

Effects of lay-led self-care education programmes

- Self-care education programmes can be facilitated by lay people, with or without a chronic condition themselves
- Programmes are based on individuals setting their own goals and address lifestyle changes, symptom management and communication skills
- Typical programmes run weekly 2.5 hour sessions over 6 weeks
- Evidence suggests programmes produce small, short-term improvements in self-efficacy, self-rated health and levels of exercise.
- In the UK, the Expert Patient Programme resulted in small improvements in self-effiacy and quality of life, and was likely to be cost effective.
- There is no evidence that self-care education programmes reduce routine or unplanned health service use

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Background

South Tyneside requested a summary of evidence for the effects of programmes or interventions that they might commission to help people manage their own care.

This evidence note focusses on evidence relating to lay-led self-care education programmes. We have searched DARE, NHS EED and CDSR for relevant systematic reviews and economic evaluations. We have not carried out exhaustive literature searches to identify primary studies but have interrogated reference lists and tracked citations for the identified reviews.

Evidence of effect

We identified two potentially relevant systematic reviews and a scoping review. 1,2,4

Typical content of lay-led self-care education programmes

Goal setting
Problem solving
Lifestyle changes
Identifying resources
Symptom management
Dealing with anger, fear and frustration
Communication with health professionals

A Cochrane review assessed lay-led self-care education programmes for people with a range of chronic conditions.¹ Such programmes are often, although not always, facilitated by people with chronic diseases themselves. Lay programmes can offer less formal education than professionally-led programmes and may facilitate discussions that participants may be reluctant to raise with professionals. Lay people may also provide useful interpretations of health advice for some ethnic groups.¹

The review included 17 randomised controlled trials; the majority were conducted in the USA. The most common interventions were the Arthritis Self-Management Program and the Chronic Disease Self-Management Program (CDSMP) for conditions including diabetes, hypertension, heart disease and stroke. Facilitators were generally lay people, some of whom had a chronic condition (which was not necessarily the same condition as the programme participants). Facilitators in some studies were health professionals or students. Most programmes were delivered over six weekly 2.5 hour sessions.

Overall the review found small, short-term improvements in self-efficacy, self-rated health, cognitive symptom management and frequency of exercise. There was no evidence that lay-led self-care education improved health-related quality of life, or reduced primary care visits and emergency department visits.

A more recent systematic review included 10 randomised controlled trials of the CDSMP for people with a range of chronic illnesses.² Programme sessions typically involved groups of 10-15 people and were conducted in community settings, for example libraries, community or day centres. Two of the included trials were of the UK Expert Patient Programme (based on the CDSMP), which launched in 2001 (see box for details).³

The UK Expert Patient Programme

Delivered by one or two lay facilitators with a chronic condition Six weekly sessions of 2.5 hours Face-to-face sessions, plus educational manual or video Sessions addressed:

- Communicating with health professionals
- Lifestyle change e.g. diet, exercise
- Medication management
- · Psychological issues
- Symptom management
- · Self-management
- Social support

The review found some short-term improvement across a number of health status measures including pain, depression and self-rated health; health behaviour outcomes including exercise and communication with professionals; and self-efficacy. There was no evidence of impact on health care utilisation.

Health economic analysis of the Expert Patient Programme found that it improved health-related quality of life at no increased cost, and was therefore likely to be cost effective. However, there was evidence of increased out-of-pocket costs for patients.³

We also identified a scoping review of the literature about community health champions and other similar roles where volunteers engage in health promotion work within their communities.⁴ Studies were conducted in developed and developing countries; roles typically involved health education, outreach, advocacy and social support; and addressed a range of conditions and health behaviours, including screening and immunisation uptake. The review also looked at the role of community health workers, who typically carried out activities related to healthcare and administered treatment alongside health education.

While this was not a systematic look at the evidence, the authors highlight some positive findings that suggests community health champions and similar roles increase knowledge and awareness of health issues, help people access preventative services and can support positive behaviour change, particularly when working with disadvantaged, low income or minority ethnic communities.⁴

We did not find any systematic reviews that focussed on action learning sets. However, the Faculty of Public Health Medicine has put together a tool kit to support the setting up and running of learning sets on public health.⁵ Steps in getting a learning set started are: agreeing the focus; finding the right facilitator; agreeing the target audience; and sending out information in advance. They also highlight the importance of evaluating each session at its end to help consolidate key learning points and develop future sessions.

Implementation

Over 70% of participants in the Cochrane review of lay-led self-care education programmes were women. A recent systematic review has suggested that men may find self-care support more attractive when it is seen as action-oriented, having a clear purpose, and offering practical strategies that can be integrated into daily life. 6

Many participants in the studies included in the Cochrane review rated their health as reasonably good at baseline. Careful thought needs to be given to targeting courses at those most likely to benefit.

Participants in the UK trials of the Expert Patient Programme were "self-referred" and were therefore interested and committed to developing self-care skills. Particular effort may be required to engage people who are disinclined to participate but who could potentially benefit from such a programme.³ Evaluation of the Expert Patient Programme suggests a programme that fits well with people's existing mechanisms for dealing with their condition is more likely to be successful, and self-care may be improved by addressing people's needs and access to welfare support, as well as focusing on developing self-efficacy.⁷

Recruiting and retaining volunteers will be essential to the success of lay-led education. Contact through community projects and newsletters is likely to be more successful than more formal methods of recruitment.⁴ Managing and training volunteers requires expertise and considerable time commitment.³ Programmes are more likely to be successful where there are good social networks and links in the community.⁴

References

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