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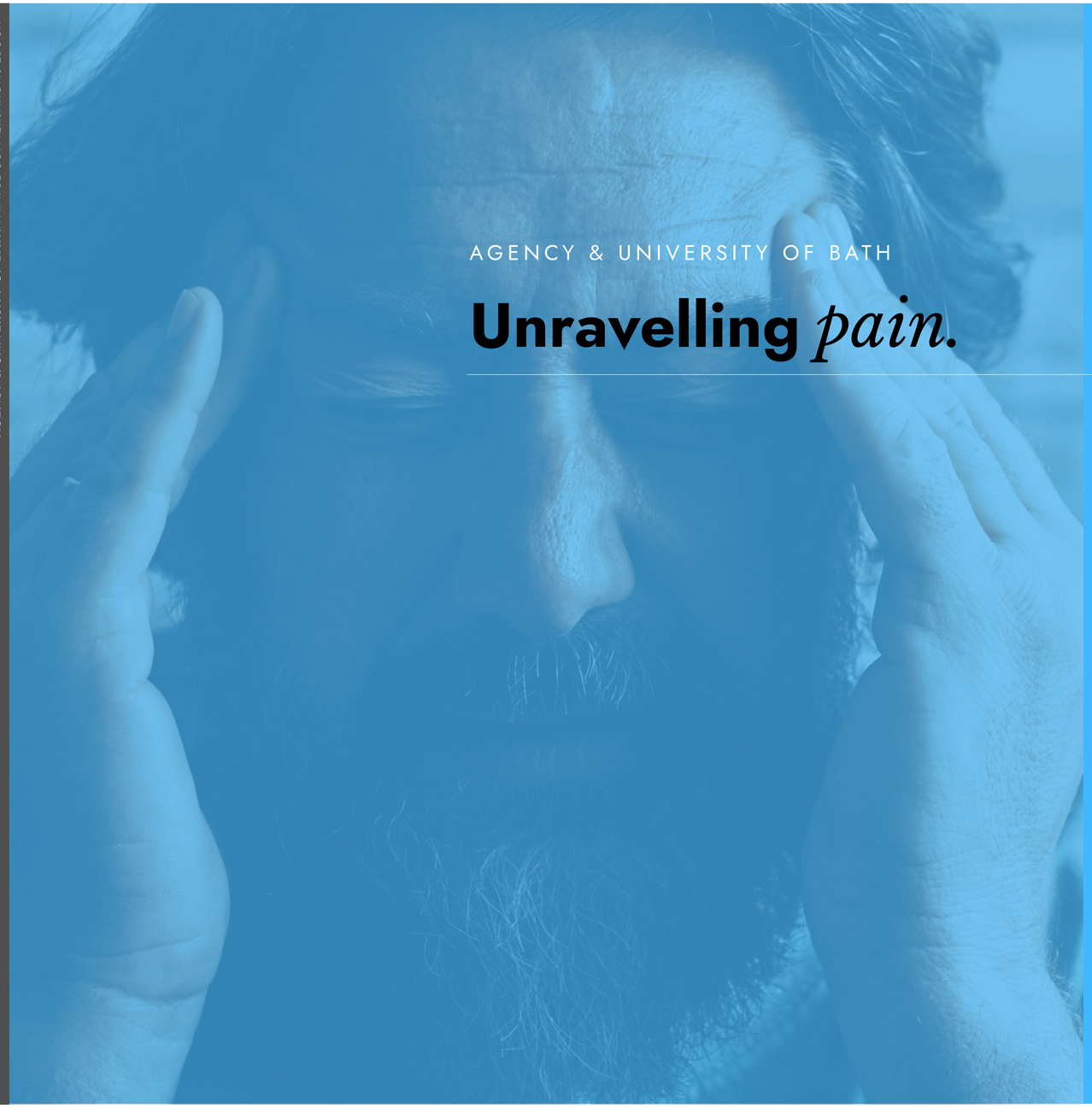
Painful *conversations:*

ENTER

Unravelling pain

Is improved healthcare communication the key to overcoming the paradox of pain?



AGENCY & UNIVERSITY OF BATH

Unravelling *pain.*

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UNRAVELLING PAIN

A conversation about why *communication about pain is important.*

Have you ever heard people with chronic pain mention that their pain 'Is not fair'?

Chronic pain affects over a third of the UK population [REF]. This is just under 28 million adults.

Pain is an inherently tricky feeling to put into words. It is a lot more than just a physical sensation.

Psychological, emotional, and biological components are attached to it [REF].

These components can influence the intensity at which people feel pain.

Depending on multiple factors, chronic pain patients may feel that their situation and pain are unjust and unfair.

Chronic pain could influence a person's daily life as it could affect how they see the world, whether the world is unjust and unfair or magnifying future threat values of the pain stimulus.

Additionally, some chronic pain patients experience this pain despite having no physiological marker for it.

This lack of physiological markers makes it difficult for healthcare professionals (HCPs) to diagnose and treat the patient's chronic pain. It is also difficult for people to convey this pain to HCPs and loved ones.

THE LACK OF VERNACULAR IN THE TOPIC OF PAIN COMMUNICATION:

The topic of pain and its descriptions must have a well-defined vernacular built around it to communicate it.

For one, pain is subjective to everyone and depends on an individual's physiological, emotional, and cognitive differences [REF].

Pain being subjective means that it can't be directly observed by those not experiencing it [REF].

The minimal descriptive language to express the nuances of pain, such as "sharp", "throbbing", or "burning", and the use of metaphorical expressions only shows a basic description of the sensation and often fall short of fully encapsulating the feeling.

What does the lack of language regarding pain cause?

This inability to communicate their suffering makes the person's loved ones and HCPs unable to understand the person's chronic pain due to it being difficult to describe.

The inability to understand a person's chronic pain makes it difficult for loved ones and HCPs to empathise and treat it.

This lack of understanding isolates people with chronic pain, making them feel frustrated and misunderstood by HCPs and loved ones, subjecting them to an unjust situation.

Describing pain is only possible with a language to communicate it effectively.

This lack of communication could lead to HCPs misdiagnosing people with chronic pain leading to ineffective treatments to control their pain.

