

Institution: University of Derby		
Unit of Assessment: 3		
Title of case study: Improving the management of painful conditions		
Period when the underpinning research was undertaken: 2003–2019		
Details of staff conducting the underpinning research from the submitting unit:		
Name(s):	Role(s) (e.g. job title):	Period(s) employed by submitting HEI:
Professor James Elander	Professor of Health Psychology	2007–present
Professor Paul Gilbert (UoA4)	Professor of Clinical Psychology	1992–present
Dr Frances Maratos (UoA4)	Associate Professor in Emotion Science	2006–present
Dr William Van Gordon (UoA4)	Associate Professor in Contemplative Psychology	2017–present
Period when the claimed impact occurred: 01 August 2013–31 July 2020		
Is this case study continued from a case study submitted in 2014? No		
1. Summary of the impact (indicative maximum 100 words)		
<p>Many patients with chronic medical conditions suffer chronic or recurrent acute pain that causes significant distress and impairment. Research at the University of Derby (UoD) has informed international policy and good practice recommendations for the treatment of pain among people with painful chronic conditions. This includes: (i) better standards and improved policy and good practice guidelines for the treatment of sickle cell disease (SCD) pain in the UK and USA, and improved clinical practice at major UK hospitals including Guy's and St Thomas' and Barts Health NHS Trusts; (ii) greater recognition and better treatment of chronic joint pain caused by haemophilia, including by the US National Hemophilia Foundation; (iii) improved treatment guidelines for fibromyalgia; and (iv) greater recognition of psychological risk factors for painkiller dependence.</p>		
2. Underpinning research (indicative maximum 500 words)		
<p>The underpinning research addressed the suffering of people with painful chronic medical conditions, including those that are painful even though pain is not the primary, defining feature of the condition, where pain is sometimes treated by healthcare providers as a secondary priority for treatment, and protocols for the assessment and treatment of their pain are not as well developed as in terminal care or emergency medicine.</p> <p>For example, haemophilia was not recognised as a chronic pain condition until very recently, despite the fact that recurrent joint bleeds were known to cause 'haemophilic arthropathy', and treatment protocols often overlooked the fact that many patients live with chronic joint pain. Other people with painful chronic illnesses, such as those with SCD, are often stigmatised by healthcare providers as drug seeking and have poorly managed pain, and the problems are exacerbated by care providers' reluctance to prescribe strong analgesics because of the 'opioid epidemic'. In other chronic conditions such as fibromyalgia, pain is widely recognised as a key symptom but treatments are limited and ineffective.</p> <p>Several strands of research in the Unit address these issues. From 2006 to 2017, Elander led interdisciplinary research on pain-related influences on quality of life among people with haemophilia [3.1, 3.2] and interventions to improve self-management of haemophilia-related pain [3.3]. From 2003 to 2019, Elander led interdisciplinary research on hospital pain management for people with SCD. This began from 2003 to 2006 with studies of patients' experiences and hospital staff judgements, and developed from 2007 to 2019 with international comparisons and a theoretical model of problematic hospital treatment of painful episodes [3.4]. The findings showed how hospital staff attitudes and behaviours affect patient experiences of care, and they identified factors to target in staff training and good practice guidelines internationally.</p>		

Van Gordon's international research programme developed and evaluated psychological interventions for fibromyalgia. These studies showed how contemplative psychological techniques such as mindfulness led to an improvement in pain intensity and pain perception, psychological wellbeing, as well as a general ability to function effectively [3.5]. Elander's research on psychological influences on substance misuse among people with chronic pain led to one of the first studies to highlight the issues surrounding dependence on prescription painkillers. This research showed that psychological factors such as alexithymia and pain acceptance could affect the risk of painkiller dependence [3.6].

3. References to the research (indicative maximum of six references)

Researchers employed by UoD on the publication date are indicated by black, underlined text:

3.1 Elander, J., Robinson, G., Mitchell, K., and Morris, J. (2009) 'An assessment of the relative influence of pain coping, negative thoughts about pain, and pain acceptance on health-related quality of life among people with hemophilia', *Pain*, 145, 169-175.

DOI: <https://doi.org/10.1016/j.pain.2009.06.004>

[This paper describes the first evidence about pain acceptance among people with haemophilia, with data from 209 men with haemophilia and multivariate analyses to assess the relative influence of acceptance and coping on quality of life.]

