**Abstract**

Background: This study investigated the impact of a literature-based intervention – The Reader Organisation’s ‘Get into Reading’ shared read-aloud model – on people with chronic pain in a clinical setting. Method: A mixed methodology approach was used. Quantitative self-report measures tested the effect of Get into Reading on participants’ psychological symptoms and function before during and after the reading group. Qualitative individual interviews and a focus group explored participants’ experience of Get into Reading. Results: Three key themes emerged from the data: the value of the literature read in terms of quality and diversity, and in terms of promoting absorbed concentration and ‘flow’; a sense of shared community; improvement in mood, function and quality of life. Conclusion: The study has demonstrated that Get into Reading can have a positive impact on the lives of people suffering chronic pain, which may help to alleviate some features of the condition with minimum risk of side effects.

**Key Words**

Reading Therapy, Chronic Pain, Literary Reading for Health, Arts in Health.

**Introduction**

This study investigated whether ‘Get Into Reading’, a literature-based intervention, was beneficial for people with chronic pain when delivered within a clinical setting. The study was conducted through a partnership between researchers from the Centre for Research into Reading, Literature and Society at the University of Liverpool, The Royal Liverpool and Broadgreen NHS Hospital Trust, and The Reader Organisation, a nationally recognised centre for the promotion of reading and positive mental health.

**Background**

***Chronic Pain***

Chronic pain, as it is medically conceived, is an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage. It is pain which persists for more than six months. Chronic pain is common, affecting between 10.1% and 55.2% of the population (Harstall & Ospina, 2003). It can be very difficult to treat and causes considerable suffering. Treatment is by combinations of medication (often causing serious side effects), interventional procedures (which may be painful in themselves) and psychological support.

Chronic pain is associated with varied aetiologies but may result from neuronal plasticity increasing the number of neurones conducting pain in the spinal cord. There can also be changes in the brain, particularly the frontal cortex. Imaging, such as functional magnetic resonance scanning, has shown that the brains of people with chronic pain can be different to those who are not sufferers (Davis, 2011; Tracey, 2008).

Chronic pain, as it is individually suffered, is a subjective experience perceived directly only by the sufferer, which can serve to distance the person from their social networks. Pain is a multidimensional phenomenon that can be described by pain location, intensity, temporal aspects, quality, impact and meaning. It does not occur in isolation but in a specific human being in psycho-social, economic, and cultural contexts that influence the meaning, experience and verbal and non-verbal expression of pain. The consequences of chronic pain are widespread and can include economic, emotional, vocational and occupational deprivation (Breivik, Collett, Ventafridda, Cohen, & Gallacher, 2006) and sufferers can become socially isolated due to both direct and indirect effects of pain, and experience reduced quality of life.

Cognitive behavioural therapy (CBT) has been beneficial to some chronic pain patients, partly due to the benefits of group work ([Sveinsdottir](http://www.ncbi.nlm.nih.gov/pubmed/?term=Sveinsdottir%20V%5Bauth%5D), Eriksen, [& Reme](http://www.ncbi.nlm.nih.gov/pubmed/?term=Reme%20SE%5Bauth%5D), 2012). However a recent Cochrane review has highlighted the relatively small effect sizes achieved with CBT interventions for chronic pain (the overall effect was significant (Z = 2.66, P < 0.01) with a small effect size: standardised mean difference (SMD) -0.19 (95% confidence interval (CI) -0.33 to -0.05)) although these were comparable with the effect sizes for pharmacological and physical treatments (Williams, Eccleston, & Morley, 2012). Given the limitations of existing interventions to resolve chronic pain, the authors suggest that a shift in focus towards a more reasonable goal such as how to live more satisfactorily with chronic pain is now necessary. Morley (2011) suggested that future research should explore how to enable patients to manage the interruption caused by pain and to reduce its interference with their lives, thereby improving quality of life and repairing damaged identities. (Interruption refers to the impact of pain on the disruption of attention and its behavioural consequences on a moment-to-moment basis.)

Although a widely recognised concept in the area of positive psychology and Occupational Therapy, flow has often been overlooked within the study of chronic pain with few studies focusing on its potential to ameliorate chronic pain (Robinson, Kennedy, & Harmon, 2102). Flow is conceptualised as an optimal psychological state occurring when a person is completely engaged in a valued activity (Csikszentmihalyi, 1990). Occupational flow describes a point at which someone is presented with a ‘just-right challenge’ where their skills are balanced harmoniously with the challenge and the person is focused upon a clear task with strong concentration and focused attention. This state is associated with loss of inhibiting self-consciousness, and a heightened awareness of present being. In this positive state, whilst engaged in an intrinsically rewarding activity, a person can feel in control, calmed, lose their sense of the pressure of ongoing time, becoming entirely present-focused. In an optimal state of flow people can also lose awareness of their physical needs and state, such as pain. Flow is a common life experience, occurring when a person is absorbed in learning, work, leisure activities or sports and it can make a vital contribution to a person’s sense of well-being. Hence valued occupations have the potential to trigger flow and theoretically modulate the pain experience. Given the occupational deprivation amongst people with chronic pain, it is likely that they are presented with few opportunities in their daily lives, where flow may be achieved. By making provision for activities with the potential to create flow it may be possible to enhance the quality of life and modulate the pain experience. Reading is such an activity and when conducted within a group setting offers the additional opportunity to overcome the social isolation that can be a consequence of chronic pain.

