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Dancing with pain: agency through pain worlds

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ABSTRACT

This article examines a series of qualitative interviews with seven dance artists in the UK who make dance works with and about their own chronic pain. It integrates research from dance studies (on dance and agency) and health-based chronic pain research (on agency with pain) to focus on individual, interpersonal, and environmental dimensions of agency with chronic pain. The research addresses therefore how the dance artists have individually acted as agents by making change in their own self-identities and working lives. Further, it highlights the importance of peers and audiences alongside the environments of performance which enable agency for the artists. Finally, the article proposes that agency is created in performance through the ‘pain worlds’ shared by the dance artists, that give felt and sensorial pathways to understanding aspects of living with pain.

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Dance; chronic pain; agency; individual; interpersonal; environment

Introduction

In 2019, I co-founded a new research network on somatic practice and chronic pain which explored perspectives from dance and health.¹ Agency with pain came up in various guises with terms such as self-efficacy, self-management, empowerment and advocacy. Meanwhile, dance and somatic discourses propose to ‘reclaim ownership’ of body experience and offer ‘somatic authority’ (Green 1999, 97) in finding personal forms of body expression, which could be figured as a type of agency. Beyond the network, I also became aware of various dance artists in the UK whose work integrated their own chronic pain experiences. I wanted to engage in a dialogue with these artists to reflect on the ‘body of knowledge’ they held on dancing with pain. What were their lived experiences of chronic pain in daily life and in the dance industry? What barriers did they face? What role did their dance practice and performance play in navigating their pain experiences? And how did they view agency or lack of it within their lives and work, as dance artists living with chronic pain?

The artists I interviewed include Raquel Meseguer whose ‘Crash Course in Cloudspotting’ (2017) incorporates movement and text, based on stories of people with chronic pain and other chronic health conditions about resting in public spaces. Sarah Hopfinger collaborated with Meseguer on ‘Turning Towards’, a research and development project bringing attention towards rather than away from pain. Currently, she is performing her own live dance and audio work called ‘Pain and I’ (2021), which

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combines movement and text. Mark Edward shares a dance-comedy-queer performance aesthetic in his work ‘What have YOU done to deserve this?’ (2019) about pain, aging, and mental health, performed by Edward with recent dance graduates. Also highlighting young artists, ‘[pain]Byte’ (2017) is a ballet-based work created by Genevieve Smith-Nunes in collaboration with Camilla Lloyd (dance), Alex Shaw (software) and students in second level education. The work examines pain theory and lived experience through ballet techniques and immersive technologies. Meanwhile, Mo Pietroni-Spenst explores pain, fatigue, gesture and communication through short duration works: ‘Untitled’; ‘(In) Visible: Tell Me What You See’; and ‘Screening My(Self): Reflections’, all submitted as part of her PhD (2019). Finally, C and Y are a duo who have chosen to remain anonymous. They are developing new work from a residency (2020) that explored their shared pain experiences through movement and drawing.²

Chronic pain is generally understood as pain that lasts for over three months with a complex set of biopsychosocial factors, which effects approximately twenty percent of the population worldwide (Fayaz et al. 2016; Raja et al. 2020; Treede et al. 2019). Lack of agency can be experienced by people living with chronic pain as ‘weakening of his or her autonomy to affect the situation’ and ‘feelings of inferiority and of being disregarded and mistrusted’ (Hellström 2001, 89). A sense of control can feel limited with chronic pain when managing fluctuating symptoms, while the invisibility of pain can lead to not being believed or understood. Duncan (2019, 228) highlights the social dimension to pain treatment since ‘[j]udgements about the patient’s authenticity when complaining of pain are prone to social biases, leading often to underestimation of pain . . .’. Living with pain also has the capacity to alter a sense of autonomy, since physical abilities may alter working patterns, family relationships, economic and social circumstances (Jay 2015).

Dancers have a high prevalence of pain connected to occupational physical strain, dance culture and attitudes to pain (Jasmin et al. 2018). Prior research exists, for example on dancers’ mapping of injury or pain and perceptions of what they qualify as ‘good’ or ‘bad’ pain (Tarr and Thomas 2011, 2021; Thomas and Tarr 2009). This highlights some barriers to agency with pain including an individual’s perception of pain and its communication. While dancers may recover from acute pain from injury, chronic pain is addressed less often in relation to dancers and their livelihood. Like many disabled artists, dancers with chronic pain face obstacles to accessing training and sustaining their careers, including aesthetic and attitudinal barriers (Aujla and Redding 2013). This is exacerbated by a ‘deficit of disabled role models in leadership positions in dance has meant that disabled dance artists are unable to clearly visualize longevity for themselves and their work in dance’ (Marsh 2016, 184). Yet, at the same time, disabled dance artists often become ‘accidental leaders’ (Whatley 2018) creating innovative ways of dancing and producing dance, a potential route for dance artists with chronic pain to experience agency with pain.

However, this lack of representation and role models might be extended by the invisibility of chronic pain as a disability. In Scarry’s (1987) seminal book *The Body in Pain*, she argues that what can be verbally represented can then be politically represented, considering the challenges of communicating pain. More recently, some recent edited collections have examined how different arts practices can gesture towards this expression and representation of pain (Polledo and Tarr 2018, Padfield and Zakrzewska 2021). Although genres such as photography, poetry, drama, and online tools are explored, dance is largely absent.³ While I do not focus primarily on communication of pain in this

article, articulating pain and being understood are essential components of agency. In particular, I address dance practice as an underrepresented form in this field of chronic pain, especially dance artists creating work with their own pain. Some of the dance artists I interviewed have written articles or given public interviews about their individual dance practice with pain, although these do not focus directly on agency (See Edward 2020; Hopfinger 2021; Meseguer 2017; Pietroni-Spenst 2019, 2021; Smith-Nunes, Shaw, and Kneale 2018) Meanwhile, Pini and Maguire-Rossier's (2021) conversational article explores cancer pain and agency through individual dance practice, highlighting personal control as well as interpersonal dimensions. In this article, I generate a holistic understanding of agency with pain through drawing together interviews with dance artists who make artistic work with their pain, alongside research from dance and chronic pain on agency.

