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Self-Management of Long Term Medical Conditions for NHS employees: Evaluation of the Improving Working Lives Pilot Project

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Introduction

There is a paucity of research examining the impact of a Long-term Medical conditions (LTMC) on working life (Munir, Leka, & Griffiths, 2003). Munir et al., (2003) found that a half of the participants in their survey reported that their illness affected their work on a daily basis, with some stating that work made their condition worse. One UK study found that amongst people with ankylosing spondylitis, (a form of arthritis with an early age of onset), fatigue was the main challenge to working life (Barlow, Wright, Williams, & Keat, 2001). Other factors were the unpredictability of the condition, pain, and limited mobility. Strategies used to cope with these factors included reducing working hours, changing to less physical jobs, working from home, becoming self-employed, or taking early retirement. It is noteworthy that none of these strategies focused on developing better management of symptoms in the work environment.

The self-management of a LTMC implies monitoring and managing symptoms, adhering to treatment regimes, maintaining a healthy lifestyle, and managing the impact of the illness on daily functioning, emotions, and social relationships (Holman & Lorig, 2000). Self-management of LTMCs occurs throughout daily life regardless of setting. Thus, people have to manage their condition not only in the home environment but also in the workplace.

In contrast to the lack of published research evidence for workplace interventions, there is a growing body of evidence to support the effectiveness of community-based self-management programmes for LTMC (e.g. Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002; Lorig et al., 2001; Lorig et al., 1999; Wright, Barlow, Turner, & Bancroft, 2003). The Chronic Disease Self-Management Course (CDSMC) is a cornerstone of the UK Department of Health's Expert Patient Programme (EPP) and is based on the notion that people with chronic disease face similar issues in the daily management of their condition, its treatment and the psychosocial consequences and is a much more 'holistic' approach. The EPP is a lay-led programme delivered to groups of 10-16 people in 6-weekly sessions of 2.5 hours each. Topics covered include goal setting, communication, and exercise.

The Improving Working Lives Pilot Project aimed to deliver the EPP to UK National Health Service (NHS) employees. The aim of this exploratory study was to examine whether EPP is of benefit to people with LTMCs working in the NHS in terms of improving the quality of their working lives, and providing support. The Improving Working Lives Pilot Project was piloted in two NHS Workforce Development Confederation (WDC) areas (Bedfordshire & Hertfordshire, and Cheshire & Merseyside). The evaluation comprised two phases: Phase I focused on EPP participants; Phase II focused on managers.

Phase I: Employees with LTMCs

Participants & procedure

Sixteen people with LTMCs (8 from each area) were interviewed by telephone at baseline; 15 were female (age range 31 – 58 years; median age 51). Follow-up interviews were conducted with 14 participants approximately 2-months after course attendance (7 from Bedfordshire & Hertfordshire; 7 from Cheshire & Merseyside); 1 participant did not respond to follow-up; and 1 provided a brief verbal explanation of reasons for non-attendance on the course. Due to time constraints, the EPP in Cheshire & Merseyside was delivered over three rather than six weeks.

Two participants did not attend the course (1 due to the distance from the venue). One participant failed to complete the course due to work pressures and another felt that EPP was not appropriate as he viewed his condition as curable and short-term.

Results

Baseline

Participants reported that several aspects of their LTMCs interfered with working life. These included limited mobility, pain, fatigue and the unpredictability of many conditions. Symptoms were aggravated by use of equipment such as computers. Most had taken time off work due to the LTMC. The overwhelming impression given by participants was that rather than managing their condition, they were ignoring it in the workplace and were 'just getting on with it'.

Managers were viewed as supportive although some participants felt their managers were not sure how they could be of assistance. Others had encountered difficulties in obtaining equipment or workplace assessments. Three participants felt the organisation, as a whole, was less supportive than their line managers.

"Anything to improve things that I do and make life a lot easier I think is welcomed by my manager." (ID13)

Self-management was viewed as a means of empowering people to take control of their LTMC.

After the course

Most participants felt that the course was well run and beneficial. They enjoyed being with similar others who had LTMCs and valued being able to take time away from the workplace to focus on their own health needs. After the course, many participants were more accepting of their condition and felt less guilty about having a LTMC that interfered with their working life (e.g. needing to take time off or reduce working hours). Acceptance was associated with feeling less 'guilty' about not being able to cope at times, being more in control and having the skills to successfully self-manage. Participants were using many of the self-management techniques learned on the course (e.g. visualisation, deep breathing).