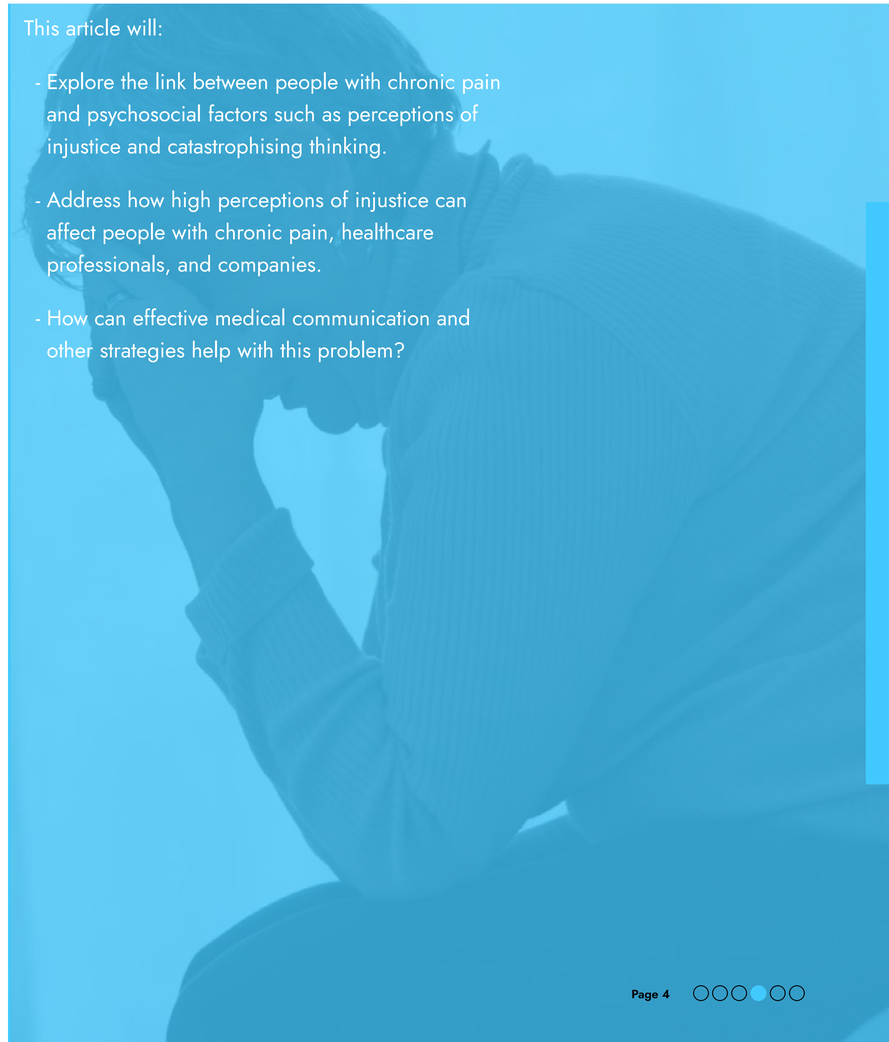
This leads to further isolation as the person with chronic pain believes no one understands their situation.

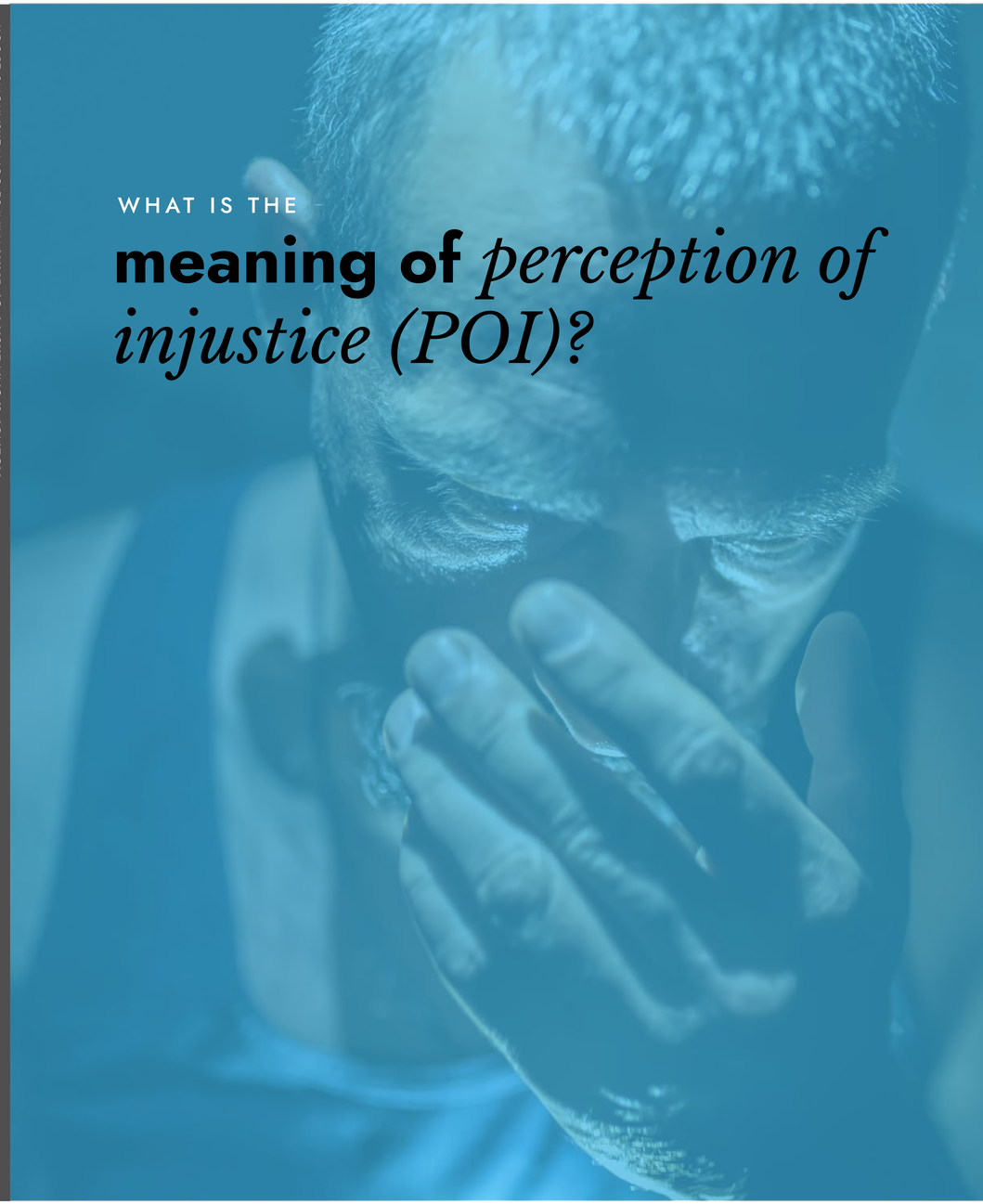
The culmination of all these factors could result in people with chronic pain no longer trusting any offer of potential treatments, no matter how well-evidenced, as they feel that no one understands their pain, therefore 'How can people help them?'.

As a result, we need to find more effective ways to communicate not only with patients with chronic pain but with their loved ones, the general public, and HCPs as well so they would be able to understand what a person with chronic pain is experiencing to prevent isolating them and increase recovery speed.

This article will:

- Explore the link between people with chronic pain and psychosocial factors such as perceptions of injustice and catastrophising thinking.
- Address how high perceptions of injustice can affect people with chronic pain, healthcare professionals, and companies.
- How can effective medical communication and other strategies help with this problem?





WHAT IS THE

meaning of *perception of injustice (POI)?*

Perception of injustice is a terminology used in a psychosocial setting. According to Sullivan, Scott, and Trost:

> Pain-related injustice perception is conceptualised as a cognitive appraisal reflecting the severity and irreparability of pain- or injury-related loss, externalised blame, and unfairness [REF].

Perceptions of Injustice are measured using the Injustice Experiences Questionnaire (IEQ) developed by Dr Sullivan and his team [REF].

Dr Michael Sullivan also mentions that:

> Perceived injustice has been shown to contribute to adverse pain outcomes independent of the variance associated with other pain-related psychosocial factors such as pain catastrophising and fear of pain [REF].

WHAT DRIVES HIGH LEVELS OF POI?

A study by *Scott et al.* aimed to systematically investigate the sources of injustice in patients following painful musculoskeletal injury [REF].

In this study, participants with whiplash injuries in motor accidents addressed various sources of injustice. This includes the other vehicle's driver, the HCP, the insurer, and family members.