***The Reader Organisation***

The Reader Organisation (TRO) is an award-winning charitable social enterprise working to connect people with great literature, and each other. Its mission is to create environments where personal responses to books are freely shared in reading communities in every area of life. Beginning life as a small outreach unit at the University of Liverpool in 1997, the national charity (established in 2008) pioneered the weekly ‘read aloud’ model at the heart of its Get Into Reading project (GIR), an established health intervention, which currently delivers over 360 groups each week across the UK. The read-aloud groups take place in a variety of locations, including hospitals, prisons, corporate boardrooms, schools, GP surgeries, libraries, community centres, care homes, asylum seeker hostels and supermarkets. TRO works with partner organisations in a wide range of sectors, including public and mental health, education, criminal justice, social care (older and younger people), local authority, corporate and voluntary. In 2012, the charity was recognised by *The Observer* and NESTA as one of 50 New Radicals in Britain, transforming society through its innovative approach, and was awarded the Social Enterprise Mark demonstrating that its trade income is reinvested for social good.

***The Reader Organisation and Clinical Care***

During the last six years, TRO has been delivering GIR in a range of clinical settings across the North West, South West and South East of England and is currently developing new projects in North East England, Scotland, Wales and Northern Ireland. Delivery partners include (in [North West](http://www.thereader.org.uk/where-we-work/north-west/liverpool-northwest.aspx) England) Mersey Care NHS Trust, Wirral Public Health, Greater Manchester West, Manchester Health and Social Care, 5 Boroughs Partnership, Cheshire and Wirral Partnership, Pennine Care, Cumbria Care, Lancashire Care; (in [London](http://www.thereader.org.uk/where-we-work/london.aspx)), Central London Community Healthcare NHS Trust, Central and North West London NHS Foundation Trust, South London and Maudsley NHS Foundation Trust, West London Mental Health NHS Trust.

TRO’s approach aligns with the ‘Healthy Lives, Healthy People’ strategy for public health in England (Department of Health, 2011), the Five Ways to Wellbeing (New Economics Foundation, 2008), and the 2011 cross-government ‘No Health Without Mental Health’ (Department of Health, 2011) which aims to improve and maintain health through early intervention and prevention strategies that tackle underlying causes - chronic loneliness, isolation and inactivity. GIR has been nationally lauded as a positive health and social care intervention and was highlighted in the Department of Health’s New Horizons consultation document as a non-pharmacological/medical intervention that can help improve quality of life.

***Centre for Research into Reading, Information and Linguistic Systems (CRILS)***

The current report has been conducted by the Centre for Research into Reading, Information and Linguistic Systems (CRILS) at the University of Liverpool. Its initial published studies on the relation of reading to health and wellbeing focused on the effects of GIR’s shared reading model in community settings (Hodge, 2007; Billington & Sperlinger, 2011), and in health care and rehabilitation centres (Robinson, 2008; Davis, 2009). Observed and reported outcomes (Robinson, 2008) for participants included: being ‘taken out of the themselves’ via the stimulation of the book or poem; feeling ‘good’, ‘better’, ‘more positive’; valuing an opportunity and space to reflect on life experience, via memories or emotions evoked by the story or poem, in a convivial and supportive environment; improved powers of concentration; a sense of common purpose and of a shared ‘journey’; sense of pride and achievement; valued regular social contact. GIR group members often report a sense of the book itself as a voiced human presence in the group and its emotional centre. GIR’s read-aloud model encourages ‘interpersonality’ both with the book, and its author and characters, and with other group members. (Davis, 2009) A recently published study on GIR’s shared reading model in prisons shows how fiction and poetry demand the kind of continuous mental agility and moral and emotional flexibility that few activities (including other arts-related ones) can demand with equivalent directness and immediacy (Billington, 2011). CRILS’s research on the benefits of shared reading for dementia sufferers found that GIR produced a significant reduction in symptom severity by promoting enjoyment, enhancing listening, memory and attention skills, encouraging a sense of meaningfulness and renewed awareness of personal identity. This study also identified GIR’s distinction from other reading therapies (self-help, for example) in its emphasis on the importance of literature and on active participatory reading. GIR produces (1) liveness, as a result of the literature being read aloud, often repeatedly, since its richness is never fully exhausted, and (2) immediacy of feeling, in responses triggered by specifics within the book or poem (Billington, Carroll, Davis, Healey, & Kinderman, 2013).

The most significant relevant research relates to the benefits of reading in relation to depression (Billington, Dowrick, Hamer, & Williams, 2011; Dowrick, Billington, Robinson, Hamer, & Williams, 2012) which identified distinct, yet reciprocal mechanisms of action in GIR, the most important of which were the roles of the **literature,** the **project worker** and the **group** process, which together helped participants to discover new, or rediscover old or forgotten modes of thought, feeling and experience. Related research suggests that the inner neural processing of language when a mind reads a complex line of poetry has the potential to galvanise existing brain pathways and to influence emotion networks and memory function (Davis, Thierry, Martin, Gonzalez-Diaz, Rezaei, & Roberts, 2008; Davis, Keidel, Gonzalez-Diaz, Martin, & Thierry, 2012).

