Using health trainers to promote self-management of chronic pain: can it work?

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Abstract

Background: In 2011, the Sheffield Primary Care Trust piloted a Health Trainer (HT) programme targeted specifically to people with chronic pain. The programme aimed to determine whether patients presenting to primary care with chronic pain would benefit from self-management support, thereby reducing the burden on primary care and secondary care services.

Methods: We conducted a formative mixed-methods evaluation of the pilot programme, focusing on four aspects of implementation: general practitioner (GP) referral to the programme, HT's ability to use cognitive behavioural (CB) approaches, short-term outcomes for clients and adequacy of resources. Qualitative data were collected via interviews with GPs, HTs and the chronic pain team; supervision sessions with HTs; and client case studies. Quantitative data were collected on satisfaction with training, HT's self-reported confidence to implement CB and clients' self-rated well-being before and after participation.

Results: A total of 143 clients with pain for 1 year or more were referred, exceeding the projected 90 referrals by over 50%. A total of 70% of the clients came from the most deprived areas of Sheffield, 40% were listed as permanently sick/disabled and only 20% were working. Qualitative analysis indicated that the CB training was delivered as intended. Clients reported that 75% of their goals were either achieved or partly achieved, and at follow-up 43% of them reported maintaining strategies for self-management. Financial resources were supplemented by indirect resources, including GP 'champions' with a special interest in pain, and a multidisciplinary chronic pain team. The prior history of working with community organizations was critical in ensuring credibility in client communities and addressing client needs.

Conclusion: A HT programme promoting self-management of chronic pain can be successfully implemented when supported by community organisations. Preliminary data indicate that the programme can be instrumental in helping clients to actively participate in identifying their own problems, set achievable goals for self-management and successfully manage the challenges of everyday life.

Summary points

Community-based Health Trainer programmes can be successfully established to promote self-management of chronic pain among clients in the deprived areas using multidisciplinary pain management teams. Utilising a community organization infrastructure that has experience of delivering successful programmes was instrumental in ensuring credibility of the initiative and access for clients. Health trainers can integrate cognitive behavioral training with their existing skills to work with clients who have chronic pain.

Keywords

Chronic pain, pain management, self-management, health trainers, community-based programmes

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Introduction

In 2011, the Sheffield Primary Care Trust received a funding award from the Department of Health Transforming Community Services Programme to pilot and evaluate the effectiveness of a Health Trainer (HT) programme targeted specifically to people with chronic pain. The business case for this programme was based on the high volume of people presenting to primary care with chronic pain and the need to investigate whether a patient would benefit from self-management support, thereby reducing the burden on primary care and secondary care services. We describe here why the service is needed, how it was set up and the service evaluation that was conducted.

Chronic pain is one of the most common reasons that patients consult general practitioners (GPs). Patients with chronic pain use health services up to five times more frequently than the rest of the population in Scotland.¹ In Europe, over 50% of chronic pain sufferers have visited a doctor three times in the last 6 months.² In the United Kingdom, a survey commissioned by the British Pain Society estimated that 'almost 10 million Britons suffer pain almost daily resulting in a major impact on their quality of life and more days off work'.³ In Sheffield, a survey of prevalence revealed that 127,626 people aged 18 years or older reported problems with pain or discomfort. The Sheffield health-needs assessment highlighted the high burden of chronic pain in the city⁴ with a survey documenting that 33.4% of adults 18 years or older reported problems with pain or discomfort. It is projected that the number of adults with chronic pain in Sheffield will increase to an estimated 153,600 in 2014/2015, and as 30% of people with chronic pain do not use services or present late for treatment, delayed referral for treatment has become common.

When people with chronic pain do use health services, they are likely to be seen initially by a GP (72%). Recent health-needs assessment demonstrates that Sheffield health services are dealing with a high burden of chronic pain with secondary care limited to seeing just 7% of even the most severely affected.⁵ Both nationally and locally, there is acknowledgement that among GPs – unless they have a specialist interest in chronic pain – there is a wide variation in skills needed for chronic pain management.⁶ The GPs may refer the patient to other community services such as physiotherapy. While the patient receives these services, they continue to be managed by the GP. When treatment in primary care is not effective, GPs refer patients to the hospital for treatment, and 40% of hospital referrals for chronic pain come from GPs.

As chronic pain occurs across a number of conditions, looking to existing support programmes and

considering how to link with them at a local level may be the most feasible option. Community programmes that support people in managing their conditions exist through the efforts of a range of condition-specific organisations, such as the UK Multiple Sclerosis Society, Diabetes UK and the Stroke Association. Another option for providing locally based community support, available in most of the health regions, is the National Health Service (NHS) HTs' initiative. The national HT programme was established in 2004 to provide a form of peer support that has been shown to be effective throughout England in promoting self-management for lifestyle changes such as smoking cessation, increasing physical activity and losing weight.⁷ The programme theory proposes that when HTs are recruited from and work in their local community, they have a better understanding of local barriers to improving well-being. They use this understanding to help people formulate realistic goals in the context of their everyday lives. The strapline for the service is 'Support from next door, rather than advice from on high'.