The study found that participants were more likely to identify the insurer and HCPs as the primary sources than the person responsible for the accident.

Whilst insurers and HCPs do not intend to contribute to psychosocial risk factors that result in a longer recovery, it does highlight the need for a change in procedure to avoid contributing to the emergence of perceptions of injustice.

TRAIT-LIKE-CHARACTERISTICS OF POI

Recently, there has been evidence that perceptions of injustice have trait-like characteristics.

Whilst it is possible to change a person's behaviour, it is challenging to alter trait-like characteristics.

Yakabov et al. mentioned that perceived injustice could be construed as a dispositional variable [REF]. This would mean that perceptions of injustice are unique responses to situations that result from one's own experience.

Additionally, *Yakabov et al.* studies highlight that trait-perceived injustice might reflect tendencies to see adverse events as injustice and is associated with higher ratings of pain intensity, pain behaviour, sadness and anger, and pronounced display of pain behaviour [REF].

PERCEPTIONS OF INJUSTICE IN A WORKPLACE SETTING

Perceptions of injustice can be measured in various ways in a workplace setting. Examples include fair play, promotion, and work flexibility.

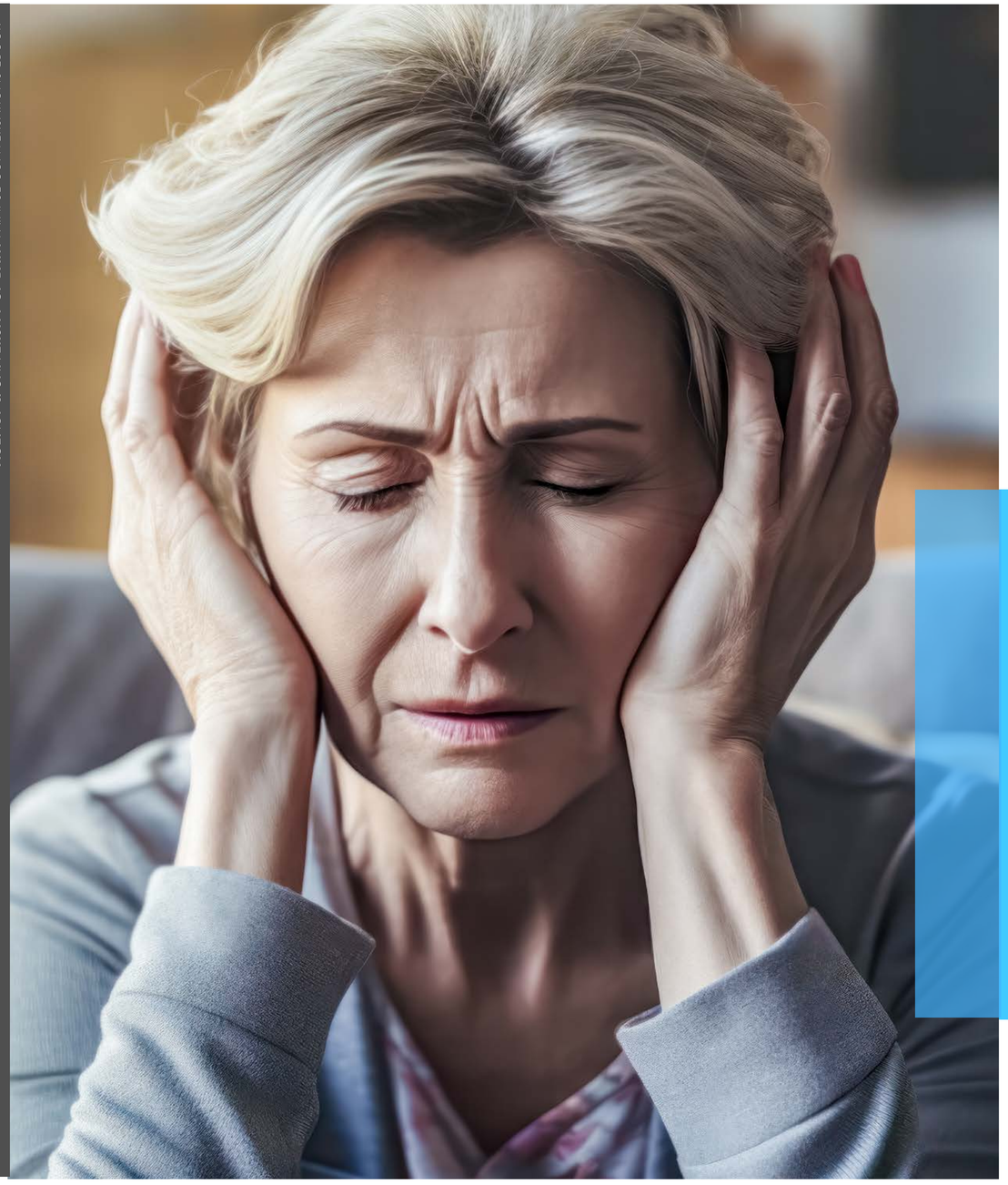
McParland, Gasteen, and Martijn Steultjens found that although men were satisfied with pay, male employees with chronic pain had lower perceptions of distributive justice regarding rewards such as recognition, promotion or benefits [REF].

Whilst some outcomes may be set, employees with chronic pain may perceive that other, more flexible outcomes and opportunities are withheld due to their pain conditions [REF].

McParland et al. mentioned that this finding is consistent with other studies. This demonstrates individuals with chronic pain can feel under threat of being stigmatised at work [REF][REF].

Additionally, *McParland et al.* suggest that employees with chronic pain may have weaker perceptions of distributive justice reflected on issues associated with working conditions [REF].

This includes flexible work hours, adjustment to the type of work, and working hours needed to manage pain.



WHAT IS

catastrophic *thinking?*

Imagine having chronic pain that interferes with your life and changes your perception of yourself.

No matter what you do, the pain doesn't disappear, and HCPs can't find the reason behind your pain.

You don't feel understood because you cannot effectively communicate your experience to everyone.

As a result, you start reacting with extreme caution when you suspect something may cause further pain.

This is how catastrophic thinking (CT) starts. It is "an exaggerated negative mental set brought to bear during actual or anticipated painful experience" [REF].

This psychosocial construct is measured using the pain catastrophising scale (PCS), encompassing the three critical factors associated with CT: helplessness, rumination, and magnification [REF].

This helplessness and rumination of CT seem to come from depression, and the magnification factor comes from patients' anxiety.

Literature shows that CT is associated with a substantive magnitude of constructs, such as anxiety and depression [REF] [REF].

Additionally, CT is associated with a temporal summation of pain and a greater inflammatory response [REF][REF].

As mentioned earlier, several studies suggest that pain catastrophising impacts pain outcomes similarly to perceptions of injustice [REF][REF].

How does the perception of injustice *affect people with chronic pain?*

MENTAL HEALTH:

Trost et al. investigated the association between perceived injustice and psychological outcomes, such as depression and post-traumatic stress symptoms, among individuals in rehab following spinal cord injury (SCI) [REF].

It was found that perceived injustice was significantly associated with depression and post-traumatic stress symptoms.

These findings were supported by similar studies on patients with musculoskeletal pain and fibromyalgia [REF][REF].

It was also found that anger inhibition mediates the relationship between perceived injustice and depression.

This relationship between depression and anger inhibition has been previously demonstrated [REF] [REF]. The finding is in line with previous research by *Scott et al.*, who found that anger inhibition partially explains the association between perceived injustice and depression [REF].