A key theme to emerge was that the course was believed to be more about *living* with a LTMC rather than *working* with a LTMC. Indeed, many participants expressed a desire for more time to be spent on strategies directly connected with work such as feeling confident when discussing their workplace needs with line managers.

"...ways of getting and talking to your boss and such like so that you felt more empowered really, rather than a victim, you know. If you were ill again or something, but, yeah I'd like to have had more, I think more of sort of help with that I think."(ID6)

"I think it would be quite handy to put more about managing things...each individual person with each, sort of, with their manager. I think that would be very helpful" (ID11)

Components of the course mentioned as being particularly useful were the exercise sessions and relaxation. The latter was being used to assist stress management and sleep. Action planning received a mixed response with some participants finding it useful and others expressing a strong aversion to it. Some participants found the course to be too 'rigid' with insufficient time for discussion. This was particularly evident among participants attending the 3-week course with many finding two sessions a week to be exhausting and not allowing them sufficient time between sessions to practice the techniques learned. The 'buddy system', where participants were asked to be supportive of each other and check on each other's progress, was not liked by a number of the participants, as they felt it was too intrusive.

"I've gone into sort of relaxation pretty big style... I've used in sort of every day for relaxing and ... I use relaxation tapes for deep sleep and it's wonderful" (ID7)

"I'm not taking as many painkillers because I'm relaxing more" (ID16)

Participants praised the tutors who were viewed as appropriate role models who fully understood the issues associated with LTMCs. Most participants would recommend the course to others.

Phase II: Managers' views

Participants & procedure

Twelve National Health Service (NHS) managers were identified: 6 participated in telephone interviews and 1 provided feedback via email (2 from Bedfordshire & Hertfordshire, 5 from Cheshire & Merseyside); the remaining 5 either could not be contacted or were not willing to participate.

Results

Only two managers knew about EPP and the 'Improving Working Lives' initiative. Several managers recognised the term 'expert patient' and associated this with a patient with expert knowledge of their condition who assists in improving standards of care. Once informed about the EPP and Working Lives project, all managers expressed qualified support for staff with LTMCs to either attend the EPP or to train as tutors. Managers were clear that any support had to be balanced against the need to ensure that service provision could be maintained, and had to take account of timing, staffing levels, and cost.

"I would like to support it, but if we were in a situation that we were very short staffed and I couldn't provide a service, if this person wasn't available then I would have problems with that."

Perceived benefits of the course were viewed in terms of empowering staff to better manage their LTMCs, disseminating information, and reducing sick leave. In turn, these benefits would result in greater productivity, improved morale and a happier workforce. Perceived disadvantages of EPP revolved around professional concern about the context of information being disseminated by lay tutors, the danger of it being seen as a way to get people off long-term sick leave, and once again, issues of cost and maintaining staffing levels.

"Ultimately a more comfortable employee because they've got their condition under control, whatever it is. Therefore, happier, happier worker!"

"The fact is that you have people with these conditions and you don't want them disappearing all the time."

In order to improve the support offered to staff with LTMC, managers wanted a pool of easily accessible information about a range of conditions including the typical limitations and restrictions that individuals have to manage in the workplace. The need for a culture change in the initial selection process for jobs was called for with increased support for middle managers that make such decisions. Again, the need to balance services provision with additional support for staff was raised. Finally, confidentiality issues around disclosure sometimes hindered managers' level of understanding regarding employees' needs and thus provision of support.

"To be perfectly blunt, sometimes you think well, are they actually pulling the wool over our eyes, are they ill or whatever, because this person is always off sick what's going on? And because you're not being given that information, it's very difficult sometimes to really understand what's going on."

Conclusion

In conclusion, this study has illustrated how an intervention designed for delivery in the community can be successfully transferred to the workplace setting. Employees attending the Programme described a number of ways in which they had benefited and how they now felt more in control of their condition. Managers were broadly supportive of extending the Improving Working Lives initiative with the proviso that staffing levels and costs would have to be balanced with the need to maintain satisfactory service provision.

A copy of the full report and more information about the Expert Patient programme (EPP) can be found at: <http://www.expertpatients.nhs.uk/>

If you would like more information about the Interdisciplinary Research Centre in Health (IRCH) it can be found at: <http://www.coventry.ac.uk/index.jsp> (see Research and Consultancy).

Biography

Dr David Ellard joined the Interdisciplinary Research Centre in Health (IRCH) in 2002 as a Research assistant where he was involved with a number of projects, including a review of self-management for those with mental illness. In 2004 he was appointed as a Research Fellow and now manages a number of projects.

David's research interests include the psychological and physical impact of cardiovascular disease and its treatments, patient education, self-management in mental health and self-management for chronic disease.

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