**Editorial**

Welcome to the first issue of *The Journal of the Effects of Self-Management for Chronic Pain Patients*. This journal will look at articles on various aspects of self-management and education and the impact and outcomes on a patient’s quality of life.

The journal was created as a result of the importance to look at the actual differences of how the intervention of self-management techniques for Chronic Pain can improve a person’s quality of life.

This first edition focuses on both the impact of self-management in the community within Health and Social Care and benefits to patients, their families and carers.

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Dr Gregor Purdie, UK, - retired GP in NHS Dumfries and Galloway and previous GP adviser to the Board  
Dr Charles Martin, UK – Consultant Anaesthetist, NHS Ayrshire and Arran

Future issues of the Journal will publish reports of original clinical research, reports of original basic research, reviews and focus articles. We therefore invite submissions.
Self-Management Courses for Chronic Pain
Overall outcomes for all Courses 2014-2015

Contents

This report provides evaluation results from 25 Self-Management courses for Chronic Pain delivered in 5 Scottish Health Board areas in 2014-2015.

The report gives a description, background and rationale of the service followed by combined results from the courses. Conclusions and a summary are provided at the end of the report.

Overview

Pain Association Scotland provides specialist training in the Self-Management of Chronic Pain for people throughout Scotland. The organisation has developed expertise in an effective interactive approach, which treats the individual as a person rather than as a patient. This approach helps to engage the individual in the principles of Self-Management and motivates them to adopt new ways of thinking based on a better understanding of their health and the options available to them.

Courses were delivered as a result of improved levels of collaboration within the Secondary Care Chronic Pain Services in - Tayside (10), Angus CHP (4), Dumfries and Galloway (3), Forth Valley (6) and the Western Isles (2) and this continues to be developed. Referrals are received from the Pain Clinics, other healthcare professionals and a small number who self-refer on to courses within their local area.

Improved collaboration and referral processes provide better Patient access to courses (speed and location) enabling them to utilise this vital paradigm of care. The service provides part of an approved exit strategy for people who have reached the end of their clinical pathway and as such helps to break the cycle of the ‘revolving door’ patients. There was a slight difference in the referral patterns which seemed to reflect how the respective Pain Clinics were attaining the 18 week waiting time criteria.

In addition to the 25 Courses provided in this period, Pain Association have also provided monthly staff led groups in Tayside and Angus (4) Dumfries & Galloway (2) Forth Valley (2) Western Isles (2). These groups provide vital on-going training, education and peer support which enables people attending the courses to maintain their skills, understanding and motivation. This is a unique resource where patients are provided with a course in their area followed by a maintenance programme in their area. Patients often comment that they are very impressed that there is continuity of support for them after the course has finished.

In addition to the courses delivered in collaboration with the Health Boards the Association has delivered 2 self-management courses in collaboration with “The Health and Social Care Alliance” in Ayrshire and the Western Isles with an average completion rate of 76%; both areas also benefit from local self-management groups providing the essential on-going support required to maintain skills acquired on the respective courses. The courses vary in length depending and are dependent on the needs of the Health Board. The duration varies from a five week course up to an eight week course – whilst the individual evaluations have shown that there are similar outcomes, input on a shorter five week course is more intensive in order to get patients to the same output stage as an eight week course.
**Aims & benefits – Health Board**

The aim of the Courses are to provide a high quality cost effective Self-Management Course that improves access to a paradigm of care that would not otherwise be provided within respective Health Boards. Since the courses ‘come’ to the area, there is a significant cost saving for each NHS Health Board area as Patients don’t have to travel to another area.

All the Courses provide the respective NHS Boards with a response to recommendations made by Health Improvement Scotland ¹. The recommendations were developed as a means to implement the Scottish Service Model for Chronic Pain which was developed as a response to the GRIPS report published in 2008 ². In addition, the Courses assist NHS Pain Services to align with the SIGN guideline on Chronic Pain ³

The Courses provide Clinicians with access to a bio-psycho-social model that addresses some of the non-medical issues that affect health. As such it provides an approved potential exit strategy from a clinical model of care.

**Aims & benefits – Participants**

The aim of the Course is to provide participants with the understanding and skills necessary to enable them to manage their condition more effectively and cope better with the impacts associated with a change in health. If this is achieved, this can have a positive impact on self-efficacy, function, mood, health literacy and a sense of being in control.

**Maximising Access**

The service is set-up in a way that maximises access for Patients and referring Clinicians. The referral criteria are relatively ‘open’ and a limit is not placed on the number of people who can be referred. On this occasion a total of 846 people were given the opportunity to attend the various courses.

**Course Content**

The Course provides participants with a new understanding of health in which the individual can see the role they can play in affecting their health and quality of life. It shows how the complex interaction of their condition, thoughts and feelings and social interactions can lead to problems that make a difficult situation worse.

During the course participants are taken on a journey that puts clinical care in context and moves them towards active Self-Management. The focus of the course is to motivate people to engage in Self-Management by improving understanding and building skills that create an effective ‘personal resource’ that people can use to improve their quality of life and sense of well-being.

An important aspect of the Course is that it imparts a new mind-set in which the individual is more inclined to see what they can do themselves, rather than to automatically rely entirely on a Medical approach.