CORRELATIONS BETWEEN PERCEIVED INJUSTICE AND SEVERE PAIN INTENSITY:

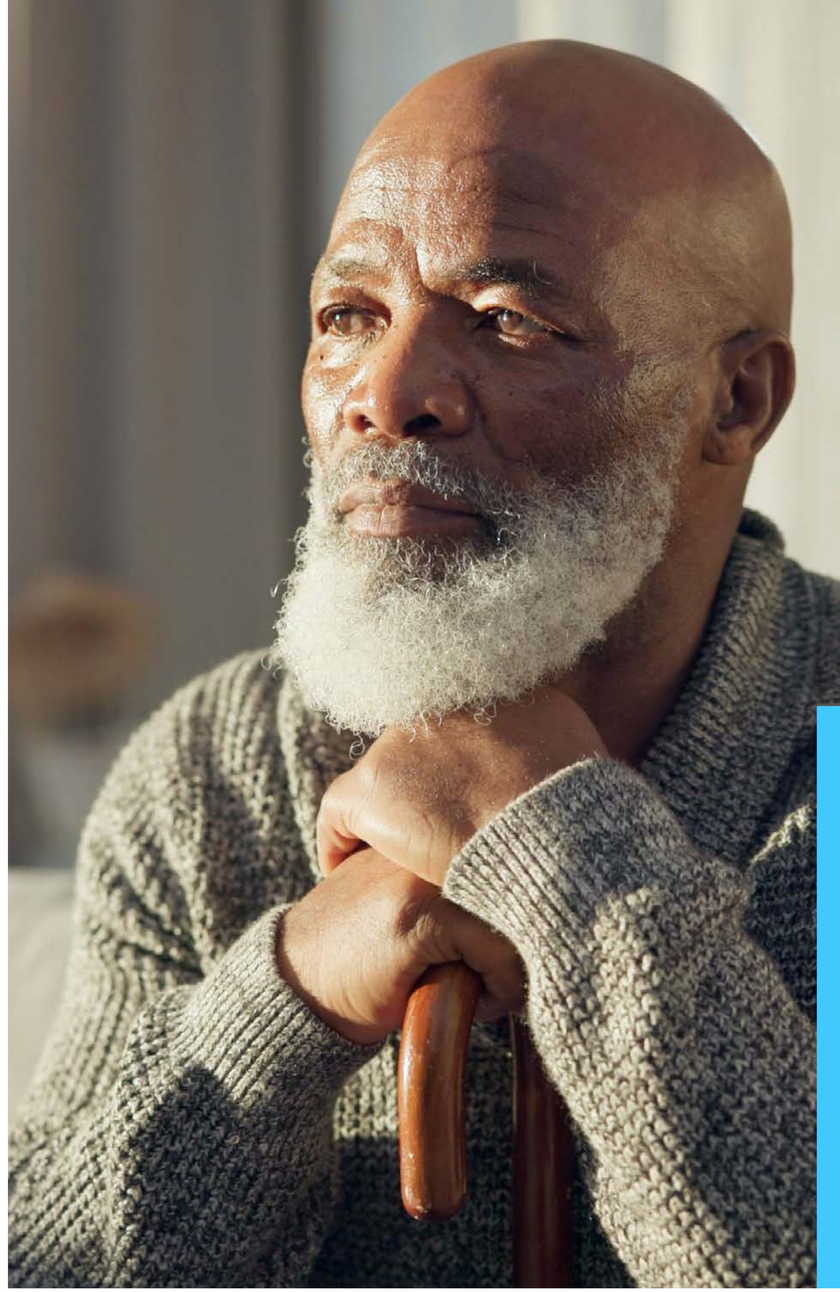
While most studies correlate with pain intensity and POI, not all do [REF].

Silje Endresen Reme et al. found most study participants have an overlap between perceived injustice and displayed severe pain intensity [REF].

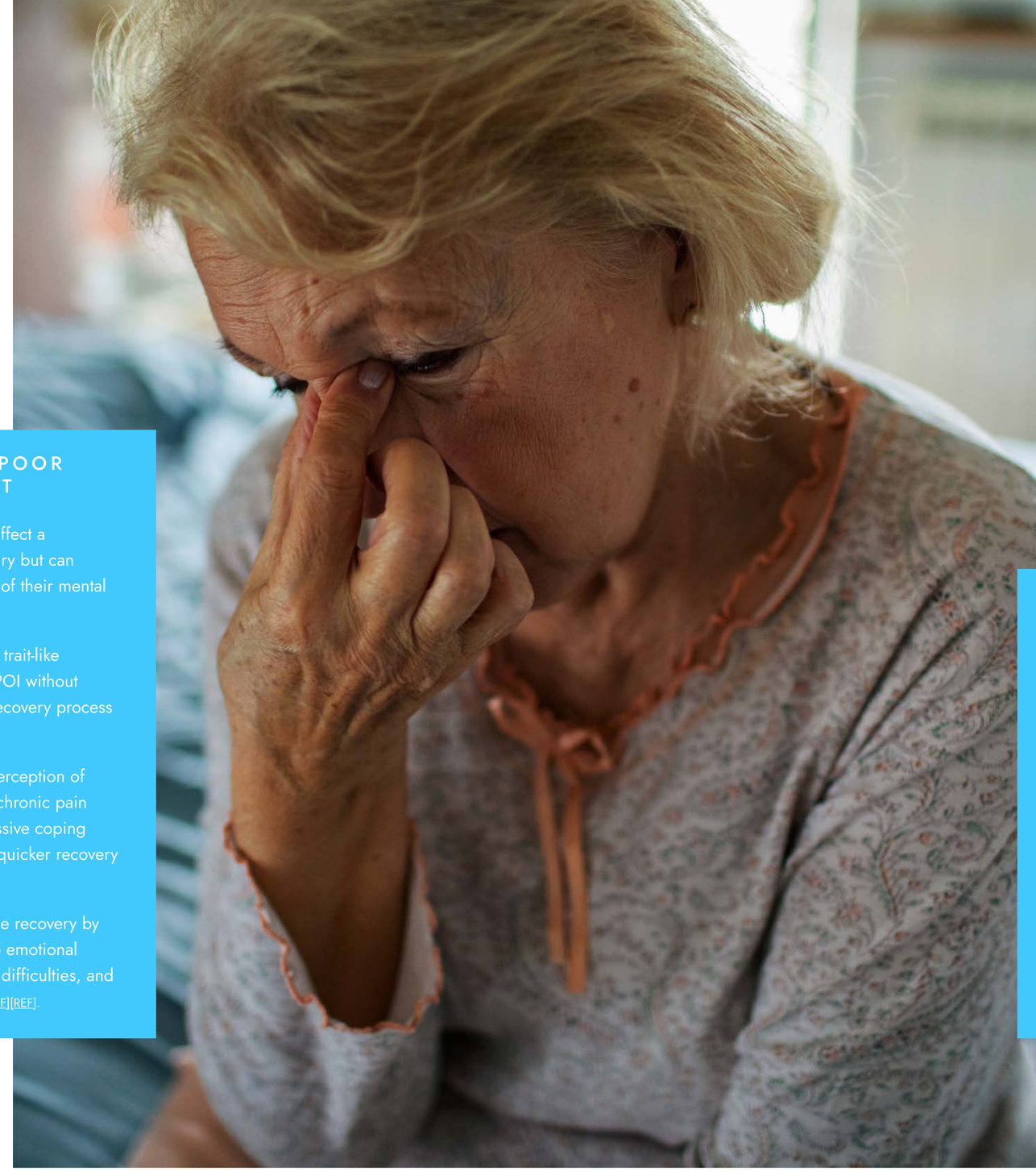
However, not all participants with extreme pain intensity showed high levels of perceived injustice.