This study builds on and adds to the existing strong evidence base in relation to GIR as a mental health intervention by collecting data for the first time in the field of physical health, where the relationship between physical and mental health is particularly close. Currently Western Medicine regards chronic pain as a reorganisation syndrome affecting the central nervous system. Due to plasticity in the central nervous system, there are substantial structural and functional changes associated with chronic pain (Henry, Chiodo, & Yang, 2011). In contrast to acute pain, that is, chronic pain can occur completely independently of any peripheral noxious stimuli. From the patient's point of view it is an emotional condition as well as a physical sensation. It is a complex experience that affects thought, mood, and behaviour and often leads to isolation, immobility, and drug dependence. In that respect chronic pain resembles depression, and the relationship is intimate. Pain is depressing, and depression causes and intensifies pain. There is a complex relationship between depression and chronic pain. Evidence suggests that there is an association. Coexisting pain and depression may represent the final point of a number of coexisting pathways (Romano & Turner, 1985). It is the 'overlap' between depression and chronic pain which makes our study particularly significant.

**Research Approach and Methodology**

The aim of this research was to investigate whether shared reading aloud and discussion of literature was associated with the relief of chronic pain symptoms and/or with changes in the mental health and well-being of chronic pain sufferers.

***The Intervention: Get Into Reading (GIR)***

GIR is distinguished from other reading therapies in:

1) emphasising the importance of serious, ‘classic’ literature and its role in offering a model of human thinking and feeling (Davis, 2009);

2) reading such works aloud so that the book is a live presence and not just an object of study or chat.

GIR is based on small groups (2-12 people) coming together weekly for two hours, to read short stories, novels and poetry aloud. Typically, a group will take several months to read a long work of prose fiction, while being introduced to new poetry at every session. Every GIR session follows a standard format, in which a ten-minute ‘welcome’ period – a transitional space where participants can mentally prepare themselves for reading, and where the TRO project worker can encourage reflection on what has been read and discussed the previous week – is followed by 60-80 minutes in which a prose work (usually a novel) is read aloud by the project worker, or by participants if they choose, with regular and spontaneous pauses for discussion. The principal feature of GIR is shared reading: all reading material is read aloud in the session itself. Regular breaks in the reading encourage participants to reflect on what is being read and how it might relate to their own lives and open-ended discussion is encouraged by the TRO-trained project worker who delivers the intervention. Group members participate voluntarily and interact in relation to what is happening in the text itself (narrative, language, tone) and what may be happening within themselves as individuals (reflections upon personal feelings, thoughts, experiences), responding to the shared presence of the text within social group discussion. Every GIR session concludes with a reading of a poem (20-30 minutes). Often selected to complement the prose material covered in each session, the poem at once introduces a new voice or language and fresh opening for reflective thinking whilst also, in its brevity and self-containment, providing a satisfying sense of completion at the close of the reading session.

 GIR offers social and individual benefits in developing both a deep sense of human selfhood and a more emotionally-sharing small community. The key elements of the model, as identified in CRILS’ reading and depression study (Billington et al., 2011; Dowrick et al., 2012), are: a rich, varied, non-prescriptive diet of serious literature, including a mix of fiction and poetry, which is non-prescriptive in respect of period, genre, author; the ‘live’ presence of literature, through skilful reading aloud, which thereby becomes accessible to participants and ensures everybody can take part regardless of levels of literacy, educational, or cultural background; readers’ control of their own involvement, contributing, as much or as little as they like, according to mood and confidence levels; the sharing of personal ideas and feelings in response to literature, which is inclusive of everyone, knitting people together in both the reading experience and a supportive community; GIR’s weekly regularity, offering valuable continuity and structure for people whose lives may be chaotic or empty.

**GIR and Chronic Pain: *Conduct of Sessions and Choice of reading material***

The core structure of GIR is flexible enough to be adapted for different settings and for the needs of different client groups. Chronic pain, or the medication taken to alleviate symptoms, can affect all aspects of a person’s daily life and well-being. Mobility, motivation, concentration and mood can all be altered with possible consequences for the engagement of GIR participants. It was anticipated that chronic pain sufferers may have difficulty sitting for any length of time and there was also awareness that they may have significant obstacles to overcome in attending sessions, such as walking any distance and accessing public transport. It is also common for people with pain to experience concomitant anxiety and depression which can impair concentration. The administration of analgesic and antidepressant drugs for people can compound these issues along with the problems of excessive tiredness, drowsiness and poor motivation.

The chief modification to GIR made by the project worker was the decision to focus exclusively on short stories and poems rather than, as usually happens a few weeks into a GIR group, commencing a novel. While shorter texts were intended to cater for potential difficulties of concentration in participants, they also made the sessions ‘stand-alone’ in nature, thus minimising the impact of attendance possibly being more fractured than for a standard GIR group.

**Research Method**

***Participants and Recruitment***

Six participants with severe and chronic pain symptoms were recruited via taster sessions offered to attenders of a pain clinic in a participating NHS Trust. The study included participants of both genders with any chronic pain condition regardless of aetiology, age and literacy level. A single GIR group was held within a hospital and run by a TRO project worker, running for a period of 12 weeks. The group ran each week regardless of the number of attendees and the project worker contacted any non-attenders prior to the next week’s session, to ensure an “open-access” approach was offered. The GIR group followed the standard format described above: weekly two-hour read-aloud sessions, involving a mix of prose and poetry. (See Appendix 4 for a comprehensive list of the reading material selected in the current study.)