The Course focuses on addressing the impacts of Chronic Pain regardless of diagnosis. In this way, universal messages can be delivered that apply to everyone. The topics covered on the course are:

- Understanding Chronic vs Acute Pain
- Relaxation skills
- Pacing
- Goal setting and Baselines
- Improving sleep
- Communication and dealing with others
- Dealing with negative and unhelpful thinking
- Problem solving
- Stress and Anxiety management
- Rebuilding confidence and self esteem
- Flare-up planning
- Communication
- Role of medication
- Acceptance & adaptation

The Course is open to Clinicians to visit. It provides them with an opportunity to experience a different model of interaction and learn more about Self-Management strategies and Psycho-Social aspects of health. During the period of this report various courses were attended by health care professionals.

**Approach**

The Course is different in kind to many more basic Self-Management programmes. It is delivered by the Lead Trainer from Pain Association Scotland, who has considerable experience and excellent group-work skills and is therefore able to work in a flexible and interactive way. This is important since participants in the past have said that they benefit from the continuity of support that this creates.

Pain Association Scotland have developed a unique combination of expertise and professional standards combined with a highly credible model of interaction which participants say is particularly effective since they feel treated as people not patients. This is vital in dealing with a group of people who may be frustrated by their journey through the healthcare system.

The Course has been developed with sensitivity to patient needs and perceptions. It is not delivered ‘out of a book’ or by Power point. This improves credibility and keeps participants engaged.

Experience has also shown that the best learning takes place in a non-linear fashion with a need to ‘zig-zag’ through the Course. In practical terms, this means that topics are delivered in a way that reflects the needs of the group as they find their own way through the course. The benefit of this interactive approach is that people feel involved and do not feel that they are being patronised or lectured at. The interactivity means that the trainer can identify blocks to progress and help people to address them. This may involve explaining things differently, or getting the group involved in a problem solving exercise.

The Course offers a non-medical approach to health problems. The trainer therefore uses non-medical terminology to explain complex concepts, simply. Metaphors, examples and stories are used to help people to learn. Although the subject matter is serious, the mood engendered in the group is friendly, interactive and personable with plenty of room for sharing and humour. This helps people to get to grips with the subject matter and motivates them to put their learning in to practice.

**Benefits of a group based Course**

The Course delivered by the Association makes full use of the benefits that can be gained from a positive group environment.

The Trainer ensures that there is a safe friendly environment and encourages everyone to take part and share as much as they are comfortable with. This is vital because many participants have issues with stress and anxiety and might find it hard to socialise. A positive environment enables vital peer support and problem solving to take place. Many people comment that they: ‘benefitted from being with others in a similar situation’, that they ‘found it helpful to be believed in public’ and that they were ‘interested to hear how others coped’.

Bringing people together with similar problems allows participants to ‘benchmark’ by hearing how others have applied the skills and principles from the Course. This gives credibility to the approach based on the idea that ‘if it worked for them, then it could work for me’.

In addition to training input, we also recognise that isolation is a major problem and so the normalisation, peer support and companionship that a professionally run group environment provides, are vital to the success of the course.
Overall Course evaluations 2014-2015

Information and evaluation results presented in this section consist of:

- Referrals
- Completion rate
- Evaluation results from questionnaires administered at the beginning and end of the course, these were:
  - Depression, Anxiety and Positive Outlook Scale (DAPOS)
  - Pain Self Efficacy Questionnaire (PSEQ)
  - Pain Association’s ‘Skills and Strategies’ Chart
- Anecdotal comments
- Patient case study

Referrals

There were a total of 846 referrals to the intensive self-management courses. Out of the 265 people who committed to attending the courses, a total of 247 people completed.

Completion rate

The average completion rate for the 25 courses was 93%.

Evaluation tools

The evaluation tools used to assess progress on the course are recognised measures that capture information about progress in areas that the Course seeks to improve. These areas include: function/self-efficacy; Depression, Anxiety & Outlook; the acquisition of skills, strategies and understanding. The Paired T Test calculator was used to compare the means of two sets of scores (pre and post) directly related to each other and to calculate the actual difference in scores and whether this was considered to be of statistical difference.

Pain Self-Efficacy Questionnaire (PSEQ)

The PSEQ measures people’s beliefs that they can continue to perform important activities despite the presence of pain. It consists of ten items, such as “I can still enjoy things, despite the pain,” and “I can still live a normal lifestyle, despite the pain.” Each of the ten statements is rated on a scale of 0 to 6 (where 0 is ‘not at all confident’ and 6 is ‘completely confident’).

The PSEQ score is the sum of the ratings for each statement (i.e. the range is 0-60). The authors suggest that a score of less than 17 would indicate that a person believes that pain must stop before commencing activity, while a score of over 40 would lead a clinician to question why the person was seeking treatment for pain.

PSEQ data is available for all participants. The chart below shows that the group’s scores are higher at the end of the course than they were at the start.
**Paired t test results**

P value and statistical significance:
The two-tailed P value is less than 0.0001
By conventional criteria, this difference is considered to be extremely statistically significant.

Confidence interval:
The mean of Group One minus Group Two equals -9.51
95% confidence interval of this difference:
From -10.38 to -8.63

Intermediate values used in calculations:
\[ t = 21.4028 \]
\[ df = 241 \]
standard error of difference = 0.444

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**Depression, Anxiety and Positive Outlook Scale (DAPOS)\(^5\)**

The DAPOS is a measure that has been specifically developed to assess symptoms of depression and anxiety in people with chronic pain.

- The ‘Depression’ score is the sum of five items consisting of statements such as ‘I feel like a failure’ and ‘I blame myself constantly’. These are rated on a scale of 1-5 (1 is ‘almost never’ and 5 is ‘almost all the time’). Scores range from 5 to 25. The authors of this test do not provide cut-off scores, but tables of norms are provided. The tables of norms include the mean scores for a pain management treatment group of 82 people, pre- and post-treatment. For the ‘depression’ scale, the pre-treatment group’s mean is reported as 15 and the post-treatment group’s mean is reported as 11.

