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Reevaluating the Language of Pain: A combination of literary and visual arts- based methods

Niamh McConaghy

Supervised by: Karen Fleming, Dr Justin Magee & Dr
Pamela Whitaker

This paper explores the impact of maintaining a daily journal using visual and literary methods (blackout poetry and mark-making), to express the experience of chronic pain. Focusing on the dialogues of six participant semi-structured interviews, following two arts-based workshops and two weeks of participant journaling, the challenges and the potential for these methods to promote conscientious self-management and effective pain communication is explored. The results of this study are evidenced to produce therapeutic benefit and encourage an expressive and individualised, alternative method for constructing a narrative of chronic pain experience.

Keywords: chronic pain, self-management, communication

Introduction

Chronic pain is a global health problem, affecting around one in every five people worldwide (Dureja *et al.*, 2013). As a multicausal phenomenon, the effects of chronic pain (e.g. unemployment, arguments with loved ones) can also influence the physical experience. This complexity can create difficulty in differentiating between influencing and effecting factors of pain, which can therefore, impact the ability to communicate the total experience to others. The barrier in pain communication, however, is not only the result of such complexity, as it is also widely argued that pain resists vocabulary because there is a lack of sensory confirmation available in which to fully understand it (Scarry, 1985).

Whilst there are behavioral and symptomatic questionnaires to help clinicians understand pain factors, to assist in planning relevant treatment and management strategies, it is often argued that these methods do not fully communicate the lived experience of pain. Furthermore, whilst metaphorical language may provide, to an extent, a sense of relatability to understand pain experience, there remains a void between the subjective lived experience of pain and external understanding (Padfield *et al.*, 2010). Accurate interpretation of metaphorical language also remains at the will of accurate subjective understanding.

Utilising arts-based methods to enhance pain communication and external understanding have been more recently acknowledged in the past decade, including co-creating photographic pain imagery (Zakrzewska *et al.*, 2019), digital pain drawings (Shaballout *et al.*, 2019) and combinations of arts-based methods within arts workshops (Tarr *et al.*, 2018) etc. There have been none though that combine visual mark-making, or poetry that is constructed from texts that are based upon health communication. This purposefully selected word source reevaluates meaning within medical language for the pain sufferer and argues Scarry's (1985) consideration that language is a barrier for pain communication. The methods used in this study encourage a varied perspective of pain experience through both visual and literary externalisation and promote an effective sense of the reality of chronic pain through reflective documentation. This study explores how merging traditional health communication language with drawing may impact overall pain communication and self-understanding of pain factors. The

self-reported impact of the methods used in this study can be categorised into three themes: (1) awareness of interconnected pain factors, (2) the use of emotive language in describing pain experience and (3) future hope within pain narrative.

Participants

Participants were recruited from a course, run by Versus Arthritis, on self-management of chronic conditions. Later, further participants were recruited through disability arts organisation University of Atypical. A final total of six participants were included and who met the inclusion criteria: (1) were over 18 years old, (2) spoke English, (3) experienced self-reported chronic pain, (4) had attended a self-management course for a chronic condition and (5) attended the study's two workshops, one semi-structured interview and completed two weeks of journaling at home. This smaller sample size of six was compliant for the research methodology of Interpretative Phenomenological Analysis (IPA) (Smith et al., 2009). This study would have preferred a gender balance, however, all participants included who met the inclusion criteria identified as female.

Procedure

Participants attended a first workshop, which explained the methods of the visual mark-making and blackout poetry. Visual mark-making was described as the process of reflecting upon the day of pain experience and create a quick drawing in reflection of it. Blackout poetry is the practice of selecting words from an existing text to create a type of visual poem (Kleon, 2014), which participants were asked to select their words by reflecting on both their drawing and of their pain experience. Participants were asked to apply these processes at the end of each day for two weeks, at home, considering all aspects of their pain experience. This paper focuses upon the impact of the first workshop and the home journaling phases.

Awareness

Externalising a health experience, whether through visual art or vocabulary, can be a form of processing and sense-making. It is argued that our interpretation of the past informs how the past makes sense (Martin & Sugarman, 2001). Present interpretations of pain are, therefore, rooted in past experience. This makes the awareness of past, present and future factors of pain an important feature in constructing a fuller narrative of pain to communicate to others. However, the biopsychosocial reality of pain means that some factors of pain can often be viewed as vulnerable or difficult to express verbally. Pain behaviors can often consequentially become accentuated if a person is not aware of them and if left unaddressed, negative factors of pain experience can continue a vicious cycle of pain-related elements. The broad theme of pain awareness that emerged in this study is sub-categorised into four topics: (1) the awareness of the individuality of pain experience, (2) the awareness of shared experience, (3) the awareness of subjectivity and (4) the awareness of utilising arts-based methods for therapeutic benefit and/or pain communication.