***Method***

A mixed methodology approach was used. Quantitative measures tested the impact of GIR on participants’ symptoms before, during and after attending the group. The frequency of monitoring was designed in collaboration with participants to avoid over-burdening them, whilst obtaining sufficiently detailed measurement to enable patterns to be identified. Qualitative methods explored participants’ individual experience of the group.

***Design***

The case series employed in the study was informed by Peterson’s process of inquiry, (Peterson, 1991) and systematic single instance case-research study (Sim & Wright, 2000) with the purpose of offering a detailed analysis of each participant’s ‘journey’ through GIR. The study combined descriptive case accounts which were informed by interviews and focus groups along with an N=1 time-series design (Turpin, 2001). Case research, such as this, uses a quasi-experimental design in which the impact of an intervention variable is tested on outcome variables through a process of repeated measurement (Sim & Wright, 2000). Each participant, measured before, during and after the intervention, is effectively their own control and comparison with other participants is neither necessary nor meaningful.

A modified A1BA2 experimental design was used with baseline (A1) and post-group (A2) data being recorded, in addition to measurements obtained during the intervention period (B). Since any impact of the reading group would not necessarily be reversed on its completion, the second baseline period (A2) refers to a follow-up monitoring period, rather than the conventional reversal phase advocated for single-case experiments (Turpin, 2001).

A focus group involving participants and the TRO project worker was undertaken to explore common experiences of the reading group. Themes explored with the group were the impact of the shared reading experience on reading habits, pain, quality of life and function along with a review of the organisation and management of the group. The findings from the focus group and self-report measures were explored individually through face to face interviews with participants. This methodological triangulation aimed to elucidate the complexity and richness of the experience, whilst enhancing the credibility of any emergent findings.

***Measures***

The impact of GIR on participants’ psychological symptoms and function was investigated using self-report measures. Repeated measurements, whilst necessary to demonstrate change, place a burden upon participants and may impede compliance or exert a confounding effect on the intervention, as their completion is not a neutral process (Turpin, 2001) with the potential to distort the results obtained. Participants were consulted at the taster sessions about the feasibility of rating their pain on a daily basis using a 0-10 rating scale along with notes about contextual events and medication. However they selected instead to complete their ratings every 12 hours, believing this would offer a more accurate picture. The feasibility of such recording was tested by participants through a trial week before the start of the project. The participants completed an assessment booklet at baseline, 6 weeks after starting the reading group, on completion of the group and when attending a post-group individual interview.

***Analysis***

The twice daily pain ratings were analysed visually and evaluated in conjunction with the respective participant. Pre, interim and post intervention measurements were compared and where applicable clinical level change was identified. The focus group and interviews were analysed using thematic analysis to identify key themes that arose from the data. The emergent themes were discussed and agreed by the group members.

***Ethics***

The project was approved by the Liverpool East Research Ethics Committee.

**Findings**

Six people participated in the GIR group, along with two carers of the participants. All of the participants and their carers were involved in the individual interviews. Five participants, a carer and the project worker were involved in the focus group. Attendance at groups and engagement in the research project varied considerably being inevitably affected by fluctuations in their condition, medical appointments and other commitments.

***Analysis of quantitative******data*** showed some positive changes in terms of pain and psychological wellbeing which were consistent with the accounts provided by the participants. An N=1 design takes the single case as its unit of value, rather than aiming to generalise or calculate averages across case studies. Hence the purpose here is judiciously to represent individual journeys undertaken through the following case summaries, selected to illustrate a range of the participants’ experiences.

*‘Steph’*

Steph is a woman in her 50s who is married with children and grandchildren. Her pain started very suddenly 5 years ago with no identified cause although initially the cause was thought to be a stroke. The following year she started to experience a persistent headache that additionally affects her vision and concentration. Headaches have continued largely unabated: ‘it’s always there, it’s there all the time and never goes’. Steph provided very comprehensive pain diaries throughout the study which were shown to her at the end in graphical form. Steph was intrigued that the graphs were ‘true and accurate’ and depicted her experience of pain. The graphs show that although there was some fluctuation in her pain, which typically oscillated around 6-7/10, she was never free from pain during the period of the study (Appendix 1, Figure 1). No notable changes in pain intensity or pattern were evident during the months of attending the group.

Over the period of the research study Steph’s mood (as measured on the BDI) and psychological health (as measured on the GHQ) remained stable (Appendix 1, Table 1), although she was experiencing a very stressful situation in the later part of the study. However, there were functional changes over time, in that Steph had returned to work and was able to manage being alone more readily, using this time to read. While quantitative results indicate that Steph’s mood or pain did not alter notably over the course of the project, qualitative findings show Steph identified a transient feeling of relaxation during and after the group and important changes in her quality of life during the period of the reading group through her return to work, her altered pain coping patterns and her enhanced social well-being (Appendix 1, Table 2): the latter was the result of the strong sense of community and belonging she now shared with her group members. Steph summed up the overall experience as ‘It’s just been a joy to me hasn’t it? I like going, I never miss’ and her strong commitment to the group was evident: ‘I dragged myself there . . . it’s that important to me’.