- The ‘Anxiety’ score is the sum of three items (eg ‘I get sudden feelings of panic’), rated on the same scale of 1-5; the range of scores is 3-15. The authors’ reported means for pre- and post-treatment are 7.51 and 5.96 respectively.

- The ‘Positive Outlook’ score is the sum of three items such as ‘I can laugh and see the funny side of things’ (rated on the same scale of 1-5; range 3-15). The authors’ reported means for pre- and post-treatment are 8.05 and 10.24 respectively.
Paired t test results – Depression

P value and statistical significance:
   The two-tailed P value is less than 0.0001
   By conventional criteria, this difference is considered to be extremely statistically significant.

Confidence interval:
   The mean of Group One minus Group Two equals 3.66400
   95% confidence interval of this difference:
   From 2.84715 to 4.48085

D = Depression
A = Anxiety
PO = Positive outlook

The DAPOS chart shows the participants scores for all three scales. Scores move in the expected directions for all three subscales (lower Depression and Anxiety scores at the end of the course, and higher Positive Outlook scores).

Paired t test results – Anxiety

P value and statistical significance:
   The two-tailed P value is less than 0.0001
   By conventional criteria, this difference is considered to be extremely statistically significant.

Confidence interval:
   The mean of Group One minus Group Two equals 2.14
   95% confidence interval of this difference:
   From 1.86 to 2.42

Intermediate values used in calculations:
   \( t = 8.8137 \)
   \( df = 480 \)
   standard error of difference = 0.416

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The difference in the N value from the 242 and the 241 of the PSEQ and DAPOS results respectively is due to one participant not completing the evaluation for the DAPOS test.

Intermediate values used in calculations:
   \( t = 15.0994 \)
   \( df = 240 \)
   standard error of difference = 0.142

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Paired t test results – Positive Outlook

P value and statistical significance:
The two-tailed P value is less than 0.0001
By conventional criteria, this difference is considered to be extremely statistically significant.

Confidence interval:
The mean of Group One minus Group Two equals -1.79
95% confidence interval of this difference:
From -2.09 to -1.48

Intermediate values used in calculations:
t = 11.5024
df = 240
standard error of difference = 0.155

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Pain Association Skills and Strategies Chart

The Skills and Strategies questionnaire is presented in the form of a radar graph. Participants are asked to rate themselves on a scale of 0 to 10 on indicators such as 'pacing,' 'understanding chronic pain,' 'dealing with flare-ups,' 'stress management,' etc. There are 12 indicators in total. A rating of 0 indicates that the respondent does not understand or implement the strategy at all; a rating of 10 indicates that the respondent understands fully and/or implements the strategy all the time.

The following radar graph displays the group’s mean pre and post scores on each of the 12 indicators.

The Self-Management skills and strategies chart shows that participants improved in all areas of Self-Management.
Evaluation Conclusion

The evaluation tools administered pre and post Course show improvements in all areas. The skills and strategies chart shows significant improvements, which means that participants have learnt the skills and strategies necessary to manage and cope better. The acquisition of these skills has demonstrated improved function and mood as measured in the DAPOS and PSEQ questionnaires.

Overall Conclusion

The 25 courses provided in the various NHS Health Board areas with a high quality cost effective provision of Self-Management courses for people with Chronic Pain. The project represents a significant ‘foot-print’ for a relatively low cost service.

Summary

- An answer to recommendations made by Health Improvement Scotland
- Enables Health Board to implement part of the Scottish Service Model
- Improved access to Self-Management for people with Chronic Pain
- Bio-Psycho-Social model
- Person centred approach
- Referrals from Primary & Secondary Care
- 86% completion rate
- Recognised tools used for evaluation
- Improvements in Self efficacy, Anxiety, Depression, Outlook, Skills and strategies

The future

The next step in terms of research is understanding the phenomena of knowledge transfer within a third sector organisation.

To date, there have been numerous valuable and informative studies which examine the significance of knowledge and knowledge transfer in a healthcare environment, most notably a review of health sector and generic management literature (Crilly et al. 2010). Informed by this literal positioning, future research will set out to explain the usefulness in adopting a POPC (Psychological, Organisational, Philosophical, Cultural) methodology where interpretation of knowledge transfer mechanisms continues to draw significant incredulity. The case study will consider the management structure and resource implication of a third sector organisation and establish if the current resource utilisation strategies adopted by the organisation can be improved. The literature review scope included healthcare and generic management domains. Using a POPC methodology (Fascia 2015), data collection included perspectives of organisational processes and structures, disciplinary fields, knowledge transfer and associations to facilitate knowledge sharing.

Other aims over the next 12 months are to:

- Increase GP referrals by 20% from the previous 12 months. This should underpin all the additional work taking place nationally within Primary Care in disseminating the message around self-management to patients and ensuring they have access to this at a much earlier stage in their pathway of care.
- Reduce the DNA rate by 10% from the previous year by increasing collaborative work within Secondary Care with health care professionals, ensuring that they are emphasizing and engaging their patients to the commitment of self-management.