Mermikides and Bouchard (2016) suggest that agency can be felt through performance practices about health experiences, that are 'contrary to the passive patient who receives care' (4) by encouraging people to 'enact, act out, up or against the passivity' (11–12). However, there are also considerable barriers to agency for dancers with pain in daily life and the dance industry. I want to consider this paradox further since there is scant research which deals directly with dance, chronic pain and agency. My proposal is that understanding dance artists' experiences of agency (or lack thereof) would be valuable for several reasons. Firstly, it can provide insights into barriers in the dance industry for the large cohort of dance artists with chronic pain. Secondly, knowledge held by dancers about creatively approaching their pain may support others, including those outside the dance industry. Further, this research expands on concepts of agency currently in circulation, in the fields of dance and chronic pain research especially, by considering multiple dimensions (individual, interpersonal, environmental).

Dimensions of agency in dance and health

Before focusing in detail on the interviews, I turn to ideas of agency in health and dance literature. Research in healthcare increasingly identifies the value of people finding meaningful ways of living well with pain, rather than focusing on cure. Self-efficacy describes how an individual is confident to manage their own health and engage in daily life activities (Wenham et al. 2018, 308) and is often incorporated into pain management. Gaining some control while living with chronic pain is a kind of individual agency, with Braun et al (2018) noting how a 'sense of agency (SoA) refers to the experience of initiating and controlling an action.' At the same time, McCracken and Zhao-O'Brien (2010, 170) also note the importance acceptance of pain and willingness to encounter challenging experiences 'without attempting to control them'. This is interesting since agency is associated with taking control of some aspects of one's life, while also letting go of others 'to allow a wider range of behaviour in response to these unwanted experiences' (McCracken and Zhao-O'Brien 2010, 175).

If agency with pain includes a balance between controlling and letting go, how might this be supported through dance practice? Current research in dance studies examines the potential for agency in professional or community dance settings, often through improvised dance practices, where agency is described in an individual manner. For example, Batson et al (2016, 2) propose improvisational dance for Parkinson's Disease, to

support agency as the capacity to ‘act in the world autonomously and independently.’ The individual participant gains active ownership or control over their own movement choices, as a way to meet their own needs and find meaning in their activity (2). This could be described as a means of letting go of control through improvisation (rather than executing learned responses) to feel a sense of control through developing personal movement styles. Meanwhile, addressing agency within professional dance improvisation, Bresnahan (2014, 86) importantly raises the ‘limiting feature on this agency . . . is the dancer’s training in learned and individual styles.’ The individual agent is understood as having autonomous choice in how they move in and respond to the world, albeit within limitations of learned social/cultural habits or trainings.

However, ideas of individual agency could be critiqued for placing responsibility primarily on the person with pain to self-manage alone, potentially leading to personal blame for pain flare-ups. This ignores factors which might also impact on pain, such as under-resourcing or stigmatisation of those with chronic illness. A recent move has been towards ideas of ‘supported self-management’, working together with healthcare professionals to increase patient ownership over their own health. Walach and Loughlin (2018, 5) discuss ‘patients as agents’ who are motivated and involved in their own health, making choices about what has meaning for them, while also maintaining support from other people. Peer support is one interpersonal structure examined in chronic pain research, associated with benefits such as ‘making a connection’, ‘a sense of purpose’ (Arnstein et al. 2002, 94), and ‘providing/receiving encouragement and support’ (Matthias et al. 2016, 2247). Chronic pain research on peer support often focuses on improving health outcomes, such as pain management, physical ability, and depression for example (Tolley James et al. 2020, 5), so that the individual can return to function well in daily life. External support might also come from healthcare professionals, carers and family members acting as advocates for a person with pain (Jowers Sullivan and Main 2007; Ware et al. 2011). Muneer (2015) highlights the need for greater collaborative efforts to address public education and advocacy in areas of understanding pain, pain prevention, treatment and access to services.

With support from other people in terms of peers and healthcare professionals being a factor in agency with pain, how might this be explored in dance practices? In dance training, Dyer’s (2010) research highlights how individual movement can reveal dynamics of power, such as between teacher and student. She examines how contemporary dance students in higher education might engage with agency in relation to their teachers, with the potential to take ownership and control of their dance trajectory. However, this is not always the case within dance training or dance companies, and the experience of pain (common to many dance artists) is not always catered for in the creative environment. There is great potential for dance professionals to consider more fully the contribution of dancers with pain, and how they might be supported by peers, dance teachers, and creative collaborators.

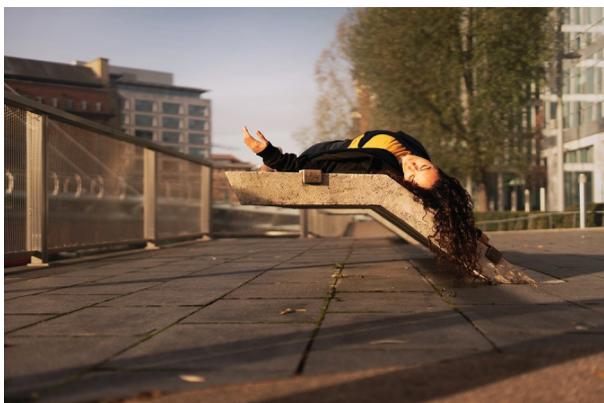
Apart from individual and interpersonal agency, environments also impact on living with pain. The social model of disability suggests that environments might be already fundamentally disabling (Goodley 2016, 32). Physical environments in public spaces or workplaces can be set up in a disabling ways, such as spatial layout for example. In chronic pain research, only occasional reference is made to material environments, such as the impact of physical comfort, temperature, light, noise, and smells for example (Hoftun

Farbu et al. 2019; Friedman and De Ver Dye 2009, 941). However, in arts and humanities research, ‘new materialist’ theories have emphasised the interrelationship between people, environments and materials. Coole and Frost (2010, 10) disrupt ‘the conventional sense that agents are exclusively humans who possess cognitive abilities, intentionality and freedom to make autonomous decisions’, and instead consider how ‘material forces themselves manifest certain agentic capacities’. So, in the case of people with pain, physical environments might exert an influence on how they experience home or work for example.