*‘Bet’*

‘Bet’ is a woman in her 60s, married with one child and grandchild. Bet sustained a back injury at work over 20 years ago and this along with a degenerative spinal condition have resulted in chronic back pain: ‘I can only describe it as cramp in the bottom of my spine and the cramp gets bigger and bigger, so I can’t move my legs . . . so I sit down and it goes away’. Bet’s mobility is impaired by her pain and she uses a wheelchair outside her home. She is reliant on her partner for assistance with activities which are part of daily living and for psychological support, especially when leaving home. Bet reported frequent anxiety symptoms which can escalate into a panic attack, especially when she is alone. Bet was a healthcare professional, a job she clearly loved and gained satisfaction from. Initially Bet no longer participated in any occupations or hobbies apart from watching television which was not particularly meaningful to her. Bet described her life as devoid of any pleasurable activities. Bet completed the pain diaries intermittently during the project resulting in periods of missing data which affect the validity of the results. From the available data it appears that her pain fluctuates but generally oscillates between 5-8/10 (Appendix 2, Figure 2). Some variation in Bet’s pain pattern was noted over the week. Bet believed this change was as a result of attending the group – ‘the group helped enormously . . . you don’t feel pain when you are discussing or reading a story’. On reviewing the pain charts, Bet had difficulty recognising her own pain pattern amongst the other participants.

Analysis of Bet’s pain ratings was hindered by the episodic data available although Bet did independently suggest that her pain was lower during the week than weekends, which was consistent with the visual analysis of the charts. Quantitative investigation of Bet’s mood, general psychological health and function did not indicate that there was any reliable and clinically significant improvement, although there was an improvement in Bet’s functioning in terms of socialising, being alone and relationships (Appendix 2, Tables 3 and 4). This was consistent with the increase in both the amount available of, and satisfaction with, her social support, and with her declared enjoyment of the companionship of the group. Qualitative exploration found that Bet, although keen to read at home, still found this difficult, whereas in the group she was able to concentrate more fully and enjoy the experience of reading and discussing the literature irrespective of her pain. Moreover, the more challenging and thought-provoking the literature, the easier Bet found it to concentrate and reduce her awareness of pain.

***‘Ken’***

Ken is man in his 50s, married with two adult children, one of whom lives locally. Ken’s pain started suddenly one night over twenty years ago with strange sensations in his feet and hands that kept him awake at night and consequently had a significant impact on his daily functioning, especially his work. The onset of his pain led to Ken taking early retirement from the civil service twenty years ago but he misses the routine of work and being able to use his skills. He has pain and uncomfortable sensations in his hands and feet which affect him severely at night. He routinely only manages to sleep for an hour or two at night with inevitable consequences for his functioning during the day and this makes it difficult for him to plan to do things being uncertain of how he will feel. Over time the sensations and pain have worsened and the aetiology of his condition remains uncertain. The invisible nature of Ken’s pain and associated lack of sleep, led to him feeling isolated because even close family could not really understand the way he felt.

 Ken managed to capture a comprehensive picture of his daily pain ratings, keeping regular 12 hourly records throughout the project, apart from a period when he was unable to attend (Appendix 3, Figure 3).Ken’s described his pain pattern as being ‘all over the place, that’s the problem’ which was consistent with the pattern that emerged through his diaries. ‘I do get periods when it’s . . . it’s relatively . . . not so bad’. The diaries showed that his morning and evening pain ratings fluctuated considerably (Appendix 3, Figure 4). Ken explained his experience in more detail: ‘I’m not the normal pattern . . . as I never know what the night is going to bring . . . sometimes I have a reasonable night and . . . next day I’m quite bright and cheerful . . . one night I was [staying with family] and I was up all night walking around . . . that’s what my week is like’.

Ken initially considered he was strong and coped with life’s difficulties by being able to ‘block them off’ but did reveal that ‘the illness does make you depressed’, and went on to explain that it was the difficulty planning to do anything that affected him most and was least understood by others. Ken discussed the impact he believed attending the group had on his mood: ‘I found going to the . . . err . . . thing on the Tuesday . . . very beneficial, I felt brighter . . . err less anxious err . . . even if I didn’t sleep that good that night, I was still more bushy tailed the next day’, which was consistent with the improvement recorded in his mood (as measured on the BDI) and general psychological health (as measured on the GHQ) when comparing the pre-group and post group scores (Appendix 3, Table 5).

Ken identified key elements of the group as the support gained from each other and the positive impact of being able to evaluate his experiences against those of others: ‘I can see some people . . . that overall are . . . worse than myself, I can think of one individual . . . there are people worse than me and trying to compensate and say to myself’ and ‘Someone was there that was worse than me . . . so talking to people like that helped’.

 Ken reported that attending the group had a positive impact on his mood, general psychological health and some aspects of his daily functioning. Visual analysis of his pain ratings indicated an improvement, for two days after the group, which was entirely consistent with his perception of both his pain and mood. Quantitative analysis of his mood, function, general psychological health and social support all indicated improvements that occurred whilst he was attending the group (Appendix 3, Tables 5 and 6). Some of these improvements were lost after the group ended but Ken attributed some of the deterioration to a change in his pain. Qualitative analysis highlighted additional benefits in terms of Ken’s quality of life, changes in his coping strategies along with the reconnection with his previous occupations such as work and reading.

***Analysis of qualitative data*** from the personal accounts, focus group and project worker’s accounts has illuminated common themes in relation to the GIR experience for people with chronic pain and the impact that attending has had on their daily lives.

*The value of the literature read*

The literature was regarded as an essential component of the GIR experience.

*Not self-help.*

It was universally felt by participants that the cohesion and comradeship, joy and animation, and the sense of anticipation, excitement and enquiry which characterised the experience were generated by the shared reading of the literature. It emerged that all participants had sought or been referred to support groups and self-help therapy in the past and were united in saying that a self-help or support group which concentrated exclusively on pain issues would not have had the same kind of impact or benefits. The skill of the project worker - in choosing the literature, in bringing it to life through her reading and comments, and in managing the group discussion - was also thought to be critical to the quality of the experience.

*Absorbed Concentration*

All participants showed a preference for more challenging texts as the difficult stories and poems made them think more deeply. The project worker had initially opted to use stories with a strong plot line or with a strong focus on ‘feeling’ or emotional response, sensing that these would work best in terms of distracting people from their pain as concentration levels required for more difficult texts would be too great and pain would intrude. In fact, it was the more difficult, more puzzling stories (by Anton Chekhov, D. H. Lawrence, Ray Carver, David Constantine) that most absorbed people. Both group members and project worker agreed that reading and puzzling together over the meaning of intellectually and emotionally demanding literary pieces, produced closer concentration and absorbed attention to details of language, and reduced awareness of pain.

*Diversity*

The variety of poems and stories, as well as the potential for an inexhaustible range of subject rather than ‘pain’-centred topics, was welcomed. Differences of view were also valued and the opportunity to express individual ideas helped engender a sense of self-worth, as did the sharing of previously unread ‘classic’ authors. The introduction to new literary material also influenced reading habits outside the group, particularly the nature and range of reading matter (books were replacing newspapers, magazines and television).Individual accounts demonstrated how the challenge of working with the literature as part of a team helped to recreate elements of previous occupational lives. The existing format of the sessions, in which one short story and poem was read at each ‘sitting’, helped members feel they could comfortably return after a break, which prevented their dropping out in the longer term.

*A sense of shared community, friendship and comradeship*

Whilst the literature was core to the experience, all participants also recognised the importance that the group’s sense of community had on their mood and pain, and the contribution made by the sharing of literary meaning to their feeling of comradeship. Connections with each other were deeply felt by participants, rooted in genuine regard and playing an important part in everyone’s week. Participants encouraged each other and took delight in others’ progress, both inside and outside of the group where some met socially. All participants agreed that the group had been beneficial in terms of coping with pain and had helped overcome the social isolation caused by their associated depression. These benefits rippled out into other relationships as participants shared the reading from the groups with spouses and neighbours.

*Mood and Quality of Life*

The shared reading aloud countered the negative effect of pain on participants’ mood, both by helping to overcome isolation and depression of spirits and by encouraging engaged enjoyment and attentive (‘listening’) relaxation. Changes in quality of life were also widely agreed upon by all participants and associated with ripple-out effects from the group. The form of such changes varied somewhat with participants referring to changes in their exercise levels, the rekindling of previously valued occupations and leisure activities, and alterations in pain coping strategies. The importance of having a meaningful focus to the week emerged strongly and the value that came from the change of routine and sense of occasion engendered by attending the group was reflected in a marked increased attention to appearance in both men and women. Participants were also very keen to take the reading material away with them and share it with others. The literature gave people another way of socialising and conversing - a sort of currency - that came out of a part of themselves that had nothing to do with the fact that they were chronic pain sufferers and in which they could take pride. A further unexpected impact on quality of life that emerged was the exercise involved in getting to the group. Not only were participants making the effort to get dressed, but some chose to walk to the group from home or the car park in order deliberately to increase their exercise, reporting physical and psychological benefits of invigoration and contentment.

**Discussion**

The findings from the personal accounts, focus group and project worker’s accounts have illuminated common themes in relation to GIR for people with chronic pain and the impact that attending has had on their daily lives.

The universal theme that emerged was the central role of the literature in the experience, which was agreed by all participants in the study. Despite the high value participants placed upon their social connections, through what appeared an emerging ‘community of pain’, they all believed that a social support group would not be as beneficial and would fail to provide the mental challenge and sense of self-esteem offered by GIR. Connections were made to work based skills and participants’ need to engage in valued and meaningful activity, which a support group could not offer.

There was an apparent contradiction between the difficulties participants reported with their concentration (due to their pain) and the project worker’s observations about their depth of concentration, especially when working with more difficult literary pieces. It appeared the more participants were focused on thinking about the narrative, language and literary aspects of stories or poems, the less they were affected by their pain or the more distanced from it they became. It was as though the extra mental effort helped shift immersion to another level and blocked out the pain more successfully.

It appeared that within the group setting, the mental challenge of the shared reading created a state consistent with the concept of flow (Csikszentmihalyi, 1990) which occurs when presented with a just-right challenge (Hammel, 2004). In this optimal state people can also lose awareness of their physical needs and bodily state becoming more fully themselves – more fulfilled and absorbed, more vitally alive – in forgetting the self, whilst engaged in meaningful activity. This paradigm concurs with participants’ reduced awareness of pain during the group session and with the project worker’s skill in providing the appropriate high-level literary challenge each week. This approach is in contrast to a graded one that may often be utilised by therapists, where the difficulty of the challenge is increased in a step wise fashion: for example, starting with a low grade challenge such as reading a short magazine article, and progressing to an undemanding short story before tackling more demanding reading. In this case, the inexhaustible fund of literary resources ensured the ‘just-right’ challenge could always be tailored to need, while participants reported that it was the intrinsic interest of the literature which made the challenge more effective for pain relief than a stepped programme.

The social connections engendered by the GIR experience appeared to run on many levels with emotional, informational, tangible and companionship strands evident in their conversations. This was in contrast to the accounts provided of becoming isolated and lonely as a result of their pain and loss of occupational roles. The term community was acknowledged by participants as more closely fitting their experience than social support. This emergent GIR community could have encouraging implications for members in the longer term since the accessibility of social support can influence an individual's ability to cope with stress, and the recognition that they are valued by others can play an important psychological role in helping people to cope with the negative aspects of their lives and health problems and improve their mood (Taylor, 2011; Uchino, 2004).

Changes in individual’s quality of life as an indirect consequence of the group also emerged as a theme discussed by all the participants. The form of such changes varied somewhat with participants referring to changes in their exercise levels, the rekindling of previously valued occupations and leisure activities, and alterations in pain coping strategies, with the group becoming a focal point in the week associated with a great sense of occasion. Given the restrictions participants felt that pain placed upon their occupational and social lives, the reported improvements in their quality of life after such a short intervention, is to be welcomed, and in the longer term may offer strategies to interrupt the cycles of pain and low mood that were reported. Although not everyone was using reading as a coping strategy at home for their pain, there were notable changes in both the amount and type of literature that individuals were reading and reported benefits in terms of pain relief and reduction in their sense of social isolation. The next step will be to support those who have not yet been able to manage to read at home, to be able to find the right level of challenge to enable them to concentrate, given the impact reported by those who have successfully achieved this.

The project utilised a mixed methodology in order to attempt to investigate the GIR experience form both a qualitative and quantitative approach. Review of the pain rating diaries was informative and the participants agreed that the charts appeared to reflect their pattern of pain. One of the case studies presented demonstrated a change in pain in the days following the group which was consistent with their experience and another case study showed somewhat lower scores after the group. However, the demand that 12 hourly recording placed upon participants was significant and due to the rapidly fluctuating nature of some people’s pain, may have been insufficient to capture their true experiences. Consequently it has proved a rather crude tool to explore such a subjective phenomenon.

Positive changes were noted for some of the psychological and pain measures administered, which were consistent with the accounts provided by the participants. However these measures, too, can only supply snapshot information about what is a constantly changing experience. Furthermore some of the changes that the participants reported were around diverse changes to their quality of life, irrespective of changes in pain and mood. The measures employed in the study, whilst partially capturing the GIR experience, did not illuminate the full extent of its impact.

In this study the combination of approaches and methods has been a strength which has enhanced the validity of the data from each source. The design has also provided participants with opportunities to check and comment further on the data collected, to ensure its validity and reliability with their own experience. Through developing a better understanding of the phenomenon of a GIR for people with chronic pain, we have identified some key aspects of the experience which demand further research. Future studies need to investigate the quality of life changes that appear to occur and to develop strategies to explore further the concept of flow that appears to have emerged within this study as central to the beneficial impact of the literature for these participants.

**Conclusions**

This study was undertaken to investigate and evaluate the power of shared literature and its benefits for chronic pain sufferers in a clinical setting and to pilot research methods and working relationships to inform possible larger-scale investigations. The findings from the study have demonstrated through the voices of the participants and measurement tools used that GIR can have a positive impact upon the lives of people with chronic pain. The study has also highlighted the need for further research into the reported quality of life changes and suggested mechanisms whereby GIR may effect these improvements. The results presented therefore constitute the first step in offering people with complex and chronic pain another intervention that may help to alleviate some features of their condition, with minimum risk of side effects. However, the preliminary nature of this study must also be appreciated and further research, within a revised and larger scale study, is now necessary to expand upon and test these findings. Such future research might usefully include control groups in order that the effects of GIR can be studied in relation to the alternative therapies to which GIR was explicitly compared by participants (self-help for example) or therapies which are common for chronic pain (Cognitive Behavioural Therapy).

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**Appendix 1: Selected case summary 1: ‘Steph’**

Figure 1 Pain Records “Steph”

 

 1 2 3 4 5 6

Time (Months)

Table 1 *Health and Functional Measures “Steph”*

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Measures****Steph**  | **Baseline** | **Mid** | **Final** | **Post Gp** |
| GHQ | 12 | 14 | 14 | 16 |
| WAS –work | 8 | 6 | 6 | 6 |
| WAS-home | 6 | 4 | 4 | 6 |
| WAS-socialise | 6 | 6 | 6 | 7 |
| WAS-alone | 8 | 6 | 3 | 0 |
| WAS-relationships | 0 | 0 | 4 | 7 |
| BDI | 27 | 24 | 28 | 32 |
| McGill- | 34 | 31 | 32 | 27 |

Table 2 *Social Support “Steph”*

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Measures** **Steph** | **Baseline** | **Mid** | **Final** | **Post-gp** |
| MOS-network | 3 | 1 |  | 3 |
| MOS-supportive | 4.2 | 1.2 |  | 5.2 |
| MOS-satisfied | 1.6 | 2.5 |  | 5.1 |
| MOS-support type | Day centre | counsellor |  | Day centre & counsellor |

**Appendix 2: Selected case summary 2: ‘Bet’**

Figure 2 Pain Records “Bet”



Pain not recorded

 1 2 3 4 5 6

Time (Months)

Table 3 *Health and Functional Measures “Bet”*

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Measures**  | **Baseline** | **Mid** | **Final** | **Post Gp** |
| GHQ | 12 | 10 | 10 | 18 |
| WAS –work | 8 | 8 | 6 | 8 |
| WAS-home | 8 | 8 | 4 | 8 |
| WAS-socialise | 8 | 6 | 3 | 4 |
| WAS-alone | 8 | 6 | 0 | 4 |
| WAS-relationships | 7 | 2 | 0 | 4 |
| BDI | 21 | 26 | 22 | 18 |
| McGill- | 21\* | 37 | 41\* | Not completed |

No clinical change in measures

\*Increase in McGill Score

Table 4 *Social Support*

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Measures** **Bet** | **Baseline** | **Mid** | **Final** | **Post Gp** |
| MOS-network | 2 | 3 | 3 | 4 |
| MOS-supportive | 4 | 9 | 5.4 | 8.5 |
| MOS-satisfied | 5.8 | 4 | 5 | 8.6 |
| MOS-support type | Consultant & carer | Husband | Husband, sister & carer | Husband & carer |

**Appendix 3: Selected case summary : ‘Ken’**

Figure 3 Pain Records “Ken”

****

 1 2 3 4 5 6

Time (Months)

 Figure 4 Pain Record (Ken’s Daily Average Scores)



Table 5 *Health and Functional Measures “Ken”*

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Measures** **Ken** | **Baseline** | **Mid** | **Final** | **Post Gp** |
| GHQ | 16\* | 0\* | 3 | 4 |
| WAS –work | 8 | 8 | 7 | 7 |
| WAS-home | 6 | 3 | 2 | 3 |
| WAS-socialise | 6 | 3 | 3 | 2 |
| WAS-alone | 5 | 3 | 4 | 6 |
| WAS-relationships | 6 | 4 | 3 | 3 |
| BDI | 34\* | 14 | 12 | 15\* |
| McGill- | 49\* | 27 | 24\* | 39 |

\*Clinically relevant change over time

Table 6 *Social Support “Ken”*

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Measures** **Ken** | **Baseline** | **Mid** | **Final** | **Post Gp** |
| MOS-network | 3 | 3 | 3 | 3 |
| MOS-supportive | 7.8 | 8.5 | 9.2 | 6.4 |
| MOS-satisfied | 8 | 7.5 | 8.3 | 5.7 |
| MOS-support type | Wife | Wife & Consultant | Wife | Wife |

**Appendix 4**

Figure 5

Texts used in the reading sessions

|  |  |
| --- | --- |
| 8/1/13 | Short stories - *The Snob* by Morley Callaghan, *The Doll’s House* by Katherine Mansfield, Poem - ‘Timothy Winters’ by Charles Causley  |
| 15/1/13 | Short story - *The Bet* by Chekhov, Poem -‘I Know Why The Caged Bird Sings’ by Maya Angelou. |
| 22/1/13 | Short story – Cathedral by Raymond Carver, Poem - ‘Kindness’ by Naomi Shihab Nye |
| 29/3/13 | *All the years of her life* by Morley Callaghan with ‘Those Winter Sundays’ by Robert Hayden and *Sunday In The Park* by Bel Kaufman with ‘A Poison Tree’by William Blake |
| 5/2/13 | *Superman and Paula Brown’s New Snow Suit* by Sylvia Plath with ‘On Turning Ten’ by Billy Collins and ‘Lullaby’ by Sue Cowling. |
| 12/2/13 | *Accelerate* by Frank Cottrell Boyce and ‘Leisure’ W.H. Davies |
| 19/2/13 | *Powder* by Tobias Wolff, *Penny In The Dust* by Ernest Buckler with ‘The Gift’ by Li-Young Lee |
| 26/2/13 | *Fanny and Annie* by D.H.Lawrence, *The Road Not Taken* by Robert Frost |
| 5/3/13 | *Welding With Children* by Tim Gautreaux with ‘To Edwin at Eight Months’ by Steve Ellis |
| 12/3/13 | *In Another Country* by David Constantine with ‘When I am old and grey’ by W.B.Yeats. |
| 19/3/13 | *A Poetics For Bullies* by Stanley Elkin with ‘The Good’ by Brendan Kennelly |
| 26/3/13 | *Loose Change* by Andrea Levy with ‘Geography Lesson’ by Carol Rumens |