References

1. Health Improvement Scotland Update report on Scottish Pain Management 2012
   www.healthcareimprovementscotland.org
2. GRIPS Report Update Second edition July 2008 published by Health Improvement Scotland
   http://www.healthcareimprovementscotland.org
3. SIGN guideline 136 Management of Chronic Pain published December 2013 by Healthcare Improvement Scotland
   http://sign.ac.uk/guidelines/fulltext/136/index.html
   European Journal of Pain, 11, 153-163
   May: 109 (12):181-8
Anecdotal comments

Was uncertain about the course, grew on me after the first session. Relating stress to pain was a revelation to me. The session on relaxation/stress management was most enjoyable and thought provoking. Relating communication etc to stress – pain and the remedial issues were very interesting. Group participation was useful but sometimes rather distracting – would have preferred to hear more from Mr Sizer! The course has given me new direction and chain of thought. Overall I enjoyed the course and would like to participate by attending the local group.

I've come a long way during the course. I've picked up a lot of good ideas. Putting relaxation into practise – this is something I never thought I could do. I now don't feel like I'm the only one going through chronic pain. It's been enjoyable, looking forward to the review.

It's been good for me to come and listen to others and I've benefitted from the sessions. Looking forward to the review. I will attend the Arbroath group. Glad I came.

I have really enjoyed this group. It has been nice to be around others that understand how I am feeling. The information contained in this course has been helpful and interesting. I feel I have the tools now to help make my pain better and to cope better in a flare up situation. I have enjoyed the relaxation part of the group, it has made a great difference to my stress and anxiety levels. This group has picked me up again when I have been feeling down and given me a weekly boost.

It has been an eye opener for me, I have learnt so much about me and pain. I feel I have come so far in such a short time, from not being competent to being in control of my life. Sleep was a nightmare, now I sleep every day, it is more calm and controlled. The relationships are much better. Phil is a very good trainer.

Now walking confidently mostly without sticks!

The course has opened up my eyes on how to cope and relate which helps me from day to day with stress and pain management. It has been really good and would recommend it to anyone. I was drinking 25 cups of coffee a day, but due to relaxing and staying positive reduced to 5 cups a day, changed my life. Thanks Phil.

This course is a real eye opener to all things that go on in life/body in regards to pain and how it corresponds to each and every body's life. Phil is fantastic at getting everyone to open up and see the bigger picture in regards to pain. Phil is fantastic and does a great job, lots of respect to him. Very enjoyable and informative. Manages topics very well with everyone even the ones that can’t relate. He's managed to help me mentally with how I look at things and always there to listen to my "life" and how my family life is complicated and he's helped me manage this better. Highly recommend to professionals to send others on this course. Keep up the great work Phil.

I have enjoyed it. There has been things I can relate to and I have taken on board things which have been discussed which in time I hope my pain will improve but my problem is putting the things I know I do wrong into practice. With the result I have learned to live with what I have. BUT thank you for the course. It has been a pleasure with the teacher and the company.

I have enjoyed the self-discovery journey that the course has brought out in me. I am very practised in helping others be the very best they can be in mind, body and soul but I quickly realised when starting this course I have not done this for myself. It was very much a case of "Don't do as I do, do as I say" which on reflection is quite hypocritical which I had not judged myself to be. I am certainly more enlightened than when I started, have more tools at my disposal to facilitate my own management of my conditions which will only be of benefit. I found Phil to be an inspirational speaker, capable of giving and receiving to and from the group and I have thoroughly enjoyed
the experience and will continue to grow because of it. Many thanks!

Phil is great at explaining both situations and ideas. He is a very good tutor. My biggest problem about the entire course and all its ideas and processes is to remember what I need when I need it. The handouts are good especially to be able to look back and try to remind myself. I am glad I attended this course and I will be continuing to attend the monthly meetings. Thank you for running the courses.

This course has helped me cope with understanding my feelings. People in the group talking and knowing how they must feel. Good course, would like to come again.

Good to be in the company of others in a similar position. Have learned new skills to enable me to handle pain better. Pacing and breathing skills have been useful.

Really enjoyed this five week course. I found I most helpful in lots of different ways. I can now relax and cope a lot better.

The course increases awareness that you are not the only person suffering pain that effective management of your condition can enable you to lead a normal life albeit with the pain. You can do anything that you want to do and if you choose your options carefully and with thought the pain becomes secondary and you can manage everyday life, you make the choices that mean you can cope better.

You still feel pain but not the intensity that you probably felt before you came on the course. Easily understood lessons that are in all cases clearly put forward.

Thank you for re-enforcing techniques that when you think about it are just common sense.

I learned quite a lot do things in the 5 sessions and can feel the benefit already. Some things I have already tried in the past, but hearing them again from Phil and up to date info enforced my old techniques to work even better. Information was clear and understandable.

Also in a relaxed friendly atmosphere with breaks at just the right time. I would have liked more information at a faster pace. Very happy with course results.

I have found the course very helpful – being with people in similar situations with no judgement or criticism lifts the morale. Phil is an excellent group leader with plenty of interaction and a great deal of patience. I have learnt to relax more when in pain and to distract myself and cope with the stress.

Really enjoyed this 5 week course. I found it most helpful, I learnt to do pacing.

I feel that the course has helped me with decisions that I needed to make about my life. I was aware of most of what has been discussed but I now feel for the most part that my life can be easier to control.

I found the course very informative. No-one has talked to me about chronic pain until now. Also being around people in a similar situation is very good and I found them very supportive. I now know there is a reason for the pain and it’s not in my head. I am glad there are follow on sessions as I am struggling coming to terms with it. I feel I benefit from the support and info from the group and I am glad I came. I was initially not going to bother as did not see how it would help but I have been proven wrong. The group is a VERY GOOD idea!