Recent dance scholarship has grappled with the idea that materials have agency, proposing they work in ‘confederation’ with the dancer to inform movement (Kramer 2015). Such work decentres the role of the human performer as an individual agent and instead highlights movement as emerging in relationship with material objects and environments. For disabled dance artists, objects such as wheelchairs and crutches may powerfully inform movement and creative approaches to motion. At the same time, Polson (2013, 58) challenges the idea that these are ‘the locus of agency behind the artistry in the performance rather than the performers . . . what they are not is authors of the artworks, or choreographers or performers in the performances, in which they are used.’ While in agreement that the person’s agency is important as they explore disability and pain, I also argue that the inherent qualities of materials have much to offer a discussion of agency and empowerment. I align myself here with the work of Graham (2009) on Fibromyalgia, which considers agency as multiple human and non-human factors that collectively instantiate change over time to shift perceptions and therefore treatment of pain. I suggest it is therefore also important to reflect on how non-human factors and environments can be empowering (or not) in the work of dance artists, through the stage and performance materials (such as space, air, time, light, sound, texture).

Methods: dialogues with dance artists

Following from this review of literature on pain, dance and agency, I now turn to the research methods. In this study, I wanted to enhance an understanding of dancers with chronic pain and their dance practices. I undertook a search in the UK for dance artists who make choreographic work with and about their own pain, sourcing artist websites, publicity, performances, writing and social media links. Other artists were found by word-of-mouth through the Somatic Practice and Chronic Pain Network or through the dance artists interviewed. This ‘snowball’ approach introduced artists to me who were at different stages of their engagement with their own pain as a subject matter for art-making. All of the artists interviewed have had their dance work about chronic pain, disability and/or physical limitation in the public domain (for example, through their websites, public performances, sharing of work, residencies, and writing), so I did not target individuals with undisclosed chronic pain. Although I identified further potential artists to interview, I paused recruitment at saturation point where no new patterns and themes were developing, so I could conduct in-depth, qualitative analysis.



Raquel Meseguer Zafe, *A Crash Course in Cloudspotting*. Image: Paul Samuel White.

The dance artists include women in their 30s-40s, one man in his 50s, with two participants describing ‘queering’ as part of their work. They are spread out geographically in different parts of the UK (South East, South West, London, East Midlands, North West, and Scotland), either working within higher education (full or part-time) and/or independently in the dance sector. They experience a range of different conditions and symptoms that they described as including spondylolisthesis, frozen shoulder, back and neck pain, pelvic pain, fibromyalgia, ME and fatigue. They developed pain at different periods of their lives; several indicate the effect of dance industry working conditions on their body over time. Typically, they experience daily long-term pain and discomfort exacerbated by more intense flare ups, with a range of sensations and symptoms which persist and impact on their lives significantly.

Interviewees have been making artistic work with and about pain between one and ten years. While some artists know each other, or collaborate, others work alone and feel more isolated. Their work covers varied dance techniques and aesthetics, including ballet, queer performance, live art, contemporary dance, and somatic practices. All are dance artists in that they trained in dance and/or choreograph dance works. However, the scope of ‘dance’ in this article is broad since the artists could not always follow traditional dance routes due to their health. They access training when and how possible, adapting forms to their own abilities, and drawing on other art forms, where appropriate, to the content of their work. Most are self-managing their capacity to work part-time in dance or education settings due to pain.

The interviews were discussed with the ethics committee at the Centre for Dance Research, Coventry University and then submitted for approval through the Coventry University Ethics System. Considerations focused on the fact that this research involved participants sharing sensitive personal information on health issues, so I considered who to approach, the kinds of data needed, how the interviews would take place and the secure storage of the data. As part of the ethics process, I therefore wanted to approach participants who were willing to talk about dance and/or pain, especially those whose work on pain was already in the public domain through performance, residencies, writing, and talks. Participants self-identified as having chronic pain, chronic illness and/or disability. As a group, they are people who are actively working in arts/health in academia or professional practice, and/or as chronic pain activists/consultants. The

interview questions were developed to support a discussion of themes related to their dance practice and performance with chronic pain, rather than requiring participants to disclose medical details, unless they chose to do so. The idea was to draw on the expertise and knowledge of participants to discuss themes which contribute to future thinking and practice in the area of dance, chronic pain and agency. Participants received a participant information sheet, consent form and draft questions/interview prompts in advance. I also indicated that breaks could be taken for self-care with chronic pain, considering that I was interviewing participants for an hour or more. The research was focused on online interviews, rather than engaging in in-person workshops or performances, as interviews took place during the COVID-19 pandemic. As the interviews were online, I reflected on the need for a quiet space where I could confidentially record the interview without interruption. Coventry University support safe recording and storage of data, including an institutional professional Zoom software subscription and Onedrive cloud-based storage service. Ethical approval was received prior to interviews taking place.

I conducted qualitative, in depth semi-structured interviews on Zoom between August 2021 and November 2021. Most readily agreed to be interviewed, although the nature of what qualified as pain was raised by one person, while others expressed the desire to read the article before publication. One of the artists wishes to remain anonymous due to the personal nature of the discussion. As a result, I have anonymised two of the artists since they work collaboratively (identified as C and X in the article). Interview questions were largely around motivations, inspirations and the context for the development of dance work. I had developed these from my literature search on dance and chronic pain, however, the interviews often drifted into different topics. Hence, when I was analysing the interviews, this necessitated using a hybrid of inductive and deductive approaches (Swain 2018). Thematic analysis was utilised as a flexible approach to the data, focusing on researcher interpretation of 'the ways individuals make meaning of their experience' (Braun and Clarke 2006, 81). Pre- and post-empirical codes were integrated to provide a richer understanding that reflected both the literature and the interviews. These eventually narrowed down into a core set of themes. For this article, I focus on the theme of 'agency', with sub-themes of individual, interpersonal and environmental agency. I creatively alter the traditional qualitative interview structure and headings, choosing not to have a separate findings/discussion section, and instead developing a narrative format that integrates the themes and discussion. I have chosen not refer extensively to the performances but rather focus on the accounts of the dance artists in making creative work about pain. This is because I focus on the intentions, practices or ideas embedded in their process, rather than an analysis of the final performance works. While I bring arts and health together, this article analyses dance as an artistic practice, rather than dance primarily as a therapeutic intervention. This article does not discuss a targeted group with a specific, shared pain condition; rather it brings together a range of perspectives and attends to lived experiences.