A local HT programme was established in Sheffield in 2009. HTs are employed in the voluntary sector via the Healthy Communities Programmes to support people in addressing lifestyle changes. As the programme currently operates, HTs receive referrals from a range of sources including primary care and self-referrals, as well as referrals through a linked programme of community health volunteers, called Health Champions. HTs receive training via a Level 3 Certificate for Health Trainer course. The course is accredited by the Open College Network (OCN), giving participants the equivalent of a National Vocational Qualification Advanced Diploma in nationally recognised competencies to enable them to practice as HTs (http://www.nocn.org.uk/learners/qualification_levels_and_equivalences, accessed 19 August 2013). After qualification, the HTs receive regular individual and team supervision and are required to collect before and after data on well-being, general health and achievement of health goals via established national data collection tools.⁸ The approach that HTs use when giving lifestyle support to clients is described as 'listening, supporting, empathising, motivating and supporting change, giving clients confidence, and facilitating access to local services and groups'.⁹ They provide the following:

- Emotional support: listening to the client's challenges in terms of managing and helping them to reflect on what they would like to be able to manage.
- Informational support: information on the condition is offered as and when the client needs it.

Figure 1. Community Chronic Pain Programme patient eligibility.

- Instrumental support: clients are ‘signposted’ to services, groups and events that can help them to achieve what they set out to do.
- Affirmational support: clients are encouraged to keep on trying when they encounter setbacks and supported to set more realistic goals for their situation.¹⁰

Recent experiences in using HTs to provide support for chronic pain indicates that they can incorporate this peer support with a cognitive behavioural (CB) approach to self-management.¹¹ A recent Cochrane review of psychological therapies for chronic pain indicated weak to moderate effectiveness for cognitive behavioural therapy (CBT) in terms of pain, disability, psychological distress and catastrophic ways of thinking about pain,¹² and a second review indicates that CBT is effective in helping people to manage chronic non-specific back pain.¹³ There are very few studies, however, that evaluate the effectiveness of programmes located in the community setting and none that evaluate delivery by paraprofessionals.¹⁴ Before establishing permanent community-based programmes, it is important to assess the ability to implement the programme in terms of adequacy of resources, acceptability to patients and providers.¹⁵ We aimed to establish the feasibility of a pilot programme offered by HTs to supplement the lifestyle advice currently given with CB peer support to self-manage pain.

Establishing the Health Trainer Chronic Pain Programme

The programme was established in the wider context of a pre-existing and well-established national model of

HT support. The elements and processes needed to establish a Health Trainer Chronic Pain Programme (HTCPP) included conducting a health-needs assessment, setting up a multidisciplinary team, mapping what is already offered, identifying appropriate patients for referral, piloting a referral pathway, providing CB training and monitoring implementation. Each of these stages is described briefly below.

The team included people who could contribute their experience and perspectives of primary care, secondary care, community care and service users. We mapped the type of service that a person with chronic pain currently receives at each point on the patient pathway. Patients who had experienced persistent pain for more than 3 months were identified by practitioners and referred if it was felt that they could benefit from a self-management programme. Eligibility criteria were circulated to health practitioners (Figure 1).

The team set up a new referral and support pathway using their detailed experience of what would work across primary care, secondary care and community settings (Figure 2). GPs with a special interest in chronic pain presented the new service to colleagues and disseminated the referral criteria.

The funding award covered CB training, HT services and formative evaluation. The number of eligible patients per practice was estimated alongside the number of patients who could be seen by a HT within a 9-month time period. It was important to obtain adequate numbers for the evaluation, so priority was given to general practices with an interest and willingness to participate and familiarity with the HT programme. The first five practices were recruited in July 2011 with a further three coming on board several months later to ensure that we reached our referral target.

Figure 2. Health trainer referral and support.

Members of the Sheffield Community team – which comprises district nurses, GPs, physiotherapists and HTs – were invited to participate in CB training. The training had three aims: (a) to ensure that all members of the team became familiar with the CB approaches that would be used by the HTs, (b) to increase understanding of the initiative and garner support in terms of referrals and (c) to enable HTs to support and empower people to become more confident to manage long-term pain. The 2-day training was coordinated by national experts using materials from the Pain Toolkit.^{16,17} HTs then provided individual support to clients for a maximum of seven 1-hour sessions over a period of 2–6 months in accordance with the national practice guidelines.^{18,19}

Self-management programmes require collaboration across primary and community care systems, and evaluating the early stages of implementation is key to determining how well potentially successful interventions can be implemented in real-world settings.²⁰ We evaluated programme initiation and implementation using the following broad questions:

- Training: was the chronic pain training effective in terms of giving HTs the skills needed to help clients?
- Recruitment and referral: did the programme recruit GPs who could achieve the target for referring clients? Did the HTCPP reach the intended population?
- Implementation fidelity: were HTs able to provide a CB approach to self-management? Was the programme delivered as intended? Was it changed in any way as a result of trying various things with clients?
- Short-term outcomes: were clients able to actively participate in identifying their own problems, set achievable goals for self-management and move towards healthier lifestyles and healthier environments?
- Resources: was the pilot funded adequately?