I have found the course to be very helpful in changing the way I look at day to day issues. The highlighting of stress management and pacing have been the most important aspects covered (for me at least) I now find I am looking for ways to avoid “Boom & Bust”. One aspect I feel a lot of people would benefit from would be a hand out for partners/spouses/family – highlighting how much they can help just by understanding the issues we face each day and the type of thing they can do to help (e.g. less demands on your time and energy). Overall very worthwhile.

Being dyslexic and diabetic back and right leg takes over one’s life, but trying to break down
the illness into lists and breaking down into smaller parts and tending to each.

What did I think of the course, at first I thought it was a weak psychological approach to make you feel better (it’s all in your head). As the course proceeded I gained a better understanding which I related to. The lecturers were good as far as trying to explain a very difficult subject. Thoroughly enjoyed.

Relaxation exercises very good. I’m still trying to practice these. I realise that others are not mind readers and I have to tell them when I’m feeling down and in pain. The course has been helpful overall.

This course was very helpful to me. It made me think about things differently and although I was in a lot of pain it was worth it.

The course gave me a lot of info about pain. It is a totally new concept to what I thought before. Good info on medication. Bad points – sitting for too long. Really good course.

I found the course enlightening and worthwhile and useful. I now have a more informed mindset on how my condition affects my life.

I feel the course has helped me understand how to cope with dealing with other people about my pain. Also being able to tell people when I’m having a bad day whereas before I would keep things to myself and go quiet. Also understanding how other things e.g. stress can affect your pain. Thank you.

Very informative – physiotherapists talk was invaluable in many respects.

Looking forward to attending the support meetings. The ongoing opportunity for support will be invaluable and encourage me to follow the guidance from this course.

I enjoyed the course, it has helped me cope with my pain. I feel I am not the only one and I am not alone in dealing with pain. Thank you for your support.

Course has helped pacing – can take a break from activity and return to it. Before would normally finish the job before taking a break. Relaxing – now use relaxing techniques especially before sleeping which has helped. Thinking – now consider what I have already done rather than what still has to be done. Doing – take more time to read and go for a walk rather than always chores to be done. Feeling – because of all the above feeling more relaxed and don’t stress about things to achieved.

It has been helpful to gather with others who understand what pain is. I now try to pace myself, asking family to help out with chores. I used to force myself to go to Aberdeen to see my daughter even though feeling rubbish, I now don’t feel as bad when I say I can’t go. The whole course has been good as it is making me aware of how I feel. Talking about my feelings is difficult, but it is getting easier. I now make sure I take time for myself even when at work over lunchtime I go into a quiet room to chill, I didn’t think I would be able to, but I am very glad I did.

Pain Association group I feel has been helpful. Our group I feel are really good, it’s good listening to what they are saying. I feel the strategies that Phil has put in place are helpful and make sense. I love the relaxation, I feel you drift off to a beautiful place. It has made me pace myself better and made me feel good about myself. It’s not just pain that I suffer from so some of the topics he puts across have been helpful. Nothing bad to say, 5 star.

This group has helped me understand why my mental health is affecting my body physically. Pain and stress go hand in hand. If I replace stress by relaxing daily and trying to be positive my pain reduces. I have found the sessions at times extremely uncomfortable, especially talking about thoughts, feelings and stress. As a type A life has been continually stressful. I need to be disciplined to pace myself and try stress reducing activities to help myself. Changing my thoughts and feelings is going to be hardest of all. Having deep rooted psychological issues, I feel it is too hard to deal with at times. Overall
good course, good facilitator and easy to understand content.

The class was very productive, it helped me to understand my condition better and to pace myself more.

The course was helpful and friendly. There was a nice relaxed feel in the group.

The course was good and well explained with lots of different topics discussed which were all relevant to my pain. The most relevant topics for me were relaxation and pacing.

Realising that there were other people who understood me and have had similar experiences removed my feelings of isolation. Being able to talk and share with fellow sufferers has been invaluable. Phil has provided me with an insight and understanding as to why I feel the way I do. He has provided me with a form of words to allow me to communicate how I feel to those close to me. Relaxations, pacing and changing mindset by focussing on the positives in my life have allowed me to better control my stress and anxiety and to act prior to situations getting out of control. This has also allowed me to manage flare ups better. The tools to manage pain and the proper techniques in how to use them have been a revelation to me. I believe that this course is a must for all sufferers of chronic pain.

I have enjoyed the course immensely, I feel it has changed my outlook in life. I listen more to others, take in information and see how it will affect me and others around me. I am understanding my pain a lot more now, I find I am pacing out my day and finding time to relax a lot more. I have gained a lot more confidence in myself and enjoyed the company in the group. I find Phil is very easy to listen to and treats everyone the same and is also a good listener. This course has been excellent for me.

Since the class started 6 weeks ago, I feel more confident to speak to other people as I am quite shy. I have felt I am more relaxed as I do this before I go to bed, but if I am in a lot of pain does not make me feel that my muscles are more relaxed as well. I think I will keep going to the local group as I have been doing more reading to keep my mind relaxed before bed.

Class was very interesting. Made me look and analyse pain. Gave me a reason to stop and take 5 - 10 minutes an hour to close my eyes with the help of listening to someone talking whilst relaxing. Looking at my illness in a different way. Knowing that thoughts can help your pain, not a tablet.

Pacing myself more, leads to relaxing more. While still hitting slightly more achievable targets find I can more positively self-talk myself. Don't feel so isolated by the pain and the restrictions it causes. I understand more about the ups and downs of pain and feel I’ve been given the tools to cope better.