As a thematic analysis, I have drawn on the approach of Braun and Clarke (2006) in identifying patterns across the data. While the words and experiences of the dancers are given precedence, I recognise my role in interpreting the data. To bring forward my argument, I therefore emphasise key patterns, examined through quotation, narrative and analysis. As Braun and Clarke note, this involves addressing 'themes or patterns across an (entire) data set, rather than within a data item, such as an individual interview or

interviews from one person' (2006, 81), which means that unfortunately 'some depth and complexity is necessarily lost' (2006, 83). As part of the analytic process, I have narrowed down the extracts included rather than include all quotes related to that theme. I don't claim to fully represent the words or experiences of each individual, but aim to develop significant themes which examine agency in dancers with chronic pain. I have endeavoured to provide sufficient data extracts while at the same time, 'The extracts in thematic analysis are illustrative of the analytic points the researcher makes about the data' (2006, 94).

The question of agency arises in the research process, since as a researcher I can arguably shape and control the interview questions and resulting narrative in the article. However, I subscribe to Haraway's call for 'situated knowledges' where the 'object of knowledge be pictured as an actor and agent; and this can be done through the 'power-charged social relation of "conversation"' (Haraway 1988, 592–593). I aim to listen closely to subjective accounts of dance artists living with pain, valuing their embodied perspectives. I see the dance artists as agents, with whom I am in conversation. Throughout the article, I remain in the present tense where possible to give a sense of the current, live and ongoing nature of this dialogue. At the same time, I hold the position of 'outside' researcher, rather than talking primarily about my own experiences.⁴ Nevertheless, my perspective as a practitioner-researcher informs my analysis and writing – including ways of understanding knowledge as contained not only in the performance outcomes, but in the processes of the practice (see Barrett 2007; Jones 2009; Nelson 2013 on practice research). The nature of this research, then, is that it acknowledges lived and changing experience, values creative practice and process, while also aiming to produce a collective viewpoint on this complex topic.

Individual agency

I now turn to the interviews, and limiting factors on agency for the dance artists. Their comments are revealing and include 'living with chronic pain for all these years, I've definitely not felt much agency in that experience' (Hopfinger) and 'one of the things that I most struggled with . . . is feeling like I didn't have any agency' (Meseguer). This lack of agency is felt in relation to healthcare support and in daily life social situations with the dance industry seen as a further barrier while living with pain. Y refers to dance projects as 'mistreating' her body: 'I used to dance very brutal like I overused my body, literally falling and breaking and bruises everywhere, and you just go on because you're passionate and you're young and then at a certain point you're not young anymore, and then you realize 'ouch', this is really killing my body.' Meseguer comments on the limited dance contexts she can work in now since 'dance practices often push the body to do incredibly virtuosic, incredibly physical things – not all dance but, but a lot of it.' C and Pietroni-Spenst acknowledge the mentality of working through pain and injury in the industry. Pietroni-Spenst suggests that 'It was very much about the visibility of dance and what you're giving to the spectator, so it was always about what is the audience seeing, not what are you feeling – if you're in pain, push through, if you've got an injury, push through.' Smith-Nunes and Pietroni-Spenst both mention the problems of intense blocks of training and rehearsal for those with chronic pain. Edward queries 'conventionality' in techniques as a form of 'body discrimination in dance culture.' The idea of 'fitting a mould' is raised by both Edward and Pietroni-Spenst, with ideas of what is 'flawless'

or ‘strong’ in dance. Smith-Nunes comments that ‘with ballet it’s very much a sort of young person’s domain and a specific body type domain so there’s quite a lot of body fascism.’ The emphasis on youthful, able-bodied dancers as the epitome of dance leads to expectations of certain physical and energetic characteristics. The artists dance training or traditional dance careers have been truncated through the lack of industry consideration of pain (Smith-Nunes, Pietroni-Spenst, Meseguer, Edward, C). Their experiences reflect the ways in which encultured habits and ideals limit the potential of dance artists with chronic pain.



Mo Pietroni-Spenst, *Screening My(Self): Reflections*, film still.

The artists describe taking individual agency through acceptance of their pain and its associated experiences. It could be argued that through leaving behind their past dancing identities and generating new approaches, the dance artists are learning to live well with and self-manage their own pain in daily life. Meseguer suggests that ‘it took me a long, long time to begin to accept my experience really and start to maybe see other aspects of it so sometimes I say that I only started to live well with pain when I stopped trying to get better.’ Edward notes that ‘I’ve got to accept it and as I was doing that, I started to actually have more agency again coming back, with who I am, and what I do.’ Pietroni-Spenst comments ‘I think when I was improvising, it forced me to accept the reality of my performing body and its limitations . . . am I going to keep pushing a body that can’t achieve something that it wouldn’t ever be able to achieve? I need to adjust my expectations there’. A sense of embodied agency is reignited by the dance artists through their own practice, for example, by ‘bringing awareness and understanding to our own bodies and where the limitations are and actually accepting them’(C). Further C, asks ‘how do I kind of take ownership of it in a way. It does affect everything I do and so kind of effects my being in the world, so how can I use that as a as a form of empowerment for myself, for my practice. Rather than try and hide those aspects, because they are who I am and therefore they don’t need to be hidden, it’s taken me a long time to come to that.’

Acceptance of chronic pain leads artists to reframe their work as innovative and generative, with agency as a form of creating exciting new modes of dance practice and performance. Pietroni-Spenst explains how ‘by accepting my disability, this was how I could contribute something new and something authentic that really helped me to take agency.’ Meanwhile, Hopfinger suggests ‘that (pain) also can be the source of the creative work . . . that feels like another level of agency.’ Most of the artists move away from the

dance forms they had previously engaged with, by working with other disciplines (visual art, theatre, writing, digital media) that accommodate them and their new aesthetics. In this way, the dance artists assert individual agency through control in shaping the way they make work, while also letting go of past ideas/ideals of dance. Edward comments that:

'I can actually just stand up with a microphone and entertain for two hours and create certain works that actually allow me to have power and empowerment and engage an audience that are sitting there and actually fully enjoying it without me having to do all these different things now with the body, that's not what I need to do anymore and I'm quite happy with that. Its taken a while to get to that because when you get poorly, you're not comfortable in your own skin as well, so there is kind of like this dualism going on, where there's probably an existing "you", some kind of core authentic you and then all of a sudden you've got this pain and illness and things going on with you, and then you go into a state of flux, trying to cling on to where my identity, professional work has been for a long time. And then eventually you just gotta let go, I think I can't do this, I can't fight this, I've just got to go with it.'

Beyond the individual as agent, socialised and encultured forms of moving can both limit and inform dancers living with pain. Although Smith-Nunes stopped dancing after surgery, she returned to ballet as an adult. She describes how she appreciates the control and support of her back in the ballet forms, while also acknowledging she is 'not pushing it to the limit, just pushing it to the point where you know it's going to be some good but you're not then going to stay in bed for a week.' Rather than subscribing to ideals of how they 'should' move, many of the dance artists describe experimenting with movement and form, finding creative movement modalities that support their dancing bodies. Hopfinger comments on how 'agency now I think it's about really having the permission to do what I need.' Countering existing approaches to dance, Pietroni-Spenst says 'I gave myself time to stop doing what I thought was the right way of creating movement or dance and I allowed myself for it maybe even stop being dance as such.' While pain makes it no longer possible to engage with certain dimensions of technical training, the artists enhance their artistic practice through exploring the dialogue between their bodies in pain and their dance backgrounds.

Interpersonal agency

The social stigmatisation of living with an invisible disability is one of the main issues raised by the dance artists. This permeates how they are viewed, such as when C asks 'do people really believe I'm in pain, because I don't look like I'm in pain?' Pietroni-Spenst also notes that people think that 'you're making it up, or that it isn't real or that it's in your mind.' C explains how signage related to the COVID-19 pandemic that says 'do not enter if you feel unwell' intensifies the need to hide chronic health symptoms from others for fear of being misunderstood and excluded. Concealing pain results from being not believed or excluded, as Smith Nunes notes: 'Essentially, hide your pain, because it just makes your own life easier, it's just dealing with other people's reactions to pain and the kind of boredom they get of long-term limitations. And it's just easier to just pretend, not even pretend and actually that's the wrong word, I think it's now a conditioned response.' Edward also comments that: 'For years I've been pretending to be well. Because of the "over the shoulder" culture, "whispering you out" culture, you're constantly just, we're all performing, but when you're performing wellness all the time, it becomes really, really exhausting.' Meseguer suggests that concealment is endemic in the dance industry, commenting 'especially if you're a dance

artist you've probably spent a long time trying to hide the fact that you're in pain.' She alludes here to the image of health and physical prowess associated with dance, and masking pain as a strategy to avoid being disregarded.

Several of the artists discuss developing a sense of agency through peer support, by collaborating or connecting with like-minded disabled dance artists to share important conversations, practice while experiencing pain, reduce isolation and generate a critical mass to influence change. The emphasis on these connections is not usually on improving health outcomes but on collective agency by supporting each other and creating work while attending to their shared needs. The collaborative project by C and Y involved shared neck and shoulder pain, explored through movement and the development of caring protocols for working together. C comments that:

'We kind of checked in, and I think there's this thing about listening to each other and having a more rounded awareness of the other person as well . . . I think that it was just really helpful for us to be together and having this dialogue and this exchange but also giving each other space as well, that was also part of it. These moments where we kind of come together, but also time when we needed to have our own space and to do whatever we needed to do, it was a space that we held.'

Meseguer and Hopfinger, although producing separate works, have collaborated on 'turning towards' pain residencies and exchanges. In these, they also questioned what kinds of movement might come from their own bodies with chronic pain, rather than trying to adapt other practices to suit them. Hopfinger notes that:

'I felt really the need to reach out to others. It can feel quite private having pain. And it was really amazing to connect with other artists, so I connected with Raquel Meseguer through the the context of both having chronic pain and being artists so we were really thinking about turning towards our pain differently . . . we explored the idea of adapting practices. From things that we know from our training and our professional experience and how do we adapt that but then we also became less interested in that and more interested in what would a chronic pain practice be if it really comes from our chronic pain experience, what kind of movement practices come that might actually be kind of new practices.'

Pietroni-Spenst who originally felt very isolated in working with chronic illness through dance, notes that 'when I started extending my research network and meeting other people in similar situations to me . . . I felt like I was taking agency for myself, but then sort of joining with other people in a sort of bigger fight for recognition or for understanding and so certainly it was it has been a very empowering process.' She highlights a need for advocates in the dance industry, since 'I know what it's like to not be able to speak up for yourself but it's easier to do it for somebody else.' Meseguer acknowledges the importance of networks and community 'to get inspired and feel heard and seen' and 'to feel validated', and suggests that her work is deeply informed by disabled peers: 'I feel like it's very informed, is almost a collective practice, you know, an informal collective kind of practice.' Community building creates an impetus and support for change with other disabled artists as 'there's something of a shared understanding about having to navigate the world very differently to other people that feels really supportive' (Meseguer). So, beyond removing themselves from dance structures that exclude them, or solely depending on individual agency, the dance artists also create their own supportive interpersonal structures.



Sarah Hopfinger. Pain and I. Image: Tiu Makkonen.

For dancers with pain, I suggest that agency can be found through the individual approaches to movement they develop, in dialogue with supportive peer communities, which challenge existing dance structures and social experiences. This process does not attempt to return to a body functioning in a normalised society, but in fact generates new ways of moving with and understanding pain through dance practice. This has the potential to support future generations of dance artists struggling with chronic pain, including how to pursue a career and make dance work. Edward layers his performances with references to body discrimination, aging, masculinity, homophobia, mental health and class, along with chronic pain, as an intersectional approach to performance. He collaborates with and mentors emerging young artists to develop their own autobiographical dance work, inspired by the ethics and critical thinking required in dealing with such issues in performance. He notes: 'I'm interested in exploring ideas of politics, identity politics, and engaging younger people, especially the dance students that I work with at the moment in terms of empowering them.'

Sharing dance work made by artists with chronic pain with a public audience is of course also central, as a form of performance as advocacy. Smith-Nunes wishes to 'raise awareness that it (pain) is complex and changing on every single day and just because today's okay, but come five o'clock I might be in bed again and that's totally normal'; hence her work educates audiences on pain theory and representing the realities of living with pain. Reflecting on and understanding pain is highlighted by Hopfinger as audiences engage with her work. She explains that 'people who have experienced it with chronic pain have had really strong reactions in terms of it just feeling like space and homage being paid to the experience . . . For those that don't live with chronic pain, they feel like they've got insight into something that they can't understand.' Meseguer identifies the role of dance to reach audiences in terms of felt sense and emotional connection: 'I suppose my hope is that, I don't like this term raise awareness, but that that it touches people, (creates) empathy. And that will change, hopefully, the way we can think about the spaces we create and how we can be together. I think that my ultimate desire is that all events are integrated and that attitudes and culture changes.' Further, Edward also promotes playful advocacy to connect with audiences, stating that: 'if there is

a soapbox, there'll be a feather boa with it and there'll be glitter and there'll be sequins.' Here, he describes the importance of objects and stage spaces to provoke experiences as well as reflection, addressed in the next section.

Environmental agency

In the interviews, the artists discuss the physical occupation of space interlinked with the metaphorical sense of 'taking up space' as a disabled person who wants to articulate their experiences. Hopfinger comments that 'I haven't really had space to even be able to go into the to the diversity of what it is. I felt like I needed to create that space because there wasn't really space for it.' Meseguer also identifies the need for 'claiming space for stories that we don't normally give much air time.' Taking up physical space is important to C and Y – who comment on the value of being able spread out in the space of a dance studio with large sheets of paper to trace their impressions of pain. They are also 'giving each other space' to care for their pain and general wellbeing in the creative process. Hopfinger notes that 'it felt quite freeing or liberating for me, just the enactment of the performance and even just the making process . . . having that creative space was literally me getting agency with it.' Pietroni-Spenst also describes that taking time and space allows her to 'really drill down to how I can see that experience and then to express that to other people, it was really a way of taking agency.' Taking up space is an active role on the part of the dance artists, however they also identify how space alters their experience of themselves. Space can therefore be seen as taking an active 'shaping' role for the dancers, offering a sense of legitimacy, repair, and opportunity to explore and understand.

Apart from space, the dance artists discuss enacting pain experience in a material way through image, movement, sound and other performance media. Working with visual media, Y notes on their incorporation of drawing into performance: 'it's not about drawing beautiful things but it's about the negative space and the empty space'. As C and Y move with their pain, they hold chalk or charcoal that leave marks on paper taped to the ground and walls. This leaves traces that visualise the invisible 'negative space' of pain, that might otherwise be unacknowledged, misbelieved or disregarded. There is a reimagining of how pain might be seen, felt, and enacted in public space – pain becomes material and the material then creates recognition.

Stage environments serve not only to represent or make visible pain experiences but to invent situations where performers and audiences with pain can be integrated into the 'pain world'. Meseguer comments on how her dance background informs her 'aesthetics of rest' and 'horizontal spectatorship', through sensory materials such as sound, light, and texture. The performance space includes low sounds and lighting, loosely draped fabrics and places to lie down: 'the aesthetic that is emerging is incredibly atmospheric and sensual. I think it creates spaces that invite you to drop into a different sense of time. I guess it's quite symbolic in the way that we connect people through the lights and through the sound. It's very stripped back and allows for the audience to conjure the stories. But it's very kind of texturally rich and dense this space with the music and the kind of fabrics in the space. I think all add to this texture.' This restful space enables both disabled and able-bodied people to access the performances, and encourages listening and receptivity to the experiences of people with pain. Meseguer also experiments with formats, including a booklet to go along with the audio performance during the pandemic: 'I feel like that booklet sort of

encapsulates the aesthetic of the whole project really in the way it unfolds and opens and the weight reveals the stories in kind of different ways and the simplicity and the stripped back nature of it, but also the texture of the fabric and it's the care that's been put into it and the hand maintenance of it.' A range of ways to engage with performance materials encourages the audience in taking time to engage with sensory qualities, that convey the restful ideas in the work, as well as increasing accessibility.



Residency image - moving with chalk. Image: dancer 'C'.



Genevieve Smith-Nunes, [pain]byte, film still.

Not all the performances take up a restful aesthetic however. Smith-Nunes works with ballet and multimedia as ways of sharing patterns of pain, since her 'ballets were representing the manifestations of pain and also the patterns and . . . the pain signals in the brain.' In her work, sensors, lights and colours depict flare ups, while Virtual Reality presents distorted bodies to give a sense of her 'pain world'. Working with environments layered with sound and movement can have dynamic or agitating dimensions. Smith-Nunes suggests that the VR experience in pain[Byte] shares 'darkness, its dystopian . . . there's a hidden inner city of pain'. While she does not want audience to feel pain, their entry into an immersive experience of her world may be confronting, so she advises them in advance of what they might witness. Pietroni-Spenst also plays with the role of the witness audience and her experiences of vulnerability through the use of glass boxes and mirrors. She comments that:

'I created these screens around my body, because I felt I felt over exposed, I think, in a way. I explored this idea of covering myself, concealing myself in some way, and the focus became more about spectatorship when people were looking at me through the one way mirror. I was only seeing myself reflected, so I felt like I'm not being watched, I was safe, because it was just my familiar reflection. But they knew I wasn't judging their spectatorial choices, so a lot of them came very close and I think actually a lot of the issue with chronic illness, while it's a very personal journey, it's about how other people respond to that.'

Provoking and playful experiences can also work side by side, as Edward uses speech, objects and movement in addressing difficult issues. In his work, 'What have YOU done to deserve this', he includes a bed (the place where someone is confined when they feel unwell), personal diaries, a mirror ball, along with other items. These materials convey a personal and intimate space, the complex layers of personal identity and memory. Interwoven is the voice of someone in pain, and interactive elements where audiences can join in. Edward's combination of movement, sound and objects explore painful subjects in playful and engaging ways. He notes that: 'I'll lie down on their (the dancers) backs and they carry me and the microphone and there's a feather boa. It's all fun and playful but at the same time it's also talking about the discrimination about the older body, the fatter body and the body that you can't see is in pain.' Hopfinger also fills the air with the voices of pain, developing multiple modalities for engaging with her work including a live dance performance with spoken language, an audio work, and online audio/image/text based piece. She comments 'with 'Pain and I' it is quite a difficult listen, I think the audio piece . . . but I think it also is almost celebratory. It's almost like there's the feeling within chronic pain, there's all the kind of heaviness of it and there's loads more than that, there's like these uplifting moments or these feelings of energy that come from it.' Working with space, sound, image, objects, movement and virtual worlds, the dancers develop their own environments that depict and support chronic pain worlds. The environments, in return, offer new potentials for exploring, awakening, contesting, enlightening and communicating pain experiences, as well as 'making space' for mixed-ability audiences.