Methods

We conducted an interventional implementation study, where the focus is on piloting and evaluating

implementation of a new programme in order to develop initial evidence regarding the feasibility, acceptability and potential effectiveness of the programme and to begin to identify key contextual influences and other factors influencing effectiveness. Mixed-methods formative evaluation is normally used for this stage of research, to regularly review the process of setting up and providing the service. The feasibility and utility of quantitative impact data are reviewed alongside qualitative data that explain how the programme was delivered and the mechanisms in the surrounding context – such as providers' attitudes and patient acceptability – that influence uptake and delivery.²¹ The community teams were actively involved in the evaluation because we wanted to capture the perspectives of practitioners in terms of the feasibility of implementing the service. Data addressing the evaluation questions were collected via client interviews; the routine documentation that is required by the national programme such as Personal Health Plans, behaviour change questionnaires and diaries;²² case studies that clients prepared with the HTs; interviews with HTs and GPs and supervision meetings with HTs. Short-term outcome data were obtained by using the national HT scales for self-efficacy, general health and well-being.⁸

The interviews were classified as service evaluation by the NHS Primary Care Trust, and research ethics approval was not required. We aimed to interview clients who were ready to complete or who had completed the programme. All clients were given an information sheet describing the evaluation by the HT. Interested clients completed an informed consent form containing their contact details, which was passed on to the evaluator (J.H.). Telephone interviews were used, with the exception of interviews needing a translator. The interviews were open ended, asking for client opinions on the programme. A topic guide was used to prompt people to discuss negative aspects, positive benefits, the type of support received and comparison with other forms of support (pain clinic, physiotherapy, primary care, Expert Patient Programme). Interviews lasted between 15 and 45 minutes, and clients were reminded that they could finish the conversation at any time. Of the 40 clients who completed the programme, 33 volunteered to be interviewed and 18 were contactable over a 3-month period from March to June 2012. This is close to desired number of 20 interviews and a 54% response rate is considered good for this type of telephone follow-up. Findings from the interviews were analysed by the evaluator (J.H.) using thematic analysis.²³ Data from client interviews, HT interviews, client case studies and Data Collection and Reporting System (DCRS) were triangulated and emerging themes were periodically fed back to the Chronic Pain team for discussion and review. Areas

needing clarification were identified and included in subsequent interviews.

Short-term outcome data were captured from the national HT DCRS on goal setting and ability to achieve goals,⁸ as well as clients' self-report of changes in well-being at the beginning and end of the programme (WHO-Five Well-being Index; <http://www.who-5.org>). Quantitative data were extracted from the DCRS by the HT supervisor (A.M.) to preserve client confidentiality.

Results

The training was very well attended with all professional groups represented. A total of 30 people attended the first session in June 2011 and 24 attended the second session 3 weeks later in July 2011. Satisfaction ratings for the programme were excellent. Participants consistently rated themselves higher in terms of knowledge, ability and understanding of chronic pain after their second session. There was an increase in knowledge ranging from 4% to 21% for those who completed knowledge tests before and after the training.

At the end of the 9-month period, a total of 143 clients had been referred. In all, 13 referrals came from secondary care and the remaining 131 from general practices – exceeding the projected 90 referrals by over 50%. The successful referral rate was attributed to having GPs with a special interest in pain who could champion the initiative, recognition from referring GPs that the usual services for pain management did not cover all the patients' needs and prior positive experience of working with the generic HT programme.

In all, 70% of the clients came from the most deprived areas of Sheffield. A total of 35 males and 72 females accessed the service. The vast majority of clients were in the 36–65 years age range. A total of 40% were listed as permanently sick/disabled, while 25% were retired, indicating that some took early retirement. Only 20% were employed, either full-time or part-time.

In terms of implementation fidelity, findings indicate that the programme was delivered as intended. GPs were referring people with long-term chronic pain in accordance with the eligibility criteria, and there were no inappropriate referrals. Supervision meetings and HT interviews indicated that the CB training was also being delivered as intended. This was determined by the evaluator (J.H.) who interviewed HTs to determine whether they were using the recommended tools and by comparing their practice accounts with the list of skills addressed in the training programme. Use of the tools and skills was confirmed via client accounts. Clients described using the person-centred model, which helps people to reflect on their experiences with chronic pain in terms of symptoms, moods, thoughts, behaviours and life

Table 1. Change in self-efficacy, health and well-being.