Excellent course. Very useful and thought provoking. Good information, put across well in a safe supportive environment. I have been able to make positive changes with consequent benefits of decreased symptoms (pain & fatigue) and an increased sense of well-being. Thank you Phil. I look forward to the sixth session & the maintenance/monthly sessions. Even if some of the info/discussions covered areas I’ve previously worked on (or have been covered in previous sessions) I have felt the benefit of repetition as I have seen some aspects from a different perspective or just found the re-enforcement useful in motivating a change in my thoughts/feelings/behaviour. The course has been worthwhile and despite requiring effort it has been of benefit to how I feel pain and what I can do to make things better. The amount of negative thoughts I have had in the past have decreased and my understanding of pain has shifted somewhat. How the course has been delivered in a relaxed and fun environment rather than in a “medical” setting makes a difference i.e. not a hospital setting. Well worth the effort and highly recommended.

The course was intensive, with bits of jargon which was explained to us visually or orally
which was good. I learnt a lot of new things about pain but find it hard to remember it all and apply it so really need to concentrate on the sheets given out. It has been helpful to recognise how to break cycles that are not helpful and to see how other things cause more pain. I would have liked the sheets to be even more technical/descriptive than they were to totally summarise what we learned at each morning, by ending with actions that we need to perform. I felt at times the course was more aimed at mobility problems which are not relevant to me as I have only neuropathic pain.

I have found this course very interesting and have recommended it to others.

Having things written down makes it make more sense in your head.

Most importantly I have learnt to relax and hopefully this will help me to cope with the pain, particularly in bed. I cannot cope without medication but with this, life is bearable if difficult. Most important is not to give up doing what I want to and realising any limitation.
Case study

REFLECTIONS on SELF-HELP MANAGEMENT PROGRAMME run by PAIN ASSOCIATION SCOTLAND

Nov 2014

**Patient Perspective:**

I have found the programme hugely beneficial and enjoyable.

The 6 week intensive course was well designed to cover the basics of pain self-management and was informative and motivating.

Phil is a superb facilitator and makes each session relevant and interesting.

The atmosphere is welcoming and participants report feeling “safe”.

Phil listens to the group in the monthly sessions where the topic is not set and responds to ideas and any needs expressed, taking the session in the direction that is most useful for the group.

One participant, who says she has been attending for 3 years, said that she learns something new at every session.

I had previous knowledge and had already used many of the techniques and strategies mentioned. However, Phil presented the information in an interesting way, sometimes offering a different angle or perspective and generally using illustrations and often humour to explain a point.

The techniques are simple and practical – although often more difficult to adopt and maintain.

I have made every effort to attend each session as I know I will leave the session motivated – if not inspired!

The benefits to participants are physical (everyone reports feeling better after a relaxation session); mental (greater understanding, knowledge, strategies for dealing with pain) and social (feelings of cohesion, not being alone and social contact).

Several members of the group also attend hydrotherapy together and meet out-with the group.

Attending the sessions has given me more control over my symptoms which now impinge less on my life, but has also given me more tools to use to improve my overall health, well-being and quality of life.

I hope the service will continue to run because the benefits are clear to those that have attended.

**GP Perspective**

I work part-time as a General Practitioner. I qualified in Medicine in 1985 and have been working on the Island of Lewis for 24 years.

As a medical practitioner I feel this service compliments the standard services offered within the NHS and offers a refreshing new model for patients suffering with chronic pain to consider.

From my experience in General Practice I am aware of the number of patients that get “stuck” with chronic, painful conditions and the limitations of drug therapy and surgical management.

This approach can enable participants to take more control of their condition and it makes
practical and realistic suggestions on how participants can improve their situation.

I have had positive feedback from patients who have attended the course, who feel it has helped them change their lives and live more comfortably with their long-term condition.

I am also aware that other patients have been attending the group for years and have recommended it to others as being useful.

The skills taught are relevant for addressing the issues surrounding chronic pain, but are also useful to address stress and may help other un-resolved chronic symptoms – or the suffering associated with these symptoms. Many of these self-help skills are actually basic life skills that all patients would benefit from.

As a GP I am encouraging patients who, I believe, would benefit from this service, to attend. I am highlighting the service to colleagues in primary care but also within the wider multi-disciplinary team.

I think this service is invaluable. Both elements are hugely important - the 6 week intensive course and the monthly group meetings.

I hope that this approach of self-management in chronic conditions is valued and supported to ensure more effective and efficient management of these patients.
The significance of Health and Social Care Sector involvement for Scottish chronic pain patients.

Author: Sonia Cottom

Abstract: Chronic pain is a major clinical challenge in Scotland and across Europe as a whole. It is estimated that 18% of the population are currently affected by severe chronic pain. In the United Kingdom, approximately a third of the population suffers from chronic pain. The severity, cost implications and effect of Chronic Pain on sufferers' lives has delineated the importance of third sector involvement for chronic pain patients. This involvement focuses on improvements to the quality of life for sufferers, through the controlled delivery of self-management support groups. Through monitoring and diligent reporting mechanisms, quality of provision is able to be matched to specific requirements of patient cohorts. This enabling characteristic is an important resource for many sufferers and validates the important position held by third sector providers of resource for chronic pain sufferers.

Introduction

This article will discuss Health and Social Care Sector (Third Sector) involvement with Chronic Pain patients from the perspective of Pain Association Scotland. This viewpoint is important because, as some observers note, the third sector is by nature unsuited to singular definitions and often narrowly concomitant with the idea of voluntarism. The view of this proponent is that a third sector organisation comprises of a mixture of social organisations both private and public and most certainly a societal process and far beyond deleterious provisions of something which is “not-for-profit”. Additionally, to conclude an acknowledgement of differential focus, in that, on the one hand economic focus may be on the associated NHS wealth distribution of long term conditions, whereas sociologists maintain a perspective of value driven motivation by a patient or cohort of patients. Therefore, it is important to reveal the underlying boundaries and parameters which encompass a third sector organisation, specifically related to chronic pain patients.

