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Where There is Pain, There is Always a Person

Where there is pain, there is always a person – and that person suffers, lives, survives and at times thrives alongside that pain. That person is always at the heart of all that we do in research, in medicine, and in allied caring roles – but so often that person feels unheard, misunderstood, ignored or denied. This is both a truth and an untruth, and as ever when we consider people we fall into the mire of nuance, complexity and messy. We also have community when we have people – and that community, one of systems within systems is even more messy and inscrutable. But it drives pain and it drives suffering and cannot be removed from any consideration of any pain experience.

Part of trying to bring some unmessy to the world of Pain and Rehabilitation is my inclusion on the editorial board. I am a person with lived experience of persistent pain, from early back pain as a teen to young adult through to 17 years of serious trigeminal neuralgia which disabled me significantly and changed the trajectory and spirit of my life. In 2018 I learnt more modern interpretations of pain science, and it formed the foundation of a transformative recovery. I still have pain at times, and I endeavour to live a lifestyle that prioritises self-care and management, but the sheer breadth of change is astonishing and something I am endlessly grateful for.

I do not have a clinical background beyond what I have experienced as a patient but I am a scientist by training even if my later career was equine based not human. Since my recovery and the on-line flourish of Covid 19 I have become part of some wonderful research groups and know some in the PPA well through working with them and more members through their support of the Footsteps Festival and Flippin Pain.

With the Footsteps Festival I ran a Journal Club for a few years, alongside Dr Chris Penlington of Newcastle University. The aim of this club was to bring together people with lived experience of pain, clinicians and researchers of all stages. The club excelled in providing a collaborative egalitarian space where new research was presented, discussed and dissected, often with enlightening and surprising results. This is what I hope we can start to bring in spirit to this journal, stepping outside the somewhat tight parameters that journals and clinical research can cleave to. Inspiration for doing this will always be welcome!

The papers we bring to you in this edition create a story of both hope and dismay, micro and macro. Clair Jacobs' paper shows how collaboration and really hearing humans in pain can help effect very important positive change. Cass Macgregor's paper shows how vital understanding can be generated by hearing the voices of those not usually heard and how the systems designed to support can be part of the damage and the support. Alasdair MacSween's paper shows how people in pain are failed by the lack of consistency and differences in the way services are provided, if at all, around the UK and the Guidelines and Pathways formed to prevent this.

The same paper does show that the building blocks are there, but these are often the bare minimum and a person in pain would experience each course in a totally different way. Jacobs shows that individual Pain Management Programmes (PMP) can enact changes that would benefit so many if they were widely adopted but as MacSween highlights the Guidelines formed to provide the person in pain a hope of good quality care are lacking due to – as the paper comments *"a paucity of robust, pragmatic evidence of the effectiveness of CPPP".* If the Guidelines cannot be relied upon is the messy winning?

However, how does the need for reflection and ability to change the way PMPs work based on collaboration with patient voices sit with the more rigid nature of NICE guidelines?

The NICE Guidelines exist to keep patients safe and accessing treatment that is evidence based and good quality, but do they truly centre the person in pain? Are they fit for purpose or not? MacSween certainly suggests not.

Jacobs' paper shows the importance of checking in with the participants and actually hearing their thoughts – of being responsive and keeping the person's experience at the centre of the programme. It's an inward-looking work, intimate, qualitative, but with a potentially large positive effect. MacSween's

paper in contrast is an outward looking work, an overview - data driven and not intimate at all but with a potentially large positive effect. Two ends of the spectrum with Macgregor's paper straddling both – the intimate understanding of a more marginalised experience which highlights with brutal impact the damage non-responsive and punitive impersonal systems have on people's pain experience.

Jacobs

Trauma informed care – it's more than a buzz word or tick box as Jacobs' paper shows just by changing the way one pain management program (PMP) interacts with its participants. By publishing the paper and showing how the changes will be useful this has the potential to influence not just other PMPs but other clinicians and other programmes or courses that involve getting patients together in group settings. Thus, we hope that the paper has the ability to change things on a slightly broader level than might be first thought.

The paper also highlights how rich, effective and useful collecting information directly from people in pain in their own words can be. They are then filtered through the interpretation of the researchers, a bias that is recognised. I wonder what effect having an additional non clinician interpreter would have?

My inclination is to support the involvement of a person with lived experience in every part of research – from inception through to interpretation, discussion and promulgation. This paper is, in my eyes, undoubtedly enhanced by the patient participation group that they mention and which appears to be heavily involved in the PMP and how it functions.

This is a lovely paper and it handles the participants very respectfully, with dignity and care.

The important premise of this research is that the biggest predictor for effectiveness of psychological treatment is a solid therapeutic alliance with a good bond between the person in pain and the clinician. By embracing trauma informed principles this bond appears to be enhanced and nurtured.

The themes teased out in this paper are all fascinating and useful, both in practise and in guiding future research. The effect of the peer group dynamics would be an intriguing aspect to investigate, and I hope we see such work in this Journal soon.