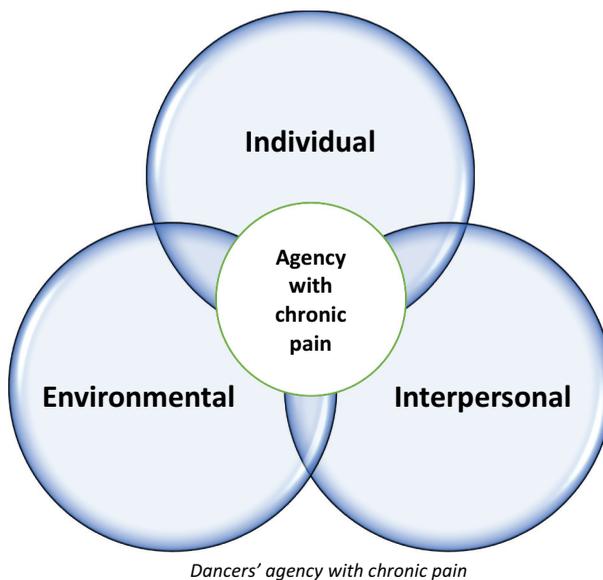


Mark Edward, What have YOU done to deserve this? Image: Brian Sayle.

For the artists, having space and materials to explore their pain through a creative practice is an important intervention in the current dance and social landscape. Interestingly, this group of dance artists often create their own structures and environments where they are not seeking legitimacy or externally-given empowerment. Their work generates environments which represent or care for bodies in pain through material factors of image, sound, space, objects and movement – these environments are important to the artists due to the invisible nature of their disabilities. By taking into account how social and material dimensions inform they ways in which they are afforded move, the primary role of the individual dancer is challenged in their work (see Gibson 1979). Material environments and objects further have the power to inform how pain is understood and accessed by audiences.

Dancing with Pain: A Conclusion

I set out to understand how dance artists are creating work with and about their pain, and what this might reveal about agency (or lack of it). The interviews highlight that the barriers – obstacles to training and normative aesthetics – faced by dance artists living with pain resonate with those of other disabled artists (Aujla and Redding 2013, Whatley 2018; Marsh 2016). In an industry where certain attributes of strength, energy or movement qualities are favoured, this may further exacerbate existing pressures to mask pain or ‘perform normal’ (Sheppard 2020). Although prior dance research examines notions of individual or social agency, or considers account materials and environments, I shine new light on how different forms of agency work together when dancing with chronic pain.



Dimensions of agency with chronic pain. Image: Emma Meehan.

I connect the autonomous action of the artists in their dance-making to acceptance and control described in the health literature. While dance industry conventions pose

barriers, the artists resist existing conditions through acceptance of pain and working with it. They tap into agency through generating their own dance practices and works which respond to pain in its full complexity. They find ways 'to think pain otherwise, to produce painful new knowledge . . . and, in doing so, to re-imagine our (shared, pained) futures' (Patsavas 2014, 216). This is not a narrative of an individual heroically overcoming illness or becoming a 'normalised' and 'productive' society member. Instead, the practice gives attention to ongoing and complex lived pain experiences, while also highlighting interdependence with environments and other people.

The dance artists highlight peer networks as a source of support and way to lobby for change together. The focus of these communities is generally not on pain management (unlike the health literature), but rather on recognition, support, validation and advocacy. Further, they engage in a kind of 'public advocacy' different from that in chronic pain research (Jowers Salazar 2018; Smith 2020, Sullivan and Main 2007; Ware et al. 2011) by offering 'felt' experiences and exploring how dance performance can creatively engage audiences. I therefore situate interpersonal agency as one which deals with the social dimensions of living with pain, through connecting with peer communities and public audiences. Rather than focusing on the person with pain as having a problem to be improved, this shows how the person with pain contributes knowledge and skills in a valuable exchange for all involved, where 'individuals can be interdependent yet self-determining' (Silvers 2017, 38–39).

The dance artists also take a lead in imagining and enacting empowering environments and invite audiences to understand and experience pain in new ways through the qualities of artistic materials (space, time, air, light, sound, objects, textures and so on). Significantly, I suggest that the creative, material, sensory and embodied approaches of the dance artists stimulate forms of agency not described currently in the chronic pain literature. Their work imagines 'pain worlds' where artists, peers and audiences, with and without pain, can gain access to an experiential understanding of pain. The artists place traces of their invisible disabilities in the public realm in exposing and playful ways, in a social environment that does not always accept or acknowledge them. However, the dance artists are not focused only on visibility. Disability and performance scholars contest the 'spectacle' of their bodies being examined and observed, choosing to be 'an active maker of meaning, rather than a passive specimen on display' (Sandahl and Auslander 2005, 3). The dance works go beyond the senses of being seen and heard, to a wider array of effects, especially being touched by and immersed in the articulations and sensibilities of living with pain.⁵

Previously learned patterns or norms of dance may no longer be accessible to dancers with pain (such as body position, pace and motion in space); thus, dance training can become a normative space where people with pain cannot function. As described, the dancers interviewed generally move out of (unsupportive) social structures of dance training or dance companies, choosing to generate their own work, gaining agency through dance as a form of disrupting both the socialised body and dance 'ideals'. Simultaneously, partnerships, such as funders, educational institutions, healthcare workers and cultural organisations, are important for the work of the artists to flourish. Indeed, support infrastructures are vital in changing the focus on chronic pain from being an individual problem towards understanding deeper enabling or disabling infrastructures. Whereas self-efficacy, self-management and patient empowerment could be viewed as shifting responsibility onto the person with pain, a reconsideration of empowering pain environments

might both address allocation of resources to enhance patient independence and encourage exploration of interdependence. It is crucial to consider how the interlinking nature of social and material environments can create barriers, shape experience or enable participation. In discussing agency through a series of professional dance works, Prickett (2016, 54) suggests that ‘body practices push beyond established technical vocabularies and representational strategies’ while ‘dances can illuminate different ways of thinking.’ Calling attention to restrictive movement languages is not only an individual act but a social one, by shifting ways people might see and present the moving body.