3.2 Elander, J., Morris, J., and Robinson, G. (2013) 'Pain coping and acceptance as longitudinal predictors of health-related quality of life among people with hemophilia-related chronic joint pain', *European Journal of Pain*, 17(6), 929-938.

DOI: <https://doi.org/10.1002/j.1532-2149.2012.00258.x>

[This paper provides longitudinal analyses of changes in coping and acceptance and their influence on quality of life among people with haemophilia. The findings can inform the choice of targets for interventions to improve adjustment and quality of life.]

3.3 Elander, J., Robinson, G., and Morris, J. (2011) 'Randomized trial of a DVD intervention to improve readiness to self-manage joint pain', *Pain*, 152, 2333-2341. DOI:

<https://doi.org/10.1016/j.pain.2011.06.026>

[This paper presents an RCT of a DVD self-management intervention for patients with haemophilia-related chronic joint pain. The intervention improved readiness to self-manage pain and the findings inform development of services and interventions for people with haemophilia.]

3.4 Elander, J., Haywood, C., and Beach, M.C. (2011) 'Respect, trust, and the management of sickle cell disease pain in hospital: comparative analysis of concern-raising behaviors, preliminary model, and agenda for international collaborative research to inform practice', *Ethnicity and Health*, 16 (4-5), 405-421. DOI: <https://doi.org/10.1080/13557858.2011.555520>

[This paper employs data from hospital patients in the UK and USA for analyses of factors influencing interactions between patients and hospital staff in the treatment of painful sickling episodes. The findings are used to set an international agenda for improving respect and trust in health care for people with SCD.]

3.5 Van Gordon, W., Shonin, E., Dunn, T., Garcia-Campayo, J., and Griffiths, M. D. (2017). 'Meditation Awareness Training for the treatment of fibromyalgia: A randomised controlled trial'. *British Journal of Health Psychology*, 22, 186-206.

DOI: <https://doi.org/10.1111/bjhp.12224>

[This paper describes the first randomized controlled trial to evaluate the effectiveness of a second-generation mindfulness-based intervention for treating fibromyalgia syndrome.]

3.6 Elander, J., Duarte, J., Maratos, F.A., and Gilbert, P. (2014) 'Predictors of painkiller dependence among people with pain in the general population', *Pain Medicine*, 15(4), 613-624.

DOI: <https://doi.org/10.1111/pme.12263>

[This paper provides the first evidence about the roles played by alexithymia and pain acceptance in analgesic dependence.]

Grant funding

G3.1 2014–2017 Barts and the London Charity: Sickle Cell Analgesia Pathway Evaluation (SCAPE): Optimising management of the acute painful crisis of SCD using buccal effervescent fentanyl and oral oxycodone. Telfer, P., Elander, J. GBP196,462 (GBP6,046 to UoD between 2014 and 2015)

4. Details of the impact (indicative maximum 750 words)

The insights provided by the research enabled the impact of pain in chronic conditions including SCD, haemophilia and fibromyalgia to be more widely recognised and better understood, and have contributed to better standards of care for these vulnerable, under-served groups of patients.

Impacts on national and international policy and good practice guidelines

The research on hospital pain management for people with SCD influenced multiple national and international policy and good practice guidelines, including the *Standards for the Clinical Care of Adults with Sickle Cell Disease in the UK – 2018*, which were produced by the Sickle Cell Society in partnership with the UK Forum on Haemoglobin Disorders, in consultation with, “leading healthcare professionals and sickle cell patients” [5.1].

The research also influenced the US Centers for Medicare and Medicaid Services Office of Minority Health’s 2018 guidance on *The Invisible Crisis: Understanding Pain Management in Medicare Beneficiaries with Sickle Cell Disease* [5.2], and the US National Academies of Sciences, Engineering and Medicine’s 2020 framing of *Prescribing Guidelines for Acute Pain*, which used the research to conclude that SCD patients, “may be at special risk of under-treatment for pain” [5.3]. The research also featured in guidance for policymakers and practitioners on methadone prescribing for patients with SCD, in the *Handbook of Methadone Prescribing and Buprenorphine Therapy*. This book was first published in 2013 and remains influential, having been downloaded 27,000 times [5.4].