The study concluded that extreme pain intensity could be present without high levels of injustice, but high levels of perceived injustice rarely present without extreme pain intensity.

Therefore, pain-related injustice appears to be a unique feature inherent in some patients with extreme pain and should not be considered another expression of extreme pain intensity.

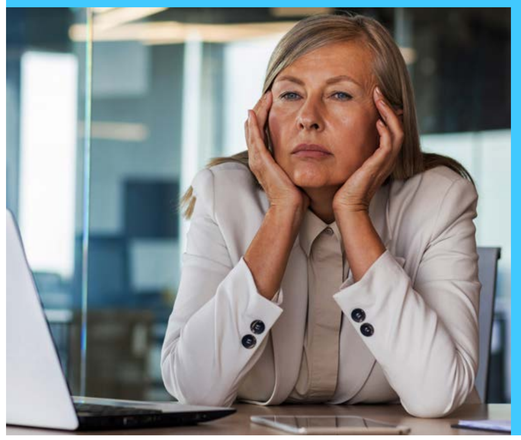


How does the perception of injustice *affect people with chronic pain?*



AFFECTING WORK PRODUCTIVITY

Perceived injustice has been associated with greater chronicity and severity of pain, prolonged work disability, reduced functioning, the persistence of symptoms of depression and post-traumatic stress, heightened displays of pain behaviour, and medication use [REF].



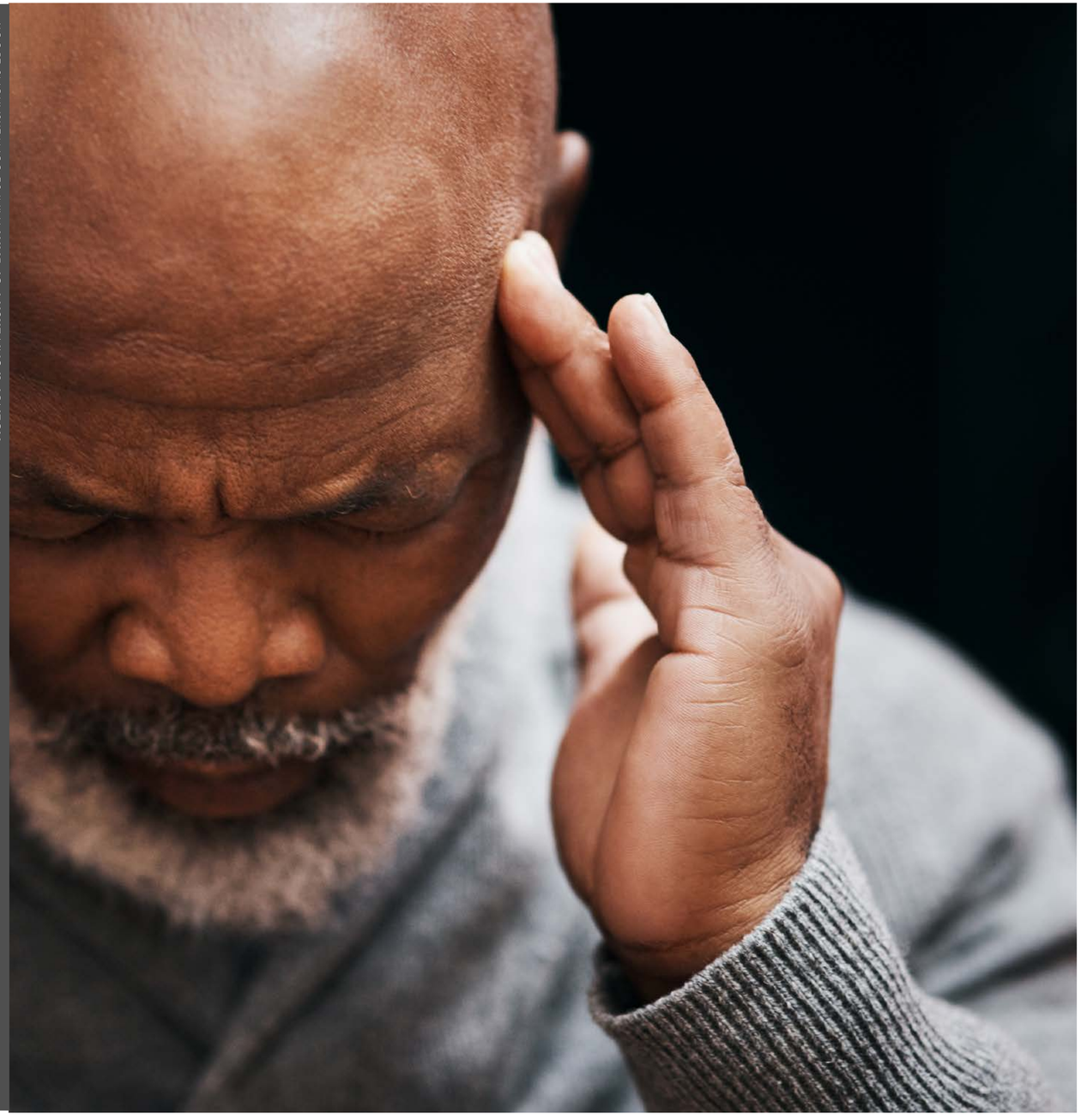
DELAYED RECOVERY/POOR RESPONSE TREATMENT

Perceptions of injustice don't only affect a person's physical recovery after injury but can also negatively impact the recovery of their mental health as well.

Carriere et al. mention that POI has trait-like characteristics that could augment POI without eliciting events and impeding the recovery process [REF].

Scott et al. mentioned that a high perception of injustices could cause people with chronic pain to feel "stuck" and thus result in passive coping mechanisms that do not facilitate a quicker recovery [REF].

Perception of injustice could impede recovery by leading people with chronic pain to emotional distress, attentional disengagement difficulties, and maladaptive coping mechanisms [REF][REF].



How does the perception of injustice *affect HCPs?*

HIGHER PERCEPTIONS OF INJUSTICE MEAN A SLOWER RECOVERY RATE:

HCPs want their patient to be in less pain as soon as possible and to recover comfortably.

As mentioned earlier, a high perception of injustice could affect the recovery of patients with chronic pain.

This would mean that patients would be in pain longer than they should.

IMPEDING DUTY OF CARE:

Not understanding the cause and severity of a person's chronic pain could lead to a misdiagnosis and subsequent undertreatment.

Undertreatment of a person's chronic pain would mean the pain remains, resulting in an unmet HCP duty of care to their patients.

Additionally, the chronic pain remaining could affect a person's decision to go to an HCP.

They could be more hesitant to receive future treatment, further exacerbating the pain and problem, potentially making it more challenging to treat.

How do perceptions of injustice *affect companies?*

REDUCED WELL BEING:

Employees with chronic pain and a high perception of injustice may experience heightened stress, anxiety, and emotional strain, such as higher levels of anger [REF][REF].