Understanding agency is important in chronic pain research in order to address existing barriers and health inequalities (Wallace et al. 2021), reduce stigmatisation, and find pathways to autonomy and empowerment. Prior research has highlighted the lack of agency experienced by those living with chronic pain, stemming from the inability to ‘control’ the fluctuating bodily symptoms, and the stigmatisation of people due to its invisible nature. For dancers, there is also the challenge of working in an industry that relies on bodily ‘performance’ and encourages people to conceal pain, to maintain an appearance of ‘strength’ and to push through painful experiences. Agency was therefore an important part of the journey for the artists interviewed, who reimagined what dance could be and how they might explore artistic expression through movement while living with chronic pain. In this article, I propose a holistic consideration of agency with chronic pain, engaging individual autonomy, empowering environments, and collective advocacy which examine barriers to and capacities of people living with pain. I suggest that these multiple facets of agency work together to enact and imagine change of perception, understanding and potentially the treatment of people with chronic pain.

Agency, however, does not simply need to move from individual to collective action and on to environmental changes. Rather, I propose that these are viewed as interlinked elements that work together. I suggest this could have implications for dance training and performance settings, to consider these dimensions of agency in making accessible and inclusive dance programmes and workplaces. Further, this approach could be integrated into chronic pain management to integrate different aspects of agency in health and wellbeing programmes. While this research has developed from the literature and interviews around chronic pain, this approach could be applied in future research around agency with other kinds of chronic illness. Finally, this research shows how dancers with chronic pain have much to contribute to expanding definitions and forms of dance in the field. Creativity through the moving body is something that people living with chronic pain are skilled at, having to adapt with their changed bodies (Macdonald 2020) – and this is a resource as well as a challenge.

A full consideration of how the dance industry might support dancers with chronic pain is beyond the scope of this article. However, several ways of supporting the agency of dancers with chronic pain were suggested by the dancers interviewed, which I briefly mention here. Firstly, Edward notes that the mantra ‘acknowledge, accept, adjust’ may be useful for individuals, however it could also be useful for organisations. Dance training or performance companies could consider how to acknowledge this large cohort of dancers with chronic pain, accept that this changes the approaches and outputs possible, and adjust programmes accordingly, to access the full potential of these creative artists. Pietroni-Spenst suggest a ‘long and lean’ approach supports chronic illness, with timetabling that allows for pacing over time, exploring the output levels possible and consideration of flare ups as part of training and rehearsal schedules. Access ‘riders’ which detail the needs of each

individual to perform at their best and funded work aides to step in when required can offer some practical support. The important and developing role of dance science is praised by Y in considering how to support the longevity of dance artists careers, which currently has a focus on acute pain and injury prevention. This may mean that younger dance artists, when dance science principles are embedded in their training and performance, may be less likely to develop chronic pain. However, there are still others who do not find their pain developing from injury – dance science research which explores chronic pain in dance practices needs to be expanded further in future. In terms of dance funders and resource organisations, the dance artists identified the need for ‘time and investment’ or ‘platforms’ (Hopfinger, Y) in order to enhance peer support and to deepen an understanding of ways of dance with chronic pain. For an experience so invisible and hard to pin down, having time and space is useful to fully understand what new practices and aesthetics may emerge. In this way, agency with chronic pain is not only a consideration of the dance artists involved, but can be supported by the industry at large.

Future research agendas will need to consider the challenges outlined by Berger (2018, 212) for ‘those unable to practice political agency’ due to their disability, often impacting on their social and economic position. While this article undertook a qualitative approach to analysing interviews by a range of artists in relation to chronic pain and agency, I suggest that prospective research might consider the impact of race/racialisation, ethnicity, gender, religion, sexuality, nationality, education, socio-economic status, maternity, as well as forms of dance, for example, on the pain experienced by dance artists and the work they choose to make. Further, there may be limitations in terms of who openly identifies their chronic pain and has the capacity to communicate it with public audiences through dance practice. Future research would need to consider how to facilitate and resource a wide range of artists with pain to participate in such practice and research. Additional practice research would also be needed to understand the applicability of this dance knowledge, the holistic understanding of agency with groups in the community with chronic pain. However, in this article, I focus on synthesising qualitative interviews with dance artists living with chronic pain in the UK with concepts from both health and dance research to provide new perspectives on agency with pain. Through a focus on the work of dance artists, I address the value of the invisible disability of pain being creatively explored, shared and felt in the public realm, as a multi-modal approach to agency.

Notes

1. The AHRC-funded Somatic Practice and Chronic Pain Network was led by Emma Meehan and Bernie Carter from 2019–2022, to explore the relationship between dance, somatic practices and chronic pain research. A new board was appointed from March 2022. <https://somaticandpain.coventry.domains>
2. I have put in brackets the first year of performance, although many are ongoing projects.
3. Padfield and Zakrzewska (2021) *Encountering Pain* includes one contribution by dancer and choreographer Anusha Subramanyam which includes poetic text alongside photographs of her dancing, in response to images of pain generated by Padfield’s research project.

4. While I do not have life-altering chronic pain, the interviews encourage me to reflect on my own fluctuating energy and abilities as well as the experience of family members who live with chronic pain and other long-term illnesses.
5. Unfortunately, recent funding cuts in performing arts in higher education (Weale, Oakman, and Clays 2021) appear to devalue artistic practice in the UK. Further, a recent report 'Dancing Through Crises' (Baybutt et al. 2021, 7–8), analyses the impact of Brexit and COVID-19 on the UK freelance dance scene, noting a 'loss of income for a sector already severely underpaid' and that 'impacts are worse for under-represented groups' including disabled dance artists. In another recent research project 'Dance After Lockdown', 'participants talked about agency and helplessness, particularly in relation to arts funding in the UK' (Cisneros, Ellis, and McLelland 2022). I suggest these barriers are increased for those doubly marginalised such as dance artists living with chronic pain. There is a case to be made for the value of artistic practice in the ways it enhances not only an individual's life. Instead, it can also shape thinking and perception, create new aesthetics, imagine alternative environments – in this particular case – in relation to chronic pain.

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Interview questions for dance artists

- How does your work connect with the theme of chronic pain?
- What is your approach to choreography with pain? (themes, working practices etc.)
- Is reflection on pain experiences through movement part of your work?
- Does your work attempt to communicate or share pain experiences through dance?
- Is creating agency for people with pain a part of your choreography?
- Is your work primarily artistic or are there education/therapeutic aspects to your work with pain?
- What key things have you learned about dancing/choreographing with pain?
- What other choreographers working with pain influence your work? What other writers/readings?