Chronic pain, loss and the future – Development and evaluation of an innovative, interactive pain education tool

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Abstract

Background: The development of chronic pain can result in multiple losses to an individual, which can negatively impact their quality of life. Presentation of the concepts of loss and grief as an interactive educational tool may help those who live with chronic pain gain a deeper understanding of their condition. This in turn may enable more effective management of their pain. This study aims to explore the effectiveness of such a tool through the perceptions and experiences of people living with chronic pain.

Methods: An interactive pain education tool was developed and distributed with an evaluation questionnaire. Participants were invited to re-evaluate the tool three months later. Responses to the questionnaire were provided using a Likert scale and free text comments. Descriptive statistics were used to present quantitative results and inductive thematic analysis was applied to the free text comments.

Results: The pain education tool was well received by participants, the majority of whom found the process of using the tool a positive experience. Responses showed the tool helped participants express themselves and promoted self-reflection. The tool provided access to the reflections of others, which helped validate and legitimise their feelings and gain the understanding that their response to pain was normal. This in turn helped promote self-compassion and a sense of belonging, reducing feelings of isolation associated with chronic pain.

Conclusion: The outcomes of this study show the pain education tool can help individuals gain a new and more positive perspective on themselves and their pain experience, therefore helping them live with and manage their chronic pain.

Keywords

Pain education, chronic pain, pain, pain management, self-compassion

Introduction

Chronic pain is well recognised as having profound detrimental effects on an individual and their quality of life as well as on their family and friends.¹ The often insidious nature of the development of chronic pain can lead to a subtle chain of events resulting in multiple losses to the individual; ranging from everyday social activities to a sense of self-worth. There are many pharmacological and non-pharmacological strategies, including patient education, that are employed to help individuals manage this condition. However, there is little evidence to show whether the process of self-identification of losses and their associated grief can be

used effectively as a pain education tool. Such a tool could help individuals better manage their condition through an appreciation of how their chronic pain impacts on their quality of life.

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Grieving for the loss of something or someone that is valued is a fundamental and natural human response. Whilst in many cases the object of loss is obvious, such as the death of a loved one, this is not always the case. Theories of loss and bereavement have been associated with on-going health problems including amputation, dementia and chronic pain.²⁻⁵ Regarding chronic low back pain Walker, Sofaer and Holloway reported five distinct themes relating to loss; employment, financial and relationship-related losses along with loss of identity and loss of hope, all which can compound the complexity of managing chronic pain.⁵ Parkes and Prigerson observed that grief results from such feelings of loss and deprivation, manifesting as further suffering or distress⁶.

Responses to grief and loss include fear, anger, distress, despair, worry, isolation, social withdrawal, tiredness, feelings of worthlessness, loss of purpose and pessimism.⁶⁻⁸ Grief as a manifestation of the losses associated with chronic pain was described by Roy who states that "loss and grief are integral to the experience of chronic pain."^{4-p137} Boss and Yeats described health-related grief as a complex grief resulting from unresolved loss, which they termed ambiguous loss to reflect the uncertainty that the affected individual will return to the way they used to be.⁹ Doka defined grief as that resulting from losses that are not socially validated or acknowledged as disenfranchised grief.¹⁰ Ambiguous loss and disenfranchised grief can be associated with chronic pain and can occur when individuals feel isolated and unsupported in their condition. For those living with chronic pain raising awareness of its impact on their lives and recognising how they have coped may be a helpful management strategy. Such a pain management strategy can provide an opportunity for self-compassion, which is reported to help protect those with long-term conditions against difficult life events.¹¹

The management of chronic pain can be multifactorial, frequently combining pharmacological and psychological therapies¹². Self-management programmes are multi-modal in their delivery and aim to educate the patient about their pain and its management. Such programmes address physiological, psychological and sociological factors involved in pain.¹³

The reported effectiveness of these programmes is mixed. For several decades patient education has been reported as beneficial¹⁴⁻¹⁷ demonstrating improvement in mood and coping, even if there was no improvement of the pain itself. Geneen et al conducted a systematic review which suggested pain education is most effective in conjunction with other pain management approaches.¹⁸ Hoffman's meta-analysis demonstrated positive effects of psychological interventions for chronic lower back pain and positive

short term responses to multidisciplinary approaches including psychological approaches.¹⁹ However, a subsequent review by Yu et al. contends that the benefits of education in those with neck pain are small and short-lived.²⁰

In contrast, Burton et al demonstrated an education booklet for individuals with low back pain facilitated and accelerated improvements in their beliefs around pain and physical outcomes, which were maintained for a year.¹⁴ A review of psychological interventions by Kaiser et al concluded there is no "gold standard" of treatment for chronic pain.²¹ The review also suggests that the role that psychological factors play in chronic pain can no longer be ignored.