Measure	Before	After	% Change
Self-efficacy	68.4	74.09	8.32
General health	38.29	51.71	35.05
WHO – Five Well-being	29.14	44.57	52.95

situations (<http://www.paintoolkit.org>). HTs tailored the tools to individual clients, which is precisely what the training recommended. Clients related how they developed awareness of their condition, the non-judgemental and supportive attitude of HTs, listening skills of HTs, the idea of pacing and formulating small achievable plans for change and approaches to dealing with relapse. HTs said that they had received a large number of tools in the training, and that they found some more useful than others when working with clients. They noted that with further training, they could go on to use a wider range of tools. One aspect of the programme that proved difficult to use was the DCRS, which was designed by the Department of Health to record data across all HT programmes. The DCRS focuses on capturing information related to lifestyle changes in diet, physical activity, smoking and drinking – which is not particularly appropriate for the HTCPCP focus of helping clients to self-manage chronic pain.

In terms of short-term outcomes, interview data described how clients actively took control of the process of reflection, goal setting and becoming capable of achieving a healthier approach to managing chronic pain in the context of everyday life. WHO-5 well-being data from the 107 clients who completed during the evaluation period indicated that clients rated their general health, self-esteem and well-being higher after participation (Table 1). Clients reported that 75% of the goals set were either achieved or partly achieved, and at follow-up, 43% of them reported maintaining strategies for self-management.

The initiative was able to achieve its original aims within the dedicated resource by effectively using existing investment in the form of skilled practitioners and community organisations that had close working relationships with physiotherapists and district nurses who supported the initiative. Funding enabled service provision that covered not only the original target but also the 50% additional referrals that were made as a result of successful recruitment of new practices.

HTs had extensive experience of providing the generic HT programme in Sheffield, with extensive knowledge of the communities that they served. There was an embedded community organisation infrastructure that had been successfully used to launch the generic HT programme. Working from these community organisations, with their well-established community networks and their in-depth knowledge of local resources, enabled HTs to develop credibility with local people, connect

with the community and subsequently signpost people to various opportunities without having to do extensive research and networking to find local activities and information. The community organisations have high local credibility, which means that people are more likely to try a service that they support.

Discussion

Our implementation study evaluated the early stages of co-producing a modified service that was feasible and realistic for practitioners and acceptable to patients. The pilot was successful in terms of implementation fidelity, perceived utility and short-term client outcomes. The key factors that enabled success were establishment of a multidisciplinary team, partnership with community organisations, endorsement from GP ‘champions’ with a special interest in pain and recruitment of experienced HTs who received effective training and ongoing supervision in the use of CB approaches to support self-management. The pilot managed to develop an integrated service model, which is defined by the WHO as ‘the organization and management of health services so that people get the care they need, when they need it, in ways that are user-friendly, achieve the desired results and provide value for money’.²⁴

The evaluation indicated that the pilot delivered the right care in the right place, providing a user-friendly and timely response to client needs. The ‘right place’, however, deserves some consideration. While our project originally targeted deprived areas, the active ingredient was the presence of a community infrastructure in these areas, which enabled design of a locally appropriate and accessible intervention.

There were several potential weaknesses to the implementation and evaluation of the programme. A follow-up day is usually advised to reinforce skills learnt during the CB training, but as funding did not permit this we compensated by providing HTs with monthly group supervision. The time period for the pilot was only 9 months, so it was not possible to collect data on long-term maintenance. If clients were interviewed after a longer period of time, we might find that the initial positive response was tempered, particularly for clients who need longer term support in order to maintain changes in lifestyle. The ability of clients to stay connected over time as they experience setbacks – particularly when a

number appeared to be suffering from depression – needs to be questioned and should be the focus of longer term evaluation. The next step, in terms of research, would be an efficacy-oriented small-scale trial of the implementation programme to assess ability to deliver the programme consistently and accumulate evidence on impact before rolling out on a larger scale

Integrating community-based HT services with clinical services requires a combination of political, administrative and technical action. When establishing a community-based chronic pain programme, we recommend that teams (a) explore whether the existing community infrastructure can provide services for clients with chronic pain, (b) identify gaps and develop strategies for increasing capacity, (c) define needs for training and support, (d) provide ongoing supervision to support HTs in their professional development, (e) develop a plan for monitoring the process and providing regular feedback and (f) actively participate in the evaluation to promote collaborative reflective learning and practice, as well as ensuring that feedback is used to improve the service. Representatives from each discipline need to be actively involved at all stages in order to clarify roles and relationships in service delivery.

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Conflict of interest

The authors declare that there is no conflict of interest.

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