Self-reflection was encouraged throughout this study in promoting the awareness of psychosocial, influencing and effecting factors. Participant Five discussed how her created artwork informed her to question the linkage between pain factors, whilst also highlighting the therapeutic benefit of these methods;

It was kind of like an exorcism almost. "What a rubbish day I've had", but you know, once it's out on paper, it's said, and you don't have to carry it on, so it's gone, it's on the page, it's in a different format so you can leave it there and then come back the next day and looking back too, you're able to see which days you had good days and perhaps why (Participant Five, 2019).

*Need to get up
Bed instead
Predicable
Reoccurring
Sting
It can only get worse!*

Fig. 1. Participant Five, University of Atypical, Belfast, 2019.

Participant Six also reflected on previous entries of her journal, considering her individual pain influences, "It was something that I would love to be doing all the time. You know, I think, I think it'd be quite good, and you know you really should be taking notes of how sore you are. We should be really doing that, so we can kind of see if like a seasonal thing, or what we've eaten or whatever.."(Participant Six, 2019).

*Freedom is control to art,
drawing the inwardness from trauma.

In life, we can express the pain,
creating and experiencing art.*



Fig. 2. Participant Six, markers and paper, University of Atypical, Belfast, 2019.

Participant Four created figurative images of concepts that she finds comforting, like a teddy bear or a beach. She reflected upon these images and explained that these were days when she 'felt like she needed a hug'. She remembered that these were days when her mood was more negative than usual and recalls that in the days leading up to such entries, she had experienced more intense physical pain. She remembered this pain-based experience from the 'comforting' imagery and connects that 'you maybe find the next day that your heads just not right, you feel down, and you feel sorry for yourself and you're feeling low, your mood.' This participant expresses a segment of her lived experience through her figurative images and consequentially communicates her understanding of her personal connecting physical and mental effects of pain. She discusses how these methods now come naturally to her, as she explains her individual colour preferences for representing her experience, 'I would sort of associate your blacks and your greys and browns with the bad days. And the brighter days would be the orange, pinks and yellows'.

Emotive Language

When discussing journal entries, many participants began with disconnected descriptions of physical qualities of pain and the visual aesthetic of the imagery. However, once discussed, many participants seemed to become consequentially prompted to use metaphorical language e.g.: 'my chest felt as if somebody was leaning on me' (Participant One, 2019). Many participants seemed to follow this conversational approach, proportionally ending the dialogue about the emotion that is enthralled within pain experience, 'Stuck. It's how I feel. Stuck. It's like Groundhog Day. I just want to start living again and I'm stuck' (Participant One, 2019).

What began as symptom-based dialogue appeared to be prompted by the visual imagery in altering the pain narrative to focus on the emotional impact

of pain. This created a deeper understanding into the reality of daily life with pain, as fragments of the experience seemed to permeate into the conversation, constructing a personal dialogue of pain.

Shaping Future Narrative

There were many images in Participant Four's journal that were created using glitter. When describing a specific glitter-based image, this participants' dialogue switched to future tense, as she explained that it represents who she wants to be. She described these images as 'a bright day, a sparkly day' and discussed how her pain is often misinterpreted by others, stating that many only can, or want to understand her pain experience superficially. Creating the imagery of who she wants to be appears to have encouraged an efficacious approach to her pain, as she discussed that she is more likely to now make a list of questions to ask her doctor about her pain experience.

Whilst there was initial anticipation within the group to create the blackout poetry titles that accompanied the visual images, participants commented that they strengthened the overall understanding of pain when viewed together. Participant One explains one of her poems as the following, 'But this one, "start healing, acknowledge pain, acute, significant". Without doing too much, overthinking it, to me that's what I want to do. Those words just popped out.' (Participant One, 2019). Participant One explains the accessibility of this method and alludes to an efficacious future pain narrative, of which this hopeful interpretation granted an indicator of present pain processing.

Discussion

This study explored the impact of documenting pain experience, evidenced by participants self-reflection of personal pain qualities illustrated within the visual and literary journal. Participants articulated their awareness between the mental and physical impacts of pain, and some differentiated between pain effects and influences. Whilst pain diaries are not uncommon, and more recently have advanced technologically (Garcia-Palacios et al., 2014), these methods produced pride and ownership from the group. Physically extending the pain experience through pen and paper appears to have created a personal connection with the art created and from that, induced an emotive approach to pain language.

This study is predominantly based upon self-reporting measures and so, like other studies, cannot quantitatively state that pain communication has been improved. Furthermore, each of the participants expressed uncertainty as to whether the art they had created could be accurately interpreted by others. It is evident though that this approach has acted as a prompt in producing a verbally articulated personal pain narrative. Symbolic meaning was construed through both visual and literary methods, which has assisted participants to reevaluate the approach of language within pain communication. This study provided time and space to discuss the inception of the art created, to ultimately provide a fuller account of the lived experience, however, this may often not occur in reality with family, friends or frequently, time-constricted clinicians.

Conclusion

This exploratory study strengthens the argument for further investigation of combinations of arts-based methods with documentational approaches in pain communication research. It also exemplifies the requirement of time, space and conversational processes to achieve a dialogue of pain, which reflects the reality of the often-vulnerable factors of the experience, in which to be communicated.

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