Background

In addition to the Chronic Pain statistics quoted above, low back pain (LBP) is internationally recognised as a significant health, social and economic burden e.g. 0.8% and 2.1% of gross domestic product (GDP) in some US and European countries. In the United Kingdom, approximately a third of the population suffers from chronic pain in some shape or form. The consequences of this have a significant impact on quality of life, suffering and disability. Chronic pain affects individuals and their families, and comes at a significant economic cost. Lower back pain is estimated to cost in the region of £12 billion per annum in the UK in 1998, and arthritis-associated pain costs around 2.5% of the gross national product of Western nations. (SIGN 136 – Management of chronic pain) More recently it was estimated that people with chronic pain are responsible for almost 5 million GP appointments in the UK by people seeking help and relief from chronic pain and in many cases, they leave without answers and without effective pain relief with a related cost of almost £70 million to the NHS. On 29 May 2013, the Scottish Government, announced the need to accelerate improvement across all levels of care for Chronic Pain sufferers. This initiative resulted in Service Improvement Groups (SIGs)/Managed Clinical Networks (MCNs) established or in the process of being established within all NHS Boards in Scotland to drive improvements in the management of chronic pain. Informed by this national position, Pain Association Scotland has been developing support programmes for Chronic Pain Sufferers for 25 years and more recently
aligned to the Public Bodies (Joint Working) (Scotland) Act 2014, which puts in place the statutory framework for integrating health and social care in Scotland.

Is pain a Reality?

Chronic pain has a high impact upon physical, psychological and family health. Issues include, but are not limited to; depression, long-term stress, isolation, high levels of medication, poor mobility, lack of self-esteem and fatigue. Pain can be interpreted as being an isolating experience, as there may be a stigma associated with the condition.

“Chronic pain is not simply a physical problem. It is often associated with severe and extensive psychological, social and economic factors. Apart from poor general physical health and disability there may also be depression, unemployment, and family stress. Many of these factors interact, and the whole picture needs to be considered when managing individual patients. The impact of chronic pain on patients’ lives varies from minor restrictions to complete loss of independence.”

The Pfizer Health Report Chronic Pain Survey found that 58% of the people surveyed felt that other people ‘sometimes’ doubt the reality of their pain. In this regard, Chronic Pain often sets the stage for the emergence of a complex set of physical and psychological changes which add greatly to the burden of the pain sufferer.

- Isolation from society and family
- Anxiety, stress, fear, bitterness, frustration, depression, suicide
- Over-dependence on family and other carers
- Depression of the immune system and increased susceptibility to disease often associated with poor appetite and nutrition
- Overuse and inappropriate use of professional healthcare systems

This is not an exhaustive list and in most cases, chronic pain eventually dominates the life and concerns of the sufferer, their family, friends and carers. In addition to the severe erosion in quality of life of the pain sufferer and those around them, chronic pain imposes severe financial burdens on many levels.

- Loss of income imposing financial burden on family and friends
- Job absenteeism and disruption in the workplace
- Increased dependence on benefits
- Costs of healthcare services and medication

Self-Management of Pain

Supporting patients with Chronic Pain needs more than just handing out medication. Over two-thirds (68%) of patients report that their medication is inadequate at times and over one in five 22% have discontinued prescribed pain medication. The Association has continued to provide a high quality staff-led community based service for people burdened with chronic painful conditions. This is because chronic pain is multifactorial, comprising of neuropathic and nociceptive components, based on a bio-psycho-social understanding. To support patients with this condition, the Association has developed appropriate service delivery through collaborative working relationships with Health Care Professionals and extended new joint working opportunities with the majority of Scottish Health Boards. Through the delivery of training courses and self-management groups, service objectives continue to be focused on empowering people with self-management capabilities. This leads to the improvement in quality of life, health and wellbeing for many chronic pain sufferers, their families and carers and colleagues as our resources allow. Such self-management has potential to improve health outcomes in many cases, with patients reporting increases in physical functioning. It can also improve the patient experience, with patients reporting benefits in terms of greater confidence and reduced anxiety.
**Service Provision**

The Association provides around 1710 hours of staff-led self-management training for approximately 1670 participants per month. The highest percentage of referrals come from NHS Ayrshire and Arran and Fife – 21% and 23% respectively with the lowest percentage from Edinburgh and Lothian and Borders at 2% and 0% respectively. Fig (1.0) indicates the number of referrals into the service for 2013/14 period.

Fig 1.0 Enquiries

For the intensive self-management course, the service delivers an average of 24 courses per year and receive an average of 850 clinical referrals from NHS Chronic Pain Services. Figure (2.0) indicates that the highest percentage of those referred to the intensive self-management courses are between the age of 40-59, and therefore of working age. As indicated in figure (2.1), this position is in line with the outcomes of the National Scotland-wide Healthcare Improvement data collection.¹³

Fig 2.0 Age Range
This clearly demonstrates the importance of self-management to support patients back into employment, keep those who are in work at work and also to be able to have the benefit of an improved quality of life in the long-term. Overarching the referral routes, Fig (3.0) indicates the referral channels of patients to the intensive self-management courses, and shows that although the majority of referrals are from Pain Clinics (59%) for 2013/14, the percentage of GP referrals demonstrated an increase of 3% from 2012/13. This increase relates to supporting infrastructure from work going on with the respective Service Improvement Groups (SIGs) and Managed Clinical Networks (MCNs) in each health board.