IMPAIRED JOB PERFORMANCE:

As mentioned previously, high levels of perceived injustice have been associated with prolonged work disability.

This could be due to high POI increasing the severity of pain and is correlated with symptoms of depression and post-traumatic stress.

Imagine yourself trying to produce a high level of work while you are in intense pain and with your mental health deteriorating.

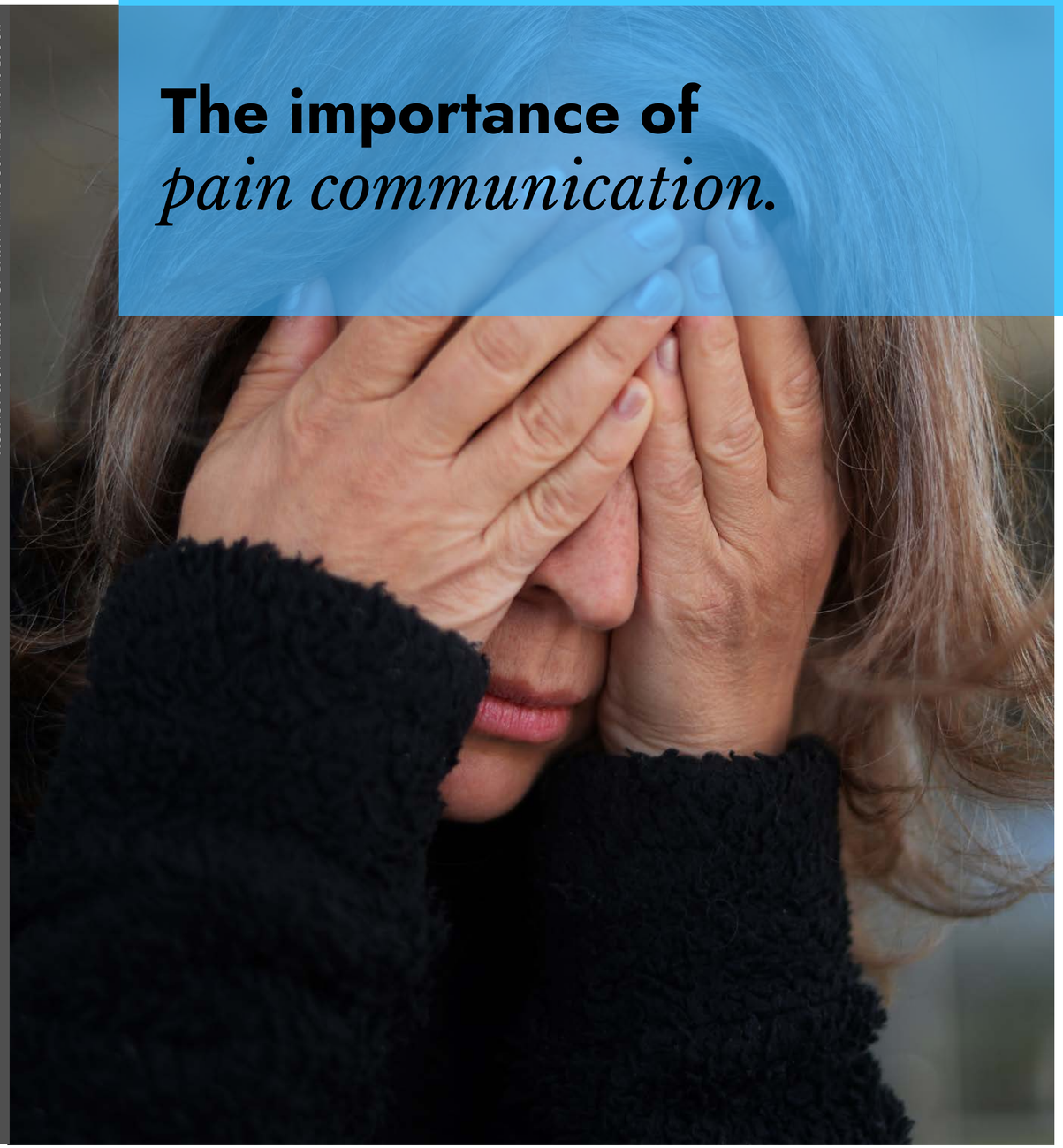
It would be next to impossible to accomplish work tasks efficiently.

HEALTHCARE COSTS:

Employees with a high POI due to chronic pain may delay seeking any future necessary healthcare services due to mistrust of HCPs' treatments.

This could exacerbate health issues and increase healthcare costs for employees and the company.

The importance of *pain communication.*



To effectively communicate about pain, HCPs need to pay attention to information sought across different modalities.

These include speech, nonverbal pain behaviours, and co-speech gestures.

However, it is to be noted that although these modalities play a significant role in pain communication, it is more complex than that, and several factors influence communication.

These factors include different experiences of pain between people, the nature of the pain, and social and cultural context [REF][REF][REF].

The level of communication about pain can be further suppressed or exaggerated depending on factors such as cultural norms, conditioning or reinforcement, and the interests of the person with chronic pain [REF][REF].

A study by Rowbotham et al. found that participants at higher pain intensity find it more difficult to communicate verbally about their pain [REF].

At the same time, the study found that the more intense the pain is, participants produced significantly longer verbal pain descriptions and more co-speech gestures [REF].

By not describing the pain adequately and receiving improper communication about pain, HCPs may inadvertently under-assess or misdiagnose patients with chronic pain.

This would result in patients not receiving proper treatment, thus remaining in intense pain. Even worse, this could create a future aversion to further treatment.

The importance of *pain communication.*

THE CHRONIC PAIN PARADOX:

David M. Morris wrote in his book The Culture of Pain that [REF]:

'Chronic pain constitutes an immense invisible crisis at the centre of contemporary life.'

This sentence encapsulates the paradox on the topic of chronic pain that despite it being an 'immense crisis', it remains 'invisible'.

John M. Hyson mentioned that chronic pain does not receive the same media attention as other conditions such as cancer, AIDs, or tuberculosis [REF].

John M. Hyson further explained that it is not seen as a public health problem because it is not fatal, has no biological purpose, and works in secret.

A DIVISION IN PAIN COMMUNICATIONS:

There is some level of division between the levels of chronic pain communication.

This division is between chronic pain caused by a known condition and chronic pain without physiological markers.

For chronic pain caused as a result of a condition such as osteoarthritis, there is a level of understanding of the underlying mechanisms of the pain.

It enables HCPs to objectively assess and quantify the pain's severity to a certain level, allowing for a more accurate pain management strategy.

Although there still isn't a language to encapsulate the entirety of the patient's pain experience, it still provides a foundation for discussions between the person with chronic pain and HCPs for clear explanations of the origin, progression, and potential treatment.

However, for chronic pain with no physiological markers, without knowing the source and underlying mechanisms causing the pain, HCPs would treat the patient with no clear goal of solving the root of the problem.

Not knowing what needs to be treated to reduce the patient's pain eliminates any way for HCPs to build a foundation of discussion between them and the chronic pain patient.

Establishing a *line of communication.*

A high level of perception of injustice is slowing the recovery process, isolating people with chronic pain, and making them feel that they are in an unjust situation. The inability to correctly communicate with people about their pain due to the lack of language could cause people to feel that there is no one who can empathise with them. To tackle this problem, we have to find effective ways to communicate the topic of pain with the general public, HR managers, and HCPs.

EFFECTIVE COMMUNICATION

The first step is to effectively communicate better with patients with chronic pain and with the general public as a whole.