Models of grief and loss have been proposed as a framework for helping healthcare workers understand the impact on health resulting from chronic pain.^{22,23} A similar framework could be extended to individuals experiencing chronic pain and to pain support groups. Patient education, incorporating theories of loss, may help individuals gain a new perspective of their pain experience. Alignment of the pain experience with the stages and emotions associated with loss, together with the knowledge these are natural responses, could benefit individuals. Support may also manifest through the realisation they are not alone in their pain experience. Feelings of isolation and disenfranchisement associated with loss may be diminished through this support.

Presenting the concepts of loss and grief in a generalised context and making them accessible to people as an interactive resource in the form of an education tool may help them to live with and gain a new perspective on their pain. This study aimed to explore the perceptions and experiences of people with chronic pain regarding the effectiveness of such a pain education tool.

Methods

The methods are presented in two sections, firstly the rationale for, and development of, the pain education tool and secondly, the evaluation of the tool.

1. Rationale and development of the Pain Education Tool

Rationale

The idea for the development of a Pain Education Tool (PET) arose from the observation of pain experiences, narrated by members of a chronic pain support group, on video for use in undergraduate pain education. The researcher reflected on the similarities between the narratives of adjusting to life following

the development of chronic pain and the process of bereavement for the loss of a loved one. The researcher approached a local chronic pain support group to help create a tool incorporating theories of loss that could help individuals understand and reflect on the impact chronic pain has had on their lives.

Focus group

Focus groups, commonly used in research to obtain qualitative data on a specific topic through discussion, are formed from individuals who have characteristics in common relating to the topic of the focus group. For this study the purpose of the focus group was to support the development of an education tool by providing their perceptions and opinions at the various stages of its development. This focus group comprised seven members of a local chronic pain support group and was moderated by a researcher from the University of Southampton.

Pain Education Tool development

A draft interactive PET was developed following a series of focus group meetings, held regularly over two years, to discuss content and design. The tool contained an introduction to theories of loss followed by a task in mapping the pain experience. The mapping task involves words commonly associated with loss being written down and linked in a way that describes the individual's experience of developing and living with chronic pain. Examples of mapped experiences, provided by the focus group members, were presented for reference along with reflections on the experience of undertaking the mapping task. A section on self-support and contact details of support resources were also included. The PET was developed in accordance with the nine principles of effective deliberative public engagement.²⁴

The first draft was presented to the entire pain support group and feedback from this led to further refinement of the booklet, including the addition of an interactive and self-reflective version of the mapping task, forming the final version of the PET. The feedback clearly stated it would much more motivating for the booklet to include the resources to complete the task to be included in the booklet rather than simply presenting the suggestion to undertake it.

Interactive and self-reflective task

The resources provided for the interactive and self-reflective task were printed stickers containing words associated with loss; blank stickers for participants to add their own words and coloured card to present the

mapping of the words. Two sets of stickers and card were included in the booklet to enable individuals to undertake the mapping task and then to repeat the task at a later date to allow comparison with the previous example. The repetition of the interactive task was designed to enable individuals to express their individual pain experience and to see how this had evolved or changed over time, providing a tool for self-reflection. A pdf version of the booklet (without the interactive task) is available at <http://www.keepinspace.co.uk/>

2. Evaluation of the Pain Education Tool

Study setting

For the evaluation of the PET the researcher and the UK charitable organisation Pain Concern²⁵ collaborated to enable a nation-wide distribution to its members. Pain Concern is a UK-based charity working to help, support and inform people living with chronic pain and those who care for them. Details of the study were posted on their website or emailed to members of Pain Concern.

Participants

Members of Pain Concern who expressed an interest via email or post and had experienced pain for a minimum of three months²⁶ were invited to take part in the study.

Data collection

Participants were sent the PET and an evaluation questionnaire via the postal service and were asked to complete the questionnaire after reading the PET and completing the interactive task. The questionnaire had been piloted along with the PET and refined following focus group feedback. The eleven statements contained in the questionnaire can be seen in Table 1 (found on page 4).

A Likert scale (1=strongly disagree, 5=strongly agree) was used to determine participant agreement with the statements about the effectiveness of the PET included in the questionnaire. Space was provided for free text comments for all questions in addition to a general feedback section.