Another important consideration from this work is how trauma informed care should be extended to the clinical staff as well as PMP participants. As a Samaritans Listening Volunteer one of the things we do particularly well as an organisation is the support of our colleagues – we debrief during and after each shift and have a support structure in place at all times – something I often hear of lacking in clinical systems. This seems to me to be a very important aspect of this paper and something I hope is taken further. Moral injury, burnout and compassion fatigue are all too real and hurt everybody. This utterly human and utterly messy reaction should be met and soothed by human compassion, empathy and support.

Macgregor

Macgregor's paper builds on her previous work for her PhD, which was innovative, clever and imbued with the sincere desire to rectify the systemic wrongs that people in pain experience and her way of describing it went some way towards unpicking the messiness that is intrinsic to the pain experience and to being human in general. I'd very much recommend that people read and reflect on that previous work if they haven't already.

In this paper Macgregor focuses on more marginalised people in pain and their experiences, in this case marginalised by their socio-economic status. Poverty is a high predictor of persistent pain and as are other forms of social marginalisation such as discrimination, housing insecurity, education level etc. Often people are excluded from research by virtue of these challenges that impair their access to healthcare and to research.

It's been my experience as a patient partner most of the people involved in a such a role in research tend towards the more educated, more economically secure, more middle class and more white, and they have intrinsic privileges based on that even if their current economic status is low. This latter is often due to living with pain. While these are valued voices, it's so important to hear the voices of as many as possible and especially those people who are not usually heard at all. This is true for both participants and patient partners.

Another reason that Macgregor's participants were considered marginalised in terms of research is because they had co-morbidities. It's an unfortunate

aspect of research that co-morbidities rule people out from a lot of research which doesn't begin to reflect the messy reality.

This paper is another lovely paper, again carried out in a highly dignified, respectful and compassionate way. What really did cut through, as with Jacobs' paper was the quality of responses from the participants, providing a rich data set. The themes picked up are very interesting and although they only talked to seven people, it feels to me that they would scale to wider experience. Further research would have to be carried out to be able to say that with certainty, but it certainly chimes well with what I have seen in anecdotal evidence.

Acceptance of pain as Macgregor's previous work found, is a *"fluid and continuous journey"* and while it's important for the person to find a way of accepting the pain or - as one of their participants said *"coping wi it",* this paper highlights beautifully how the burden of that emotional and practical work should also fall on a wider level.

Choosing and learning how to accept/to cope with your pain is also about your family, your workplace and type of work, your local community and the wider systems we all interact with. In this paper Macgregor specifically highlights the impacts of healthcare systems and the social support structures such as Social Security as well as the wider political dialogue.

This is so important both to the person in pain but to all who care or treat those people in pain yet it's a very overlooked aspect. It mirrors what Jacobs says in her paper about the more trauma informed the care is, the more effective that care is. Thus, the benefit to the patient is far higher.

Macgregor's paper highlights the effect on people in pain of negotiating the Social Security system which increases their threat levels and deteriorates mental health because of the punitive and suspicious way it operates. It seems that people on universal credit have a more precarious experience and this is one of these messy effects that snowballs and causes feedback loops that make pain experiences harder. I certainly know from my own experience that the support to return to work after pain or whilst having pain is dire. Not assisted by the universal credit system feeling punitive with an effective marginal tax rate that has a chilling effect on taking on more work. It's the cause of constant threat, fear and worry which as we know is contra-indicated in any kind of recovery.

Macgregor's paper has both micro and macro benefits and effects and, in her conclusions, she highlights potential areas where change could be effected. From better education for GPs about persistent pain to the macro change to the social determinants of persistent pain.

MacSween

MacSween's paper is the most macro, looking at how Combined Physical and Psychological Programmes (CPPP) for chronic low back pain operated in real life in comparison to what is set out in the National Low Back Pain and Radicular Pain Pathway Guidelines and other relevant Guidelines.

The results showed that there was quite a wide variation in style and content for delivery of CPPP, and that adherence to the Pathway or Guidelines was somewhat vague. The authors suggested that as a result of their study showing the messy nature of the varying outcome measures used, development of a core set of outcome measures would be sensible. This would ensure that CPPPs were effectively supporting people in pain. I would hope that the introduction of a way to compare and contrast would improve provision and reduce any "postcode lottery" effect. I would always argue that a quality-of-life assessment be included as this seems to me to be the real-world indicator of effectiveness.

It appears to me that the NICE Guidelines and the Pathway seem to be ineffective and not very helpful at this stage. What can we do to improve these?

One aspect that this paper brings forth is the feeling that people in pain are being failed by a "postcode lottery" and very dependent on an individual interpretation of those guidelines. While the key components included in the course were in keeping with the NICE recommendations and Pathway much else varies. I was most concerned that this study showed that that many areas are underserved or have no access to CPPPs for people in pain.

This was a macro paper, it's very much about data rather than the individual person in pain, however it very much joins the narrative about micro and macro effects as these courses serve the person in pain at a micro level and the paper shows how much continuity

and effectiveness at a macro level are needed. The fact that there's no guarantee that you're going to get the same quality of care depending on where you live should be of urgent interest. If we are giving a subpar experience to any people that is a real loss of an opportunity and likely prolonged or exacerbated suffering. Maybe that will be of less interest to the commissioners, but the financial cost of an ineffective service should be.

So, we have three papers, all very different and working at different levels of effect and scope. But all show that change is needed, and that the status quo is undesirable.

There is much to be done in terms of individual pain management courses, both in content and in improving trauma informed care. Marginalised people of all aspects should be given the best opportunity to access effective treatment and to have their pain experience understood. Effective and fit for purpose Guidelines and Pathways need to be worked towards.

I have a deep interest in the wider social determinants of pain – something that I feel gets less priority and attention in general and far less encouragement in terms of financial and political support in research and in general discourse. And it is daunting (and frustrating and anger inducing and fatiguing). But I consider advice deriving from the Talmud;

"Do not be daunted by the enormity of the world's grief…You are not obligated to complete the work, but neither are you free to abandon it."

We are all very comfortable with the understanding that persistent pain is a biopsychosocial phenomenon and we are better at looking at other aspects of the lives of people in pain. If we truly believe this then must we not work to ensure that wider health and social and political systems improve their acceptance and understanding of persistent pain and their role in preventing it?

As Jacobs' paper shows, trauma informed care enhances the therapeutic alliances and supports clinicians' own wellbeing. This seems to me to be an easy but not minor change that could support real progress within healthcare systems. There are many such changes that could help a struggling and pressurised healthcare system, but what of higher levels?

We know that deprivation and marginalisation is an indicator of a high prevalence of persistent pain and if we are really serious as a society about moving to preventative care model then we should try to do something about deprivation, about financial security, housing and nutrition security. We need to work on community, build back relationships – interpersonal, familial and societal, helping to reduce isolation, opportunities for trauma and increasing available support and care. We need to be providing people with good education and improving health literacy especially in this era of AI information and general misinformation. Use education in the early years to change the old narrative around pain and enhance our understanding of how our minds and bodies work in messy harmony.

Deprivation is not the only driver of persistent pain, and we must not become blinkered when considering improving preventative care, as with everything this is messy and accepting and embracing that is key.
Something Macgregor's paper clearly shows is the impact of political rhetoric, both from politicians but also from the media (mainstream and social). For a long time the narrative has stigmatised people who need support from the social security system, especially as persistent pain is invisible and subjective, although the effects for that person in pain are absolutely not. Macgregor's paper shows this clearly, and my own experience concurs, both personally and what I hear from others. The steady drip drip of negative messages allied with the punitive and suspicious contact from the DWP does nothing to reduce the sense of threat. McSween's paper feeds into this with the inference that CPPP provision is not a priority nationally, that people in pain are not priorities. Maybe the simple act of acknowledging and witnessing all this has its own power?

The scope of the *"world's grief"* in relation to persistent pain is huge and the short-termism of our political structure makes it very easy to become myopic and perhaps not fight so hard for that larger positive change and certainly it feels easy to suggest the system is not working for anyone at the moment. But we can fight both at the micro and macro level. We can make those small changes that mean a lot to the person in pain in front of us - consider that person a starfish[i] - it's going to matter to them – it might not impact on a scale of hundreds of thousands, but it sure as hell matters to that person in pain who is suffering right

now. We know that compassion, empathy and connection is fundamental in improving people's pain experience and those small interactions can have a truly fundamental impact on their lives and their experience of pain. Those kinds of experiences also help clinicians themselves who are often suffering huge moral injury negotiating these unwieldy, rigid and decrepit systems that are actively working against that compassion, empathy and human connection.

I know I'm preaching to the converted, I know what I'm saying is both obvious and impossible, but what's the alternative? It's so easy to disconnect, to become jaded, lost and desensitised, and I feel all those things. It's talking to others in groups like our old Journal Club that are an antidote, that precipitate change, movement and hope. This editorial was supposed to be crafting a narrative around the three papers we present, not a political exhortation; but here we are.

We go on with messy – and we hold much at once – we can improve daily on a micro level and work for change in years or decades on a macro level. We can hope, and fight and change lives both one at a time and many in time. Macgregor says that *"pain is unavoidably political for those at the sharp end of these experiences".*

I would argue that pain is always political, just as being human is political, but there is always common ground – we just all need to find where to stand.

Looking Ahead

In these "changing times," we have a unique opportunity to reshape pain care and rehabilitation into a field that truly serves all people, regardless of their background or circumstances. This requires not only embracing innovation but also challenging the status quo, advocating for systemic change, and prioritising the principles of EDI in everything we do.

At *Pain and Rehabilitation*, we invite you to join us in this mission. Whether you are a clinician, researcher, patient, carer, artist, policymaker or undefined, your voice matters. Together, we can use this journal as a platform to share knowledge, inspire change, and build a more equitable and inclusive future for pain care.

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[i] https://www.thestarfishchange.org/starfish-tale