According to a review, people with chronic pain view effective communication as listening to, encouraging, understanding, and understanding why the patient is in pain [REF].

A study by Porter et al. shows that patients with OA reported higher levels of self-efficacy for pain communication are associated with lower levels of pain and physical and psychological disability and pain catastrophising [REF].

The study also stated that partners of people with chronic pain reported lower levels of negative affect, the higher the level of self-efficacy for pain communication.

The importance of effective pain communication is further emphasised in the guidelines of the National Institute for Health & Care Excellence (NICE).

To quote from NICE Guideline No. 193:

"The evidence in this review suggested that the features of communication style were of vital importance in the context of consultations with people with chronic pain."

Additionally, we can raise awareness and challenge misconceptions about chronic pain by utilising strategic communication approaches.

We would also promote a more empathic, compassionate, and supportive approach to people with chronic pain.

Examples of such strategic communication approaches include:

EDUCATIONAL CAMPAIGNS

The development and execution of comprehensive educational campaigns can raise the topic of chronic pain and challenge any misconceptions.

This approach would involve the creation of materials such as brochures, pamphlets, websites, and videos which will provide accurate information on chronic pain for the education of the general public on the subject.

To show how an educational campaign can help, according to *Nkhata et al.*, just the campaign message 'stay as active as possible' is enough to increase study participants' awareness and influence health beliefs and healthcare utilisation behaviours [REF].

Examples of educational campaigns on chronic pain include Flippin Pain, a public health campaign to change how we think about, talk about, and treat persistent pain, and the National Awareness Campaign, which is associated with the British Pain Society.

Establishing a *line of communication.*

CONTENT CREATION

By writing high-quality and empathetic content and highlighting patient stories and experiences, we can raise awareness among the general public and HCPs on how people with chronic pain feel.

This content would include a personal narrative to humanise the issue and foster understanding.

By doing so, we can raise awareness of chronic pain and the injustices people with chronic pain feel, validate their feeling of pain, and provide peer support.

MULTIMEDIA PRODUCTIONS:

Using podcasts, animations, and video series can delve into the experience of people with chronic pain.

Examples of multimedia productions on chronic pain are a film starring Jennifer Anniston called Cake and an episode in the series 'House' called Painless [REF][REF].

Both of these productions shed light on the life of a person with chronic pain and how living with long-term pain could affect a person's mental and physical health.

The use of this type of resource would be able to show the lives of people living with chronic pain to foster empathy and promote a deeper understanding of the issue.

SOCIAL MEDIA ENGAGEMENT:

Around 60% of the world uses social media, making it an invaluable tool for raising awareness.

Social media can initiate conversations about chronic pain, share stories of people with chronic pain, dispel myths, engage with the general public, and provide thought-provoking content.

Changing the *language.*

In the insight 'The Weight of Words', we discussed how the words HCPs used in a clinical setting could impact patients.

It is no different in this setting as well. Sometimes patients can feel blamed for their pain if the right words are not used.

For example, catastrophising thinking is used as a terminology for HCPs.

However, when a person with chronic pain hears this in their diagnosis, they could feel that the HCPs are saying they are overreacting to the pain or that their pain is not real.

The NICE guidelines state that:

"Moderate quality evidence from four studies suggested that the use of lay language and understandable terminology is helpful when communicating with people with chronic pain."

This does not apply solely to HCPs; we should be mindful of our language.

Phrases such as "You don't look like you are in pain", "It can't be that bad", or "It is all in your head" could instil a sense of blaming in people with chronic pain.

We should try empathising with people in chronic pain instead of invalidating their feelings.

Changing the *language.*

AN EARLY EDUCATION OF PAIN AND AWARENESS IN THE WORKPLACE:

Pain catastrophising is a common construct measured in paediatric chronic pain, and perceived injustice is associated with pain and functional outcomes in children and adolescents with chronic pain [REF][REF].

A study on paediatric chronic pain patients with a mean age of 15 years by Miller et al. found that perceived injustice was associated with higher pain intensity, catastrophising, functional disability and poorer emotional, social, and school functioning [REF].

All of these effects could be detrimental to the growth and development of adolescents.

Awareness of chronic pain in the educational system could create a future generation that is more empathetic and understanding of people with chronic pain.

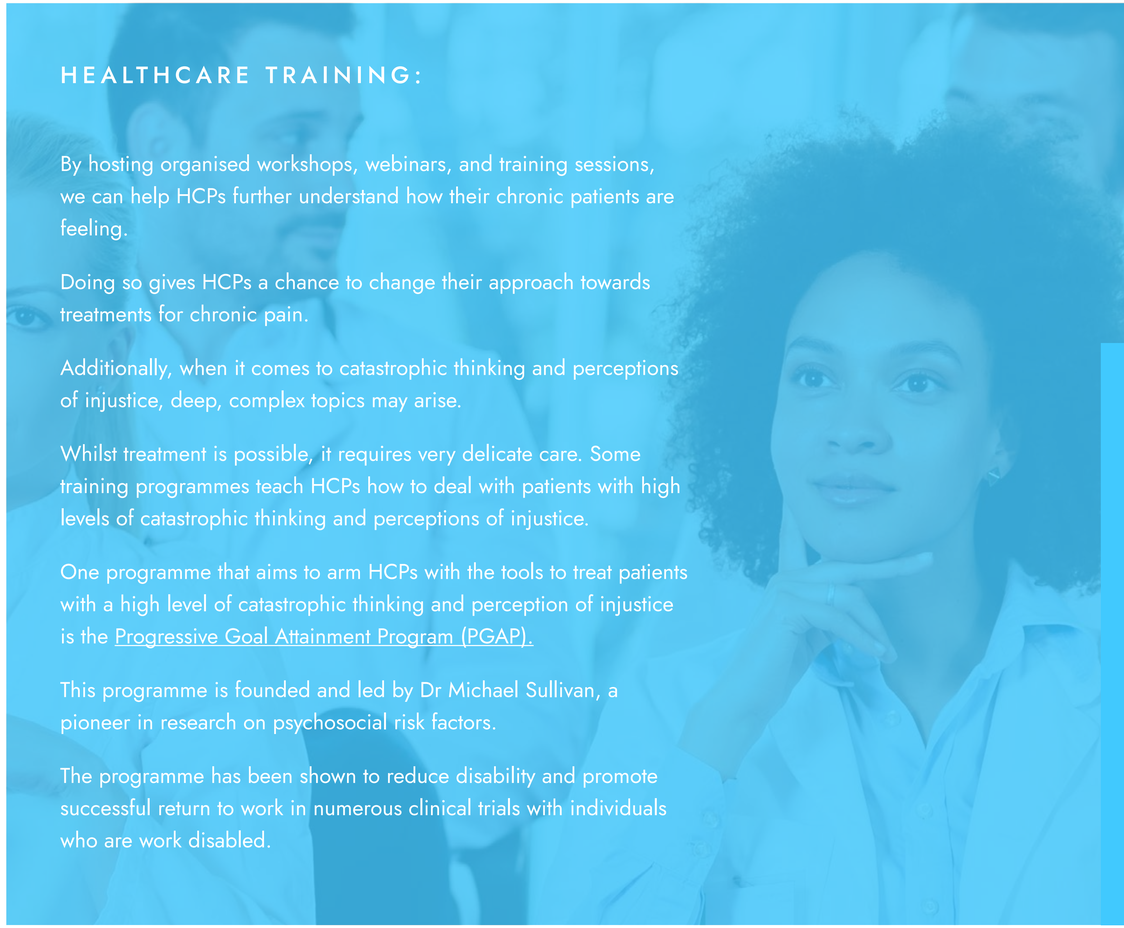
By incorporating the subject of perceptions of injustice and catastrophising pain, we could help adolescents think about whether they fit into this category.