A follow up structured email or letter was sent approximately three months after completion of the PET evaluation to determine if participants had re-read the PET or repeated the task. It also aimed to determine perceptions of the PET several months after its initial use. Qualitative data were collected in the form of free text comments.

Table 1. A summary of all the quantitative responses to the questionnaire.

Question	Strongly agree	Agree	Neither	Disagree	Strongly disagree	No answer
1. I found the pain educational tool helpful	13	21	1	2	0	0
2. I found the sticker task helpful	11	19	4	3	0	0
3. It was helpful to see how others had completed the sticker task	10	21	3	3	0	0
4. It was helpful to read other peoples' thoughts about completing the task	12	20	3	2	0	0
5. I will do the task again at a later stage to see if there are any changes in the way I feel about m pain	15	14	4	2	2	0
6. Completing the task made me feel positive	9	17	8	1	2	0
7. The task helped me gain a new perspective on my personal experience with pain	5	18	4	6	3	1
8. It was helpful to know other people have similar experiences with pain	18	14	1	1	1	2
9. Relating the stages of grief to chronic pain was helpful	14	14	4	3	1	1
10. I would recommend this pain education tool to someone with chronic pain	20	9	6	1	0	1
11. It helped me to understand how I have coped living with chronic pain	15	13	2	2	1	4

Data analysis

Data analysis was conducted by a member of the pain support group who has experience of qualitative and quantitative analysis to a doctoral level. To reduce bias, they had not been involved in the development of the PET nor had they read the PET prior to completing the analysis. Thematic analysis of free text comments was undertaken. These data were analysed using a general inductive approach, coded and dominant themes were summarised. The codes and themes were further analysed by both researchers together.

Ethical Considerations

Initial discussions were held with the focus group to establish processes to minimise potential distress resulting from discussion around loss. The focus group acknowledged the help available from of the chronic pain support group they belonged to and they had the contact details of a variety of other support organisations. It was reinforced that focus group members should not attend meetings if they felt it could be detrimental to their well-being.

Ethical approval was granted for this study by the Faculty of Medicine, University of Southampton: Ethics number: 10255

Results

In this section the demographic data of the participants and their questionnaire responses are presented

followed by the major themes that arose from the free text comments, which provides a rich narrative. These themes are reducing isolation; validating emotions; articulating feelings; difficulty using the task; self-reflecting; legitimising thoughts; lack of engagement with the task and when to use the PET. Positive perspectives regarding the effectiveness of the PET are summarised in Figure 1 (which can be found on page 5).

Demographic Data

Ninety-four questionnaires were sent out and 41 questionnaires were returned, providing a 43.6% response rate. Five questionnaires had incomplete demographic data, as a result the total number of responses presented for each category of the Likert Scale were a percentage of the total number of responses obtained for that question. Of those who responded, 79% had attended a pain management course, 83% were female and 17% were male. The majority of participants were aged 40-59 years (10% = 21-39 years, 61% = 40-59 years, 21% = 60-74 years, 8% = 75+ years) and the most common duration of pain was between 11 and 20 years (15% ≤ 5 years, 26% = 6-10 years, 41% = 11-20 years, 12% = 21-30 years, 6% = 30+yrs)

PET questionnaire evaluation data

Table 1 presents a summary of the quantitative responses to the questionnaire.

Figure 1. A summary of positive perspectives on the effectiveness of the PET.

Reducing isolation

Reduced feelings of isolation and loneliness after reading the booklet and undertaking the task was a significant theme. This theme arose in response to seeing other's experiences, reading their thoughts about undertaking the task and realising the many similarities in peoples' experiences of living with chronic pain.

"We all feel so alone with our pain that meeting or reading about others is very comforting and encouraging"

"Feel less isolated and like an alien!"

"So important to know you are not the only one with these feelings and there is acceptance and hope"

"There is a strong societal myth about the 'noble sufferer'... It's good to remember it's not just a struggle for me."

"It's like finding life on other planets!"

Validating emotions

Validation of feelings and emotions was a common response to using the PET. The isolation resulting from living with chronic pain can leave individuals feeling uncertain how others view their pain experience. It was quite common for participants to perceive that others did not believe their pain was real or their response to pain was normal.

"I would love to have been given this 12 years ago to show me I was not alone and my feelings were genuine"

"When you first meet people or read about experiences, it can be quite overwhelming as you really do think no-one else knows and you feel alone. So it's really helpful to know it is OK to feel like that"

"It made me more aware that others have experienced the same and that I am not making it up, the pain is real"

"I wish that I had been given info like this right from the start. Loss, guilt, anger and loss of identity lead to depression. Knowing that these emotions are NORMAL not just "understandable" have made me realise that I am reacting in a normal way to my situation so not just depressed or mentally ill."

Articulating feelings

With specific reference to the interactive task, participants found it useful to help articulate their feelings and acknowledge their emotions. Having a tool to use and a process to follow helped many participants to work through their experience.

"It was like borrowing words for things I couldn't communicate, which helped me articulate things and led to my own words being used. Maybe expressing myself for the first time in 10 years"

"Put my thoughts into words, but words I had not thought of using – helped me express my true feelings"

Difficulty using the task

Amongst the participants that did not find the interactive task useful, some were overwhelmed by all of the words and the process. One participant stated they had moved back and forth through the stages but they couldn't show this fully with stickers.

"I felt a bit overwhelmed by all the suggested words and an internal pressure to arrange them in the 'right order'".

Self-reflecting

Reflecting on their own pain journey was also reported as being helpful, with many stating that it was encouraging or good to see how much progress they had made, how much they had achieved and many also commented that they could now visualise a pathway through chronic pain.

"It made me realise how far I have come and how well I cope with life as opposed to the usual questionnaires which tend to focus on what I can't do"

Legitimising thoughts

Legitimising thoughts and feelings by relating them to the stages of grief was another noteworthy theme. Participants reported they could identify their own feelings and they now made sense, putting the pain experience into perspective.

"Although I had an understanding of loss theory I had not been able to relate the same to the loss of me. Normalising my loss has finally allowed me to start to move forward."

"It gives one a clear headed perspective to get a handle on what's happening."

"Very helpful. It acknowledges the loss of the person I used to be and the grief that was caused by this loss. It is OK to mourn the life I once had in order to move on to my new life."

"Showed this was a legitimate process and I had not exaggerated my feelings or had been a poor coper."

However, some participants believed they should not grieve for lost life; just find a different or new way forward.

Lack of engagement with the task

Not everyone found the PET useful, for example some participants stated there was not enough information to know how to undertake the interactive task or use the PET. Other participants did not find it useful, not as a result of the design of the PET, but due to their

own responses to their pain experience and a lack of positivity was reported by a few participants after completing the task.

"It doesn't change anything"

"I can't feel positive as no-one knows what to do about the pain"

"I still don't feel positive because I used more negative stickers, it tended to reinforce negativity and underlined how pain disrupts and dominates life".

When to use the PET

The timing of the use of the PET was frequently commented upon. Some participants thought it would be most useful at the beginning of an individual's pain journey. Others stated it may not be as beneficial for those who have experienced pain for many years as they were more likely to have found their own coping mechanisms.

"I really wish this booklet would have been given to me..... when I first experienced chronic pain in 2006. I'm sure it would have helped me and made it all less scary and out of my control"

However, other participants who had lived with chronic pain for many years felt it helped them gain a new perspective.

"It helped me give myself a pat on the back for all the progress I had made. It gave the progress some recognition"

The majority of participants would recommend the PET to others and stated they would complete the interactive task again to see if there were any changes to the way they felt about their pain and to map their progress.

PET 'follow up' evaluation

Approximately three months after completing the first questionnaire, a follow up letter or email on the subsequent use of the PET was sent to the 41 participants. There were 38 responses (92.7% response rate). When asked about further use of the PET, 47% said they had returned to it with 21% repeating the interactive task. In the three months after first reading it 57% stated the PET had been beneficial to them.

The questionnaire provided space for free text comments on participants' perspectives on the PET. A wide variety of responses were received. Many were positive stating it continued to help put things into perspective and in coming to terms with the limitations of living

with chronic pain. Providing positive steps going forward and giving confidence were also reported benefits. Others commented that it showed how far they had come and it acted as a good reminder to look after themselves.

Reasons given for not returning to the PET included that although initially helpful; participants had now moved on and some were managing their pain, others stated they were afraid that repeating the task might give less positive results and could therefore be upsetting.

Its usefulness to others was also noted, with participants reporting it was helpful for explaining chronic pain to family, friends and carers. One participant reported they found it very useful to discuss the results of the interactive task with their counsellor.

Discussion

The results of this evaluation have revealed the PET as a valuable vehicle for expression both visually and by providing the vocabulary that enabled individuals to accurately express their experiences. Using the PET was a positive experience for the majority of participants, stimulating reflection and providing access to the reflections of others. Using this unique and innovative approach helped individuals express themselves and gain a deeper understanding and acceptance of their responses to pain.

One of the more significant and unexpected findings to emerge from this evaluation was the strength of feeling of legitimising and validating emotions and experiences. It had not been anticipated that a booklet and interactive task received through the post and undertaken alone at home would provide a sense of belonging and community. This was highlighted by those who reported their feelings had been legitimised through their association with the grieving process and the subsequent realisation their experiences were shared and normal. Validation of experiences and emotions restored a sense of identity and belonging to participants, which in turn helped to reduce feelings of isolation and loneliness, often associated with chronic pain.¹⁰

Furnes et al reported that in a group setting "writing, self-revelation, and exchanges of thoughts and feelings in the group seemed to be the key tools for success. In addition, group support and access to other group members' experiences were significant therapeutic elements".²⁷ It is not thought that a sense of belonging and community have been reported in activities undertaken by individuals in isolation before.

In clear agreement with existing literature the outcomes of this study showed those living with chronic pain often experience loss as a result of this condition²⁻⁶,

which can negatively impact on lifestyle and self-perception.^{9,10} Using theories of grief and loss provided a framework that the majority of participants could relate to and helped them to gain a new or different perspective on their pain. This concurs with the findings of Furnes and Dysvik who used a similar framework to help healthcare workers understand the impact of chronic pain.²¹ For some, new perspectives enabled them to contextualise their experiences, in turn helping to acknowledge their achievements in regard to living with and managing their condition. It could be inferred from these findings that the PET promotes self-compassion, reported as a healthy attitude and relationship towards oneself. In difficult situations such as living with chronic pain, self-compassion facilitates well-being, resilience, and coping.¹¹

The follow-up evaluation three months after the first undertaking of the PET indicated this approach had value over a longer period of time with many participants continuing to reflect and develop confidence in their pain management. These results concurred with Burton et al whose educational booklet showed improvements in beliefs regarding pain that were maintained for a year.¹⁴ An additional and unanticipated benefit reported from the follow-up evaluation was that the PET helped participants explain their pain and its impact to others including family, friends and counsellors.

This current study has only examined a small, self-selecting sample. The participants were all members of Pain Concern, the nationwide chronic pain support group. This sampling could lead to bias as the participants were from a group that had actively sought support prior to this study. A good level of education and health literacy was observed in the written responses, which could influence the experience of using the tool. The PET may not have proved as effective for individuals whose first language is not English or for those with lower educational attainment and health literacy. It would also be very useful to undertake further evaluation of the tool with a broader range participant groups, including different cultures, educational attainment levels and participants for whom English is not their first language. A broader participant sample could determine if such factors impact on the effectiveness of the PET.

An important consideration when interpreting these data is the potential for bias from the analysis of the data, which was undertaken by a member of a pain support group. However, to reduce this potential bias they had not been involved in the development of the PET nor seen the PET prior to undertaking the analysis.

The PET is a valuable addition to the many existing useful and supportive educational resources available to individuals with chronic pain; these include

information booklets, websites, broadcasts, mobile applications and support groups. There are many directions for further development of the PET. A wider distribution at pain clinics would enable a more thorough evaluation of the PET's effectiveness and reduce self-selection bias. It could be evaluated alongside other resources as a part of pain management programmes to study its impact as part of a combined resource, suggested by Geneen as the most effective approach to pain management.¹⁸

An on-line application of the PET could be developed making it more widely accessible, whilst retaining and even enhancing its interactive approach. In addition, the underlying concept of the PET could be applied to a range of long-term conditions which impact on an individual's quality of life; examples include spinal injury, traumatic brain injury and multiple sclerosis.

Conclusions

The use of the PET as an effective approach in the field of pain management is evinced by the findings of this evaluation. The PET presents the concepts of loss, grief and their associated stages in a generalised context making them broadly accessible. These concepts, combined with an interactive and self-reflective task, provide an effective educational tool that follows a biopsychosocial approach, helping individuals with their perception and management of chronic pain. This paper adds to the body of literature supportive of biopsychosocial focussed education by demonstrating that this unique and innovative tool can help individuals to express themselves and to understand their response to pain is normal. This in turn can help reduce the feelings of isolation often associated with chronic pain and promote self-compassion. Whilst it should be acknowledged that the PET and its approach to pain education will not suit everyone, the majority of participants found the process of using it a positive experience. This evaluation strongly suggests the PET may help many individuals to live with and manage their chronic pain by gaining a new and positive perspective on themselves and their pain experience.

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Conflict of interest

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