In 2015, the UK government was becoming aware of the scale of opioid misuse and growing dependence on prescription painkillers among the general population. At that time, research led by Elander was among very few sources of psychological evidence about analgesic dependence. This evidence informed a report for the UK All Parliamentary Party Group on Prescribed Medicine Dependency, which helped to shape national policy on this newly emerging concern. The report highlighted psychological risk factors for dependence by reiterating Elander et al.’s (2014) conclusion that, “acceptance-based interventions could be adapted and evaluated as methods to prevent and treat painkiller dependence” [5.5]. In Europe, the research influenced the development of a best practice decision-making tool to treat and manage opioid dependence [5.6].

Van Gordon’s fibromyalgia research informed treatment recommendations in numerous guides to good practice in clinical therapy. These have included Springer’s *Clinical Methods in Medical Family Therapy* (2018), which had 1.3 million downloads since publication, and Taylor and Francis’s *Mind-Body Medicine in Clinical Practice* (2018), which provides, “resources and practical tools to help clinicians incorporate evidence-based mind-body medicine therapies into patient care” [5.7]. The research also influenced recommendations about clinical applications of meditation in Springer’s *Clinical Guide to the Treatment of the Human Stress Response* (2019), which has been downloaded 33,000 times since publication [5.7].

Impacts on clinical practice

The haemophilia research influenced the clinical assessment and management of chronic joint pain among people with haemophilia. For example, at the Henry Ford Hemophilia Centre in Detroit, which treats over 100 haemophilia patients a year, a lead Nurse Practitioner described how: “Elander’s research on chronic joint pain caused by haemophilia influenced how I worked with patients and helped promote a positive dialogue between patients and care providers to agree individual plans for managing and coping with pain” [5.8]. From 2014, Bayer Healthcare used the

research to inform their yearly pain management programmes for healthcare providers in treatment centres in the Northern and Central part of the USA, including 12 treatment centres in Michigan alone [5.8]. The findings were also translated into improved practice by international bodies including the US National Hemophilia Foundation (NHF), whose Head of Research commented: *"I often reference your material... we incorporated it into our IMPACT QOL series"*. The research also influenced the NHF's Medical and Scientific Advisory Council's Pain Initiative, which comprised the main, *"...thought leaders in the US pain movement for bleeding disorders"* [5.8].

The SCD research also influenced clinical practice by helping hospital staff to recognise the importance of prompt and effective analgesia for sickling episodes, and was used in the teaching and training of medical and other health professionals to improve hospital staff awareness of pain management issues in SCD [5.8]. For example, staff at Guy's Hospital, London, used the research to inform the teaching of psychology postgraduate students and approximately 50 clinical staff members per year, including consultants, sickle cell clinical nurse specialists, and accident and emergency department staff [5.8]. The sickle cell research led to Elander being invited to join a major collaborative initiative funded by a GBP196,462 Strategic Research grant awarded by Barts and the London Charity for the project *Sickle Cell Analgesia Pathway Evaluation (SCAPE)*. Elander's role was to lead the development of a measure of patient satisfaction with treatment for pain to be used as an outcome measure in the trials of novel analgesic protocols. A consultant at Barts Health NHS Trust, London, UK, where approximately 1,500 patients with SCD are registered, said: *"This research is part of a package of things that have influenced our ongoing efforts to improve the treatment for painful episodes that is provided for patients with SCD. The Satisfaction with Treatment for Pain Questionnaire (STPQ) will be adopted by the Trust for use in routine clinical audit of hospital services for SCD, so it will be completed by all patients 12 years and over who attend for treatment of painful sickling episodes as part of the Trust's systems for maintaining and improving standards of care"* [5.8, 5.9].

In the USA, the SCD research was used to improve standards of professional practice at Johns Hopkins University School of Medicine, Baltimore, USA, where close to 800 adult SCD patients are registered. A Professor of Medicine commented: *"At Johns Hopkins, we have used your research on pseudo-addiction to educate our doctors and nurses about pain treatment in sickle cell disease, specifically pointing out how properly to interpret patient behaviors and provide adequate pain management"* [5.8].

Van Gordon's findings were used in supporting guidance on fibromyalgia management in *UