

A clinical evaluation of a community-based rehabilitation and social intervention programme for patients with chronic pain with associated multi-morbidity

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Abstract

Background: Multi-morbidity, low mood and social isolation are common among patients suffering chronic pain and can inhibit effective self-management. We have developed the novel approach of a charity working alongside a community pain clinic to provide highly individualised therapy, support and social activities towards encouraging de-medicalisation, independence and personal development. **Methods:** We carried out an evaluation of the service using routinely collected clinic data, post discharge interviews and information obtained from the general practitioner. **Results:** Data analysis was possible in 29 of the first 30 patients. Despite initial higher than average levels of disability, there was a statistically significant improvement in mean EQ5D-3L health status, median average pain intensity on BPI and an overall reduction in clinically-significant depression using PHQ-9 scores, 19 months after participating in the project. Repeat analgesic and psychotropic medication prescriptions were reduced in both number of items (46%) and cost (46%). **Conclusions:** A community based method of holistic, integrated and individualised care for patients with chronic pain delivered by a charity, working in partnership with the NHS, was successful in improving many aspects of chronic pain related disability and reducing healthcare use.

Keywords: Chronic pain, multi-morbidity, rehabilitation, holistic, social interventions

Introduction

Chronic pain is a long-term condition associated with significant physical disability and psychosocial problems (1). A growing body of evidence underscores the importance of effective self-management of chronic health problems (2). People who are more 'activated,' i.e., who recognise that they have an important role in self-managing their condition and have the skills and confidence to do so,

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experience better health outcomes (3). Multi-disciplinary pain management programmes (PMPs) are designed to improve quality of life and reduce the impact of persistent pain on physical, psychological and social function (4).

Multimorbidity, defined as the presence of two or more chronic medical conditions in an individual (5), is common amongst patients with chronic pain. The presence of multimorbidity compounds physical disability and contributes to psychological distress and social isolation (6, 7). Patients with multimorbidity suffer a high treatment burden (8) including polypharmacy but often gain little relief from medical interventions and become highly deconditioned. This in turn limits their access to most treatment programmes.

We describe a whole person approach to this highly disabled patient group through a community based rehabilitation and social intervention programme which employs the components of the King's Fund 'House of Care' model. The intervention has been developed and delivered by a charity, Kairos Rehabilitation Trust (KRT), alongside a community pain management clinic, the Vanbrugh Community Pain Clinic (VCPMC) in South East London.

Methods

The first 30 patients referred to the Kairos Project (KP) were approached to give their consent to analysis and publication of their data. They were also asked for consent to the researchers contacting their GP for information on prescribed medication and secondary care services use.

Intervention

Criteria for entry - The participants had been referred to the VCPMC by their own general practitioner (GP), a community physiotherapist or a hospital specialist. All were adult patients with non-malignant pain for greater than three months that had been fully investigated. Their conditions had already proved unresponsive to primary or secondary care pain clinic interventions.

Assessment - All patients referred to the KP start with a comprehensive one hour assessment of their life journey and their current needs focusing particularly on identifying past achievements, aspirations and attitudes, capabilities, strengths and weaknesses as well as clinical factors which are or would hamper rehabilitation. A personalised treatment plan can then be mapped out. A holistic interpretation of the overall condition is shared with the patient in addition to what might be expected by joining the project. The patient is then invited to 'opt in'.

Re-assessments at regular intervals determine the effectiveness of ongoing treatments. The meetings are tailored to need and may include one or more of Kairos' health professionals, the participant's own GP or social worker, spouses, partners, relatives or friends. The therapeutic plan is therefore highly individualised. Patients are encouraged to play an active part in determining their own care.

Treatments and professional support

All treatments and interventions have a self-management focus and are delivered by a team of a doctor, GP with special interest (GPwSI) in pain management and two therapists. Medical and non-medical aspects of treatment run as parallel, complementary interventions. Two anthroposophic therapies (9), rhythmical massage and eurythmy (gentle movement) are delivered individually in blocks of 7-8 weekly sessions. They aim to reduce the burden of symptoms (mainly pain, sleep disturbance, fatigue, anxiety and depression) and to restore energy. The confidence and motivation required for self-management is thereby facilitated. The intensity of the interventions is graded according to patients' physical and psychological condition as well as capacity and their needs. As symptoms improve the rationalisation of repeat medication, particularly analgesics and psychotropics, becomes possible. Non-medical interventions consist of artistic, musical and horticultural activities, visits and outings. The group activities have a strong social element.

'Breakthroughs' arise from imaginative listening, sharing and exploring new ideas particularly when they come from patients: their suggestions for social

and work activities, for example the choir, have helped shape the service. Homework, for example practising movement exercises or dressing differently, hands over some shared responsibility to the patient as well as enhancing the effect of the therapy.

Some participants are supported in their applications for disability benefits for example help with filling out statutory forms and offered personal representation at Department of Work and Pensions (DWP) or equivalent medical examinations and appeal tribunals. They are encouraged to design realistic return-to-work schedules in keeping with their individual aspirations. Introductions are made where feasible to potential employers and opportunities facilitated for volunteering or further education. This can include opportunities for participants and their contacts to contribute to the KRT charity as volunteers or to lend their expertise to aspects of the rehabilitation programme itself.

All treatment regimes are personalised with one member of the rehabilitation team, usually the GPwSI co-ordinating the changes. Attention is particularly paid to the person's energy and capacity to attend when planning their care. Progress is monitored during frequent 1:1 and team meetings. The result is a regime that is highly flexible in terms of the types and numbers of sessions and the frequency of interventions. This flexibility allows care at all times to be patient-centred and delivered collaboratively.

Data collection

Patients were asked to complete the Patient Health Questionnaire (PHQ9), the Brief Pain Inventory (BPI) and European Quality of Life 5 Dimensions, 3 Levels (EQ5D-3L) at referral to the project and in July 2015 which was, on average 19 months after each patient had been discharged from KRT. At entry to the project data was also collected on demographics, type of pain, pain duration, medical history, employment and use of analgesics and psychotropic medications (items, doses, frequency and amount).

The Patient Health Questionnaire (PHQ-9) is a brief tool for monitoring depressive symptoms that is commonly used by general physicians. It has been developed for the screening, diagnosing and measuring the severity of depression (10) and is

responsive to change in the clinical setting (11). A score of less than 10 indicates mild or no depressive symptoms and a decline in score of 50% along with a post treatment score of less than 10 is considered significant clinical improvement (10).

Retrospective data were collected with patient consent by contacting the GP. Repeat medication (items, doses, frequency and amounts of analgesic and psychotropic drugs) were compared on entry to the project with repeat medication being taken in July 2015, on average 19 months after each patient had been discharged from KRT.

Data on secondary health care use i.e. the number of specialist appointments attended and the number of therapy appointments attended in the year preceding entry to the Kairos project were compared with the number of appointments attended in the year up to July 2015 when on average 19 months had passed since discharge from KRT.

Analysis

All data were transferred to an Excel spreadsheet. Last observation carried forward (LOCF) imputation was used to allow data analysis when follow up data was missing. The two tailed Wilcoxon signed rank test was used for before-after comparisons.

PHQ-9 scores were used to determine the presence or absence of depression and this was analysed as categorical data. Before and after comparisons were made using McNemar's test.

The PHQ-9 was included in the patient data set during the Kairos project because it was important to have a brief and easy to use tool for monitoring depressive symptoms.

Medication costs were calculated using the BNF March – September 2013. In calculating the numbers of referrals to secondary or tertiary care, non-pain related specialties were excluded.

Results

Twenty nine of the first 30 patients who attended the Kairos project agreed to have their data used for this evaluation. They had all entered the project between August 2011 & March 2013. Five patients were

excluded from the analysis as their first language was not English and translators had been used to help with questionnaire responses in a non-standard way. Data analysis was possible on 24 participants.

Patient characteristics

The sample (n = 24) contained significantly more female patients than male compared to those attending pain clinics in England and Wales (National Pain Audit)[12], but the mean age was similar (Table 1)

Table 1. Demographic comparisons (n = 24)

	Kairos	NPA ¹
Gender male	5	
Gender female	19	
M:F	1:3.8	1:1.8
Average (mean) age	53.62, SD 16.09	53.8
Median age	53	
Age range	25 - 90	

¹National Pain Audit.

Pain problems

All patients were allocated to a Pain Type category using the following categories: persistent wide spread pain, axial pain with or without neuropathic radicular pain, joint pain, headache, abdominal or pelvic pain (Table 2).

Table 2. Main pain problem

Pain Type		N
PWP ¹		12
Axial Pain	LBP ²	6
	[LBP + Neup/radic pain ³]	[2]
	Neck pain	2
Joint Pain	Shoulder pain	1
Headache		0
Abdominal/ pelvic pain		0
Missing data		3
Total		24

¹Persistent Widespread Pain.

²Low Back Pain.

³Neuropathic/radicular Pain.

The commonest main pain diagnosis was persistent widespread pain followed by pain localised to the axial skeleton. There was a second pain diagnosis in 15 of the 24 (62%) patients. The most common of these was headache (7/24, 29%). Sleep disturbance based on the clinical history was recorded in 17 patients. In 6 patients sleep quality was not recorded and one reported good sleep.

Data on duration of the pain condition was missing in 4 patients. In the remaining 20 cases median pain duration was 4 years at the start of the programme with a range of 0.4-38 years, inter-quartile range (IQR) 14.5.

Employment history was recorded in 21 patients, 7 of whom did not work outside the house. The majority [11] had lost their jobs because of pain problems. Three were still working but all reported difficulty with employment.

Data on previous treatments received for the pain condition was missing in six patients. The most commonly tried treatments were physiotherapy [17], anti-depressants or anticonvulsants [13], complementary therapies [11] and simple analgesics [10]. Eight patients were on opioids and seven had had injection treatments. Only two had attended a multidisciplinary pain management programme of unknown intensity.

Pain severity

Kairos patients had a higher level of pain severity at first visit to Kairos (pre-Kairos) than patients included in the National Pain Audit (Table 3).

Quality of life, mood and function

Twenty-three of 24 patients had a history of at least one other long-term condition as well as chronic pain. All 24 patients had completed the EQ5D-3L descriptive questionnaire at the start of the project. Figure 1 and 2 show the percentage of patients who reported any impairment and severe impairment respectively on entry to the Kairos Project compared with the National Pain Audit.

At initial presentation patients referred to KRT had lower life quality than those attending pain clinics

in England and Wales. The median ED5D index value of health status was 0.23 (IQR 0.294) before starting the Kairos Project as compared with 0.357 (IQR 0.395) for the patients presenting to pain clinics in England and Wales (Table 6).

Mood was formally assessed using the PHQ 9. Three of the 24 patients had incompletely filled in the PHQ-9 pre-treatment. In the remaining 21, thirteen patients had moderately severe or severe depression (score ≥ 15). Three patients had a score of less than 10 indicating mild or no depressive symptoms.

Table 3. BPI pain severity score at first visit to KRT and at initial entry to NPA

	Mean Least Pain	Median Least Pain	Mean Average Pain	Median Average Pain	Mean Worst Pain	Median Worst Pain
Pre-Kairos n = 24	6.25 (SD 2.52)	6 (IQR4)	7.54 (SD 2.17)	8 (IQR 3.5)	8.29 (SD 1.76)	8.5 (IQR 2)
NPA n = 8903	4.9	5 (IQR 3 - 7)	7	6.5 (IQR 5 - 8)	7.9	8 (IQR 7 - 9)

Patient related outcome measures (PROMS) after participation in the Kairos intervention programme

Post KP PROMS follow up data was completely missing in one patient. LOCF imputation was used. The time interval between first and last follow-up measurements ranged between 30 and 62 months with a median of 40 months (IQR 12).

Brief pain inventory

There was a significant fall in participants' median pain severity scores for least, average and worst pain after attending the Kairos Project (see Table 4). There was also a reduction in pain interference in most domains (activity, walking ability, work, relationships, sleep and life).

Table 4. BPI pain severity score at start and end of KRT participation (n = 24)

	Median Least Pain	Mean Least Pain	Median Average Pain	Mean Average Pain	Median Worst Pain	Mean Worst Pain
Pre-Kairos (K1)	6 (IQR 4)	6.25 (SD 2.52)	8 (IQR 3.5)	7.54 (2.97)	8.5 (IQR 2)	8.29 (1.76)
Post-Kairos (K2)	4 (IQR 5)	4.17 (2.84)	6 (IQR 3.5)	5.29 (SD 2.93)	7.5 (IQR 4.5)	6.37 (SD 3.28)
Significance	Z = -2.91 P = 0.0036 W = 27 P < =0.01		Z = -3.55 P = 0.0003 W = 10 <=0.01		Z = -3.195 P = 0.0014 W = 9 P < =0.01	
Change in score K2-K1		_2.08		_2.25		_1.92
Cohen's effect size		0.36		0.4		0.34

Table 5. Median BPI interference scores before and after treatment

	General activity	Mood	Walking ability	Normal work	Relationships	Sleep	Enjoyment of life	Average BPI interference
Pre-KP	7	6	8	8	6	8	6	7
Post-KP	6	6	7	7	5	6	5	6

PHQ-9

Score comparison was possible in 21 patients who had submitted pre- and post- treatment data. LOCF was used for only one participant. After participation in the project, 13 of the 21 patients had a low PHQ 9 score (< 10), compared with 3 patients before participation. This result was statistically significant using McNemar's test on a 2x2 contingency table with a p value of 0.003.

Taking the criteria of 50% decline in score as well as a post-treatment score of <10 as significant clinical improvement, seven patients showed improvement in depression after attending the Kairos Project.

EQ5D-3L

All 24 patients had completed EQ5D-3L at the start of the programme. Follow up EQ5D-3L data were missing in one patient. LOCF imputation was used to allow EQ5D data analysis.

Index value of health status data values have been shown in Table 6 along with the values from the NPA. This data was not normally distributed in the Kairos participant sample. Analysis as before and

after repeated paired measurements using the Wilcoxon signed rank test, shows improved health status after participation in the Kairos Project. This is statistically significant.

Figure 1 shows that there is reduction in the number of patients reporting impairment across the EQ5D life quality domains after participation in the Kairos Project. Attending the project has reduced the number of people reporting severe impairment in the Usual Activity, Pain and Anxiety/Depression domains (Figure 2).

Health care use

Data on medication prescribed for pain before and after participation was available in 23 patients. There was a marked reduction in repeat prescribing for both number of items of medication and cost between initial referral to Kairos Project and (average of 19 months) post discharge from the project (Table 7). This was prescribed analgesic and psychotropic medication and did not include over the counter medication taken by patients.

Table 6. Index value of health status before and after the participation in the Kairos project (n = 24) and the values from the National Pain Audit (n = 2870)

	Mean	Standard deviation	Median	IQR
Kairos 1 (pre KP)	0.284	0.17	0.23	0.294
Kairos 2 (post KP)	0.417	0.25	0.329	0.483
NPA	0.4	-	0.357	0.395
Change in score K2- K1	0.133			
Cohen's effect size	0.3			

Table 7. Changes in medication use

	Total number of medications (n)	Mean number of medications per patient	Total cost of medication/28 days	Mean cost of medication per 28 days per patient	Mean saving per patient per annum
Kairos 1 (preKP)	80 (23)	3.5	£1040.00	£45.21	-
Kairos 2 (postKP)	43 (23)	1.9	£587.03	£25.52	£256.67

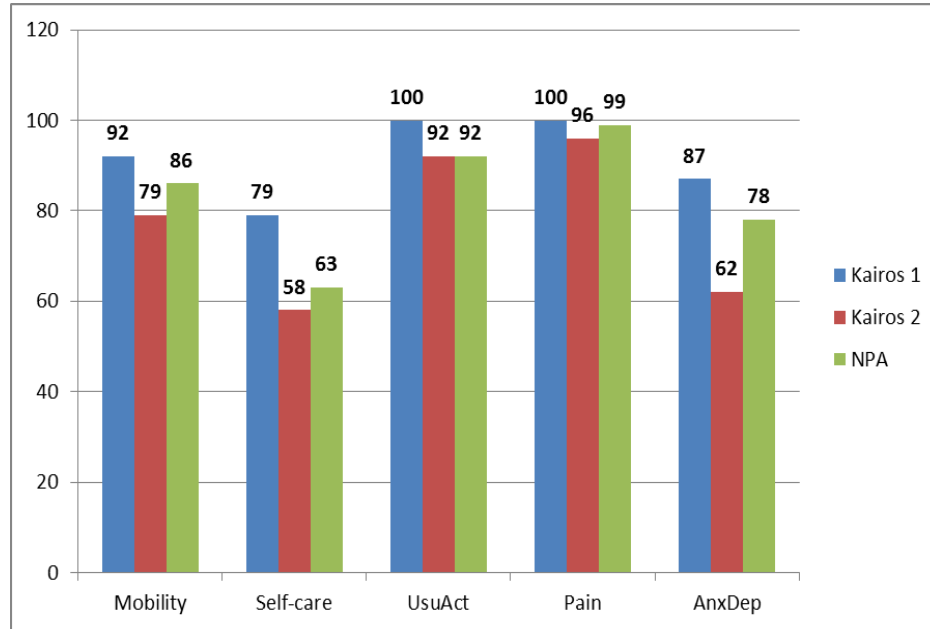


Figure 1. EQ5D-3L at first visit (Kairos 1) and follow up (Kairos 2) after the Kairos Project and at first visit to Pain Clinics in England and Wales from the National Pain Audit (% reporting *any* impairment).

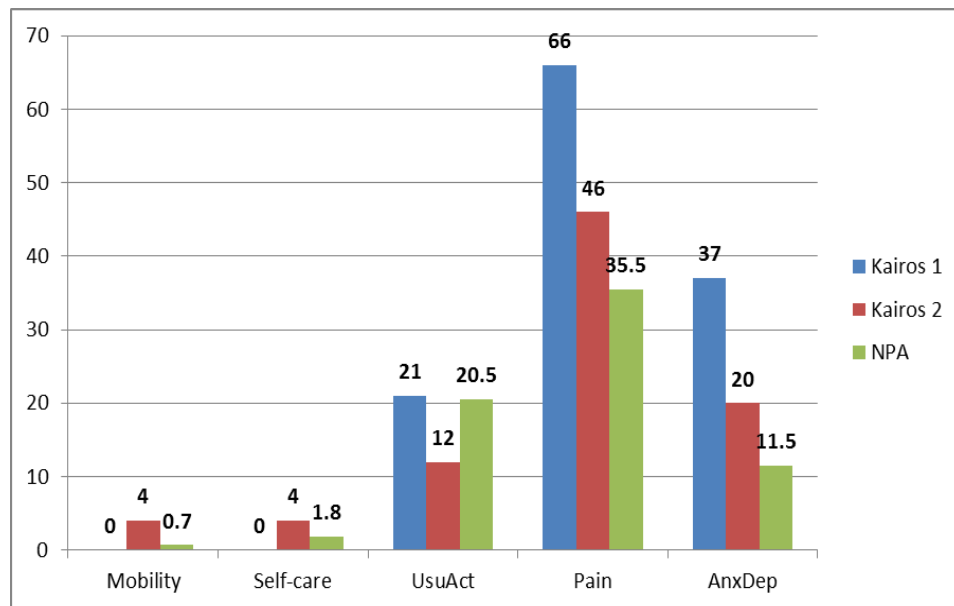


Figure 2. EQ5d-3L at first (Kairos 1) and follow up (Kairos 2) visits for Kairos Project and NPA (% reporting *severe* impairment).

The number of specialist out-patient appointments attended in secondary care pain clinics or in specialities related to pain management (rheumatology, orthopaedics, neurology, neurosurgery) fell from 68 in the 12 months preceding participation in the Kairos Project to 33 in the

12 months prior to July 2015 which was on average 19 months after the last contact with the KP in the 23 patient sample. This represents a 51% drop. There was an 86% drop in the total number of appointments attended for psychology, physiotherapy, podiatry, acupuncture and CBT from 208 to 30.

Social participation, employment support and activities post-discharge

Nine out of 24 patients made use of the project's social activities which included choir and music, gardening, craft, cookery, outings and fundraising events.

Seven received support to negotiate with statutory / benefits agencies and/or to design realistic volunteering / further education / return-to-work schedules.

Qualitative data on new social activities that had been started after KP participation was available in 23 patients. A summary of this appears in Table 8.

Table 8. Activities post discharge (mean 19.6 months)

Activity/employment status	N
returned to full time paid work	1
returned to part-time paid work	3
took up volunteering	3
took up higher education	1
were considered to have taken significant steps toward social integration	4
showed essentially no change	3
were of pensionable age	5
did not start the programme	3
Total	23

Discussion

Health services in industrialised countries face increasing challenges in looking after patients with long term conditions such as chronic pain. These challenges are even greater in patients with multi-morbidity who are often unable to tolerate or access treatments or derive little benefit from them.

Patients who are referred to the Kairos Project typically have chronic pain with multi-morbidity, associated anxiety or depression, sometimes communication difficulties, social isolation and/or problems with disability benefits. This profile is reflected in the sample's quality of life scores on admission to the project. On presentation, the Kairos Project patient sample had greater average pain intensity, poorer health status and greater pain related

disability compared to the general population of chronic pain patients referred to pain clinics in England and Wales published in the National Pain Audit.

Despite their initial high levels of disability, the participants' wellbeing improved significantly. The outcome measures data shows statistically significant change in mean EQ-5D health status (reduction in score of 0.133) and median average pain intensity on BPI (change of 2 points) after participation. The minimal clinically important difference (MCID) is an important consideration when using instruments that measure complex constructs such as disability and quality of life. An evaluation of the MCID in the EQ-5D score done using data from 8 longitudinal studies in 11 patient groups including back pain and arthritis, found the mean MICD for EQ5D to be 0.074 (range 0.011 to 0.140) (13). The MCID for BPI intensity score is a change of 2 points (14). The changes observed after participation in the Kairos Project would, therefore, be considered clinically significant.

As well as improving life quality and reported pain intensity, there was also an overall reduction in clinically significant depression using PHQ-9 scores and a reduction in participants' health care use including polypharmacy.

Chronic pain patients with greater pain severity, psychiatric problems and multi-morbidity are thought to have poorer outcomes from treatments (15, 16). Achieving progress in this patient group is challenging. It is likely that this patient group often find the principles of self-management difficult to implement. Unable to make sustained and meaningful progress, it is common for patients revert to the medical model of care in the hope of achieving symptom relief.

The Kairos Project approach encompasses all the elements of care that are essential to the management of people with complex long-term health problems according to the Kings Fund. Our data demonstrates that it is successful in dealing with the problems of highly disabled, multi-morbid and complex patients. Patients are given the support and practical help they need to discover and develop their own resources prompting a process of personal development.

The mechanisms that have contributed to this deserve further study with quantitative and qualitative

research methods. As a starting point, the differences between the Kairos approach and conventional, currently used treatment strategies for chronic patients deserve some reflection. These are based on the observations of the clinical team who have delivered the Kairos Project for the last five years.

The bio-psychosocial model is embedded in the current approach to chronic pain management (17). Despite the widespread acceptance of this model of care in treating complex conditions, the findings of the 2010 UK National Pain Audit showed that only 40% of pain services in England and 60% of Welsh services could be defined as multidisciplinary. Access to care truly based on the biopsychosocial model cannot be assumed across all secondary care services. The Kairos Project is a community service in line with the biopsychosocial model.

In pain clinics with multidisciplinary services, the biopsychosocial approach is usually delivered through pain management programmes (PMPs). These are interdisciplinary interventions with a strong psychological component that are designed to promote behaviour change towards self-management and reducing pain related disability. There is good evidence on the efficacy of PMPs in achieving this aim (18). PMPs are heterogeneous in terms of length, staff skills and intensity of input. Most are delivered in a limited time span with group-based out-patient sessions only. This limits their accessibility to highly disabled patients. Only two patients in the presented sample had been exposed to a PMP.

Although current opinion is in favour of individualised, more intensive programmes, in practice, the constraints of space, staffing and cost limit the flexibility of most programmes. Furthermore, the criteria and circumstances that should dictate which patients should be admitted to higher intensity programmes remain undefined.

In comparison, the Kairos Project has been designed as a flexible individualised approach from the outset that can deliver gentler introduction to activity. Low intensity gentle interventions such as rhythmical movement and massage in the early stages help gain patient confidence and improve sleep and anxiety. Growing trust brings greater self-confidence and a willingness to try new strategies. These initial gains allow the team to step up the challenge towards increasing activity as the person responds. In the later

stages, the patient- health provider partnership changes with more complex patient directed goal-setting towards meeting the participant's individual sense of purpose. Although general progress and engagement is monitored, there is no strict time limit on how long the different stages of the intervention would take.

Great care is taken to maintain interpersonal continuity of care. Consultation and review times are longer than is currently usual in primary or secondary care and include goal planning as well as coordinating and supporting a shared care plan. Frequent re-assessment of the patient's progress in relation to the latest intervention measures its value and then leads on to ideas for the next. Consultations carry the elements of information gathering, goal setting and action planning that are set out in 'Delivering better services for people with long term conditions' (Kings Fund) (19).

The Kairos Project has a strong social intervention element. The environment in which the intervention is delivered lends itself to flexible and easy access to social activities. Social activities can be introduced at any stage by the health professionals and patients can opt in for these by choice. This allows social re-integration for those who may have been relatively isolated for years secondary to their chronic pain problems. Participants can also opt to be deliverers or helpers in organising social activities or contribute ideas to them which enhance the sense of true active participation in the rehabilitative process.

The Kairos approach is a rare example of an intervention for a chronic condition that employs all components of the King's Fund 'House of Care' model (19) with the notable exception that it was not started as a NHS commissioned service but was set up through charitable funding. Matching the best of primary care practices with the strengths of a person-centred charity has been the key to balancing the partnership tasks of treating illness and activating the personal resources of the sufferer. Furthermore, the charity may be governed by non-medical professionals with direct personal experience of chronic illness. Its access to non-statutory funding also allows further freedom to experiment beyond traditional barriers. The end product is an intervention in line with current thinking in the management of long term conditions.

Transferability

All Kairos Project interventions are delivered in a community care setting. The approach is not disease or symptom focussed. The strength of this intervention does not lie with employing the latest pharmacological or highly skilled technical advances but with its ability to engage patients with better health behaviours including social participation. These characteristics confer enormous transferability and reproducibility to the intervention.

This transferability will inevitably depend on clinicians being able to understand and embrace the approach. Although training would be needed to reproduce the intervention, we are optimistic that the Kairos Project represents a model of care that is easily transferrable not only geographically but also to other long term health conditions.

Weaknesses and strengths

Data collection for the Kairos Project has occurred primarily for clinical evaluation and audit purposes. Reflecting real life situations, some data sets were incomplete, limiting the strength of the conclusions. Although non-English speaking patients are accepted for participation in the programme, validated versions of the questionnaires in other languages were not available to programme administrators at the time of data collection and this important group of patients had to be excluded from the evaluation.

At the time of the evaluation only 30 patients had been through and discharged from the Kairos Project. The sample size is, therefore, relatively small. Additionally, the proportion of female patients in this sample is much higher than that in UK Pain Clinics (NPA 2010). It is unclear whether this atypical gender distribution has occurred by chance or is a reflection of the demographics of the highly disabled chronic pain patient population. A larger and more detailed formal evaluation might shed light on this.

Conclusion

The results of this evaluation demonstrate that the Kairos Project approach was successful in improving health outcomes in a highly disabled patient group.

The Kairos Project is a community based method of holistic, integrated and individualised care for patients with chronic pain that incorporates the skills of health professionals and the strengths of patients.

The Kairos Project demonstrates the added value a charity can bring working in partnership with an NHS service.

The analysis of a small cohort of the project's first wave of participants shows that they are more severely affected at initial presentation than average UK pain clinic patients. Despite this, the Kairos approach has been successful in improving many aspects of chronic pain related disability, including improving mobility and mood as well as increasing social engagement and reducing polypharmacy and health care services use. The mechanisms that have driven these successes deserve further study.

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