This would allow us to identify individuals with catastrophic thinking and high perceptions of injustice earlier, allowing treatment before it further develops and affects their mental health.

Raising awareness of chronic pain in a workplace environment would foster a more empathetic workplace environment where people with chronic pain are not isolated.

Doing so could increase workplace productivity and efficiency while improving the workforce's mental health.

HEALTHCARE TRAINING:



By hosting organised workshops, webinars, and training sessions, we can help HCPs further understand how their chronic patients are feeling.

Doing so gives HCPs a chance to change their approach towards treatments for chronic pain.

Additionally, when it comes to catastrophic thinking and perceptions of injustice, deep, complex topics may arise.

Whilst treatment is possible, it requires very delicate care. Some training programmes teach HCPs how to deal with patients with high levels of catastrophic thinking and perceptions of injustice.

One programme that aims to arm HCPs with the tools to treat patients with a high level of catastrophic thinking and perception of injustice is the Progressive Goal Attainment Program (PGAP).

This programme is founded and led by Dr Michael Sullivan, a pioneer in research on psychosocial risk factors.

The programme has been shown to reduce disability and promote successful return to work in numerous clinical trials with individuals who are work disabled.

What happens if we *don't do anything?*

If we don't tackle this communication barrier on the topic of pain, then people will not be able to understand and empathise with people with chronic pain.

People with chronic pain would have no emotional support from friends and family, which could drive them to isolation and lead to mental health deterioration.

If adolescents with catastrophising thinking and high perceptions of injustice are left unchecked, it may cause further developments of the psychosocial factors, resulting in an isolated society with a negative outlook where depression and anxiety rates are rampant.

HCPs would not be able to communicate effectively with people with chronic pain, leading to misdiagnoses, undertreatment and subsequent breakdown of trust between people with chronic pain and HCPs.

Overall, a world without effective communication on the topic of pain would mean people with chronic pain could have higher levels of catastrophic thinking and perceptions of injustice, leading to a slower recovery rate and feelings of being misunderstood.

PREVENTING ISOLATION FOR SOMETHING PEOPLE HAVE NO CONTROL OVER:

People with chronic pain have no control over their pain and are isolated due to the lack of effective language to describe their experience.

By establishing an effective communication line on pain to the general public, people would be able to understand and empathise with the plights that people with chronic pain go through.

Friends and family of people with chronic pain would be able to understand the problems their loved one is going through. With this understanding, they could provide emotional and physical support to the chronically ill individual.

Adolescents with high levels of catastrophic thinking and perceptions of injustice could be identified and treated before further effects on their mental health as a method of prevention over cure.

HCPs would be able to better communicate with their chronic pain patients and understand their pain better, which could lead to more effective treatment plans.

HCPs would be able to treat patients with chronic pain with high perceptions of injustice and catastrophising thinking, overcoming a significant barrier to an effective recovery.

By establishing an effective line of communication on pain, we could help better understand the pain points of people with chronic pains and prevent them from being isolated.

Your *next steps.*

If you would like to hear more on the topic of pain research, contact Professor Christopher Eccleston.

Need help with communicating with patients? Get in touch with AGENCY to see how we can help you enhance trust, empower individuals with a greater sense of control and enable informed decision-making.

Get in touch now at **www.agencybristol.com**

Professor Christopher Eccleston

PROFESSOR CHRISTOPHER ECCLESTON - BIOGRAPHY:

Professor Christopher Eccleston is a distinguished figure in the field of medical psychology, renowned for his significant contributions to pain research and management. Born into the realm of academia, he currently holds the position of Professor of Medical Psychology at the University of Bath, UK, where he directs the Centre for Pain Research. His journey has been marked by a relentless pursuit of understanding the intricate interplay between physical experience, cognition, and emotion, particularly in the context of chronic pain.

In 1995, Professor Eccleston laid the foundation for the Bath Pain Management Unit, an initiative that would become a cornerstone in the treatment of chronic pain. Up until 2011, he directed the unit, pioneering intensive treatment programs that catered to both adolescents and adults living with the challenges of chronic pain. His innovative approaches have left an indelible mark on the landscape of pain management.

He continues to innovate pain management solutions, working to develop novel virtual reality rehabilitation treatments. He consults internationally on the development of new treatment programmes and centres, with visiting positions at Great Ormond Street Hospital, London, The University of Helsinki, Finland and the University of Ghent, Belgium.

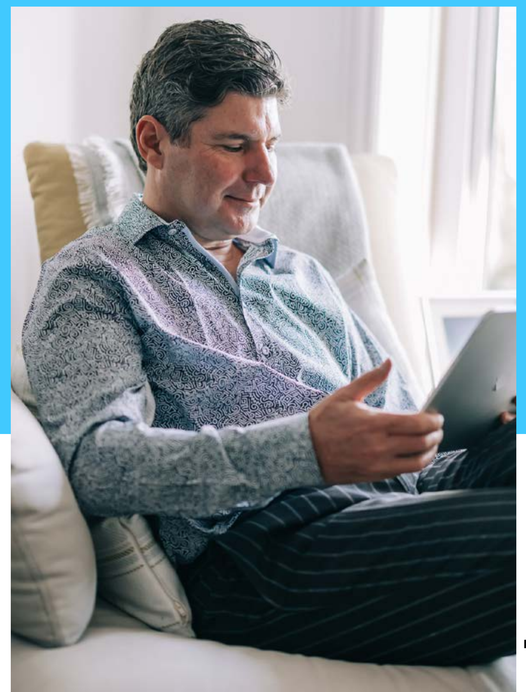
At the heart of Professor Eccleston's academic pursuits lies a deep-seated interest in unravelling how individuals interpret physical sensations, the influence of social and cognitive factors on actions in pain, and the emotional context that shapes rehabilitation concerning pain management. His multifaceted responsibilities encompass driving innovation in pain management, leading research endeavours, and providing consultancy in pain and rehabilitation.

Professor Eccleston's research portfolio covers crucial areas such as evidence-based pain management, self-management of chronic illness, assistive rehabilitative technology, adolescent chronic pain, parenting, and attentional mechanisms of analgesia. His passion for forging alliances between neurobiology and experimental psychology has driven him to address grand challenges in predicting, treating, and managing chronic pain.

Professor Eccleston has authored and co-authored a staggering 300 papers to date, solidifying his position as a thought leader in the field. His contributions extend beyond academic journals, with notable publications including "Embodied: The Psychology of Physical Sensation" (2016), "European Pain Management" (2018) and "Work and Pain: A Lifespan Developmental Approach" (2020), all published by Oxford University Press.

In 2018, Professor Eccleston won the Ronald Melzack Award for Contribution to Pain Science, recognising his commitment to advancing pain research.

As Professor Christopher Eccleston continues to shape the discourse surrounding pain management, his vision extends to creating new models of care across Europe, aiming to enhance access to treatment. His dedication to the intersection of neurobiology and experimental psychology sets a powerful precedent for future chronic pain research and management endeavours.



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