary agencies
- Liaison with specialist medical, psychiatric, and psychological services
- Continuing professional development

Evidence based summary

- Collaborative and adaptive approaches to self care that are structured and integrated into medical services improve outcomes for many chronic diseases
- Systematic setting of therapeutic goals and monitoring of clinical treatment and outcomes are integral to this approach
- Such an approach to health care will often require changes to the way in which teams and primary and secondary care services interact

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Further reading

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