This initiative encourages more referrals to self-management from Primary Care in order that chronic pain suffers have the option to access self-management at a much earlier stage. This is a positive step in preventing unnecessary referrals to Secondary Care at an average cost of £20 per patient per course.
The course content underpinning these figures includes; the relationship between stress and health (bio-psycho-social), understanding chronic conditions, relaxation, breathing and distraction techniques, experience of combined breathing and gentle stress reducing movement, communication and understanding, pacing and goal setting and dealing with unhelpful thoughts and feelings.

Since these topics are inter-related the experienced staff member leading the group can guides the pace and individual needs of participants attending each session. Figure (4.0) indicates the completion rates for the self-managed courses for the period 2013-14, which cumulates to an overall average of approx. 95%.

**Service Alignment (Health and Social Care)**

NHS Board's collaboration with voluntary sector organisations such as PAS has significant potential to improve self-management, reduce inappropriate referrals and reduce the costs for acute and secondary care services. PAS supports the current Scottish model of pain by delivering a series of self-management programmes.

The service is accessible for all Chronic Pain sufferers, even in remote and rural areas and those who are often isolated, the website enables people access to on-line self-management 24/7. In this way, the service supports the vision of the Scottish Chronic Pain Service Model by shifting the balance of care to the community. Thus, supporting patients to self-manage their pain, this service structure can reduce the impact on both primary and secondary care resources, investigations and treatments. The Association meets the Scottish Government’s objectives of being **Safe**, **Effective** and **Person-Centred** in the following ways:-

**Safe** – a key feature of this type of service delivery is that it offers an open door policy to local self-management groups whether people are referred by a clinician or simply self-refer; at no time is anyone more than four weeks away from a group meeting in their local area. These groups provide the coping skills and strategies which enable people to maintain and support an independent lifestyle.

**Effective** – the service provides an approved exit strategy for health and social welfare professionals and this effectiveness has enabled more Chronic Pain sufferers to access our service as a first step in their pathway of care. The Scottish Government’s Steering Group for Chronic Pain nominated the Association as the preferred/approved provider of self-management training and support and included our model as an integral part of the new Service Model for Chronic Pain services in Scotland enhancing local Chronic Pain...
Services. In addition, the Courses assist NHS Pain Services to align with the SIGN guideline on Chronic Pain.

**Person-Centred** – when someone is in pain they may seek help at that specific time that time. Using this model of care delivery, no-one has to wait longer than four weeks to access a local self-management group or the on-line self-management course, which enables people to have access to the support 24/7. Suffers have access to our Pain Radar Graph at any time, enabling them to monitor their own progress over and period of time.

**Service Assessment**

Monitoring and evaluation is important as it can reinforce service user benefits, and importantly, can record their improvement by using standardised tools. Within Pain Association Scotland, the Pain Radar Graph (Fig 5.0, Spider) is used to reflect progress and note unique anecdotal comments.

Fig 5.0 Spider Model

This tool is supported by DAPOS (Depression, Anxiety, Positive Outlook Score) Fig (5.1) and the PSEQ (Pain Self-Efficacy Questionnaire) tool, as shown in figure (5.2). The use of appropriate evaluation tools underpins evaluation, and in most cases validates the patient report analysis, which indicates reduction in depression and anxiety and an increase in positive outlook and self-efficacy.

Fig 5.1 DAPOS Model
Ultimately, for any provision of service, and definitely within the healthcare sector, it is vital that both health professionals and potential funders acknowledge clear benefits of improved patient health and well-being, cost-effectiveness which are overarched by the adoption of this tool and model architecture. As a consequence of this intense monitoring strategy, individuals who have participated in intensive Self-Management Programmes report more vitality, less pain, less dependence on others, improved mental health, and are more satisfied with their lives compared to those who have not taken part. Increased self-efficacy is closely related to successful rehabilitation. The service provision is specifically designed to target those in the community who are affected by Long Term (Chronic Painful) Conditions. Service provision under this paradigm, continues to address the non-medical issues which impact on people’s lives, thus, self-management programme offers a different paradigm – it is not a replacement for medicine – rather it focuses on highly relevant topics and can facilitate the change of locus of control and improve those aspects of life that only that person can improve by regaining control. In this way, the benefits are equated as giving a practical next step for someone who has reached the limits of medicine. This focus helps introduce people to, and quickly build, self-management skills, thereby creating practical positive change and leading to an improved quality of life and wellbeing. Chronic non-malignant pain continues to present a challenge not only for those affected but for all health professionals involved in their care. Additional feedback comes from staff working directly with our users, questionnaires, forums, calls to free 0800 enquiry line, positive collaboration with healthcare professionals.

**Conclusion**

Sufferers of Chronic Pain have been poorly supported in the past, and many sufferers report that their pain is not believed or that there is apathy to the condition. This discussion has shown that through a network of staff led community based self-management groups and training programmes, service provision can be developed to help with this situation. Utilised in this way, the correct service structure empowers chronic pain sufferers, their carers, family and colleagues to make positive practical changes leading to improved levels of coping, well-being and quality of life, without impacting on the already under resourced NHS services. Clearly, focused, managed and monitored resource can help sufferers understand and manage their chronic pain condition and unwanted change in health outlook by seeking positive adaptive and coping mechanisms which can ultimately lead to a better quality of life.
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