Reimagining Pain Care: An invitation to rethink pain management

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''It always seems impossible until it's done''
Nelson Mandela

The current state of pain management

Epidemiological data indicates that more and more people are experiencing chronic pain - persistent or recurrent pain that has gone on for more than three months [1] - globally with associated pain related disability, poor function and negative psychological impact [2, 3]. The demand for health services to support people living with chronic pain is projected to continue to rise [4].This is despite the growth of the research field and specialist practices of pain management. Care provision often sits under the umbrella of pain management though there is little agreement on the ideal composition of such services. They range from services that espouse a biomedical model and offer pharmacological and minimally invasive procedures focussed on pain relief, to specialised multi-disciplinary services offering packages of care including (but not exclusive to) pain management group programmes, physical, occupational and psychological rehabilitation. In the United Kingdom, these services fall under the provision of the tax funded and free at the point of care National Health Service (NHS). Specialist pain services vary in terms of which professionals are involved in delivery, their accessibility and outcomes [5, 6]. Patterns of inequity in service provision reflect wider health inequalities, with geographical areas with higher need (based on socioeconomic deprivation) having fewer services as recommended by national guidelines [7]. Compounded with difficulty securing a diagnosis [8] and stigma associated with diagnosis [9], seeking care for chronic pain is challenging.

Uncharacteristically for long term conditions, routine care for chronic pain is broadly provided in secondary or tertiary care hospitals rather than the community, is episodic, rather than continuous and is guided by a narrow range of knowledge practices and traditions (medicine and behavioural psychology e.g. CBT, ACT) that do not always account for pain being comorbid with other health conditions. Even when people access pain management services, the interventions on offer have limited and varied effectiveness and it is not clear what is most helpful for whom and in which circumstances. Many medicines are now not recommended [10] and there is growing evidence of harm related to dependence and withdrawal symptoms [11, 12]. The result is an absence of long term support outside primary care where most people living with pain have contact [13, 14]. Even then, the offer is limited in part due to the limitations of a dominant biomedical model for chronic pain.

Existing models of care have remained largely unchanged for many years and there have been calls to innovate the field of pain management to more closely match the needs of those affected [15, 16]. Where new models have been implemented, they show promise in supporting primary care, developing communities of practice and providing relational, long term care for people living with chronic pain across different facets of their lives [17, 18]. Still in their infancy, we do not yet have data on their effectiveness against existing interventions.

In sum, the landscape of pain care is messy in its conceptualisation, provision and implementation.

The future of pain care

Great ideas manifest in our collective practices and through generative conversations. Drawing on an empirical critical inquiry of the field [19], we sought to contribute to the voices calling for a reimagining of pain care by facilitating a conversational workshop. We captured and interpreted aspects of these conversations and present that below setting out a vision for the

future of pain care amidst the challenges outlined above. The workshop was convened with three objectives 1) to disseminate the results of a research project to selected stakeholders 2) to collectively respond to the research findings and 3) begin a process of articulating a reimagining of pain care in dialogue with each other.

Developing a dialogue

The workshop was conceptualised as imaginary and future focussed where participants were purposively invited for their innovative ideas and contributions, drawing on their position as lived experience advocates, practitioners, decision makers within commissioning and policy and researchers. Participants (both in person and online) were first presented with a provocation, in this case a multimedia presentation co-produced by JW with a design agency (Design Science), patients and the public, practitioners and decision makers, setting out insights from JW's empirical study and their real-world application. Rapporteurs were identified in advance and invited to record and report their reflections, capturing the spirit of the wider conversations with consent of all participants. Their reflections are included in our summation below.

A shared problem

There was a general consensus that the organisation of pain services was unsatisfactory. Central to this sentiment was the idea that pain management was a misnomer, in that outside acute pain there was little evidence and anecdote that pain could actually be controlled. Participants spoke about the unreliability of any number of approaches in meeting a goal of symptom reduction and the resultant moral injury that clinicians experienced when tasked with deprescribing problematic medicines that they may have initiated earlier in a patient's journey.

Whilst advances in neuroscientific knowledge was lauded, there were concerns about how this knowledge derived from bench could be applied in complex real-world environments as well as if health care professionals had sufficient enough grasp of pain science for it to be practicably useful. Alongside proponents of the value of pain science, there were critical voices alerting us to the ascendant hegemony of neuroscience within pain management and what other knowledge was being excluded/missed.

The proposed alternative of 'pain care' was considered to be reflective of other forms of care (e.g. social care) and introduced some grace and compassion in the overall approach to the complex nature of living with, and supporting those living with chronic pain. Fundamental to this re-imagined type of care was a shift from delivery of care to individuals which was determined by professional experts, to one with relational ways of being and humility at its heart [20]. This proposed shift would allow practitioners to engage with others and the world different to their own, in ways that are thought to foster transformative co-learning in place of more familiar hegemonic practices. Yet, as stated by many participants, clinicians are traditionally trained to act on the level of an individual only and are often disconnected from wider community resources with very little training and support in how to engage with the agencies outside health care.

Concerns were raised around the absence of a political infrastructure that could direct this change and was evidenced by the memory of stalled past initiatives such as the chronic pain policy coalition [21]. Additionally, though primary care was seen as fundamental to delivering relational continuous care for people with pain and multimorbidity, it was evident that ongoing funding and workforce concerns would limit change from this sector.

Collective transformative action

An individual would certainly struggle to do and be different within the existing established health and care systems. However, collaborative collectives and partnerships working together have the potential to move within these same systems to affect change in pain care. There are a number of critical theorists that have proposed

frameworks and approaches for thinking in this way, outside hegemonic practices and ways of knowing [20, 22-24] and we draw on their insights to propose tangible ways to reimagine pain care. They all include drawing on valuing relational and social ways of being that include marginalised voices, social and political structures, upstream interventions and redressing health inequities, all solutions our participants also proposed. For them, reimagining meaningful pain care included:

- **Community embeddedness** - co-locating pain services within trusted community organisations e.g. churches and/or spiritual healing centres, to build trust, expand outreach and create listening spaces to foster co-production
- **Wider collaborative partnerships -** to include different forms of expertise, e.g., public health activists, community workers and policy makers.
- **Disruptive practices** - for practitioners to make small changes in their own spheres ranging from the physical environments to the offer of services they include.
- **Re-centre primary care and community** as sites from which to provide effective pain care including social care, mental health care and self-care.
- **Connection and communication** - to support networked versions of pain care and to ensure equitable distribution of resources.
- **Return to rehabilitation** models in pain care - to support people in *doing* what matters in their local environments, in response to prominence of siloed education and psychological interventions.
- **Engage with meaningful evaluation** that values people's preferences e.g. social return on investment over professional, organisational or research metrics.
- **Recognise socially and politically determined determinants** of health and act proportionately to address them.

Participants suggested pathways to change at a system level, ranging from slow and iterative change relying on building the evidence base, lobbying and winning hearts and minds, to radical and revolutionary approaches that upended hegemonic structures and redistributed resources.

Reformation or revolution?

The workshop illustrated that there is no one single set of instructions on how to re-imagine pain care and how to go about *'operationalising'* it. Such a tool-based approach would be inadequate for a process that likely requires courage, imagination, and collective organising. What the workshop did model is that the process of interdisciplinary dialogue can serve as a powerful lever in breaking down silos and identifying common ground on which to build.

Foundational to this dialogue was identifying a need for a paradigm shift when it comes to our collective understanding of the very nature of pain (care). By this we mean to have a shared discernment that pain is not and cannot be conceptualised as an epistemological problem only which can then be mended with mere epistemic tools. In other words, pain is the problem of everyday living and as such, it lives outside of our clinic walls and office rooms. It is socially and politically coloured. Making this conscious acknowledgment can then serve as a personal leverage for professionals in the pain field to transcend limitations of siloed working and bridge across the disciplines and expertise, animated by the deep humanity that we all share.

The call we are making here is an invitation to each actor in the world of pain care to consciously enter the field of advocacy and social and political responsibility, manifested through deliberate actions in the service of health justice. We feel that every pain professional has a choice to make every day, to use their human and social capital in the service of more just pain care. This is no small ask, but perhaps this is where the change begins.

We recognise that, more than ever, we need genuine conversations as a form of revolutionary praxis towards enacting change. So, let us have those conversations - with our communities, with peers, with policymakers - and let us carefully organise projects which remove barriers to access and create inclusive and relational spaces for new, more compassionate pain care. A type of care where managing pain is not the only offering, but a care where a full human flourishing is on the horizon of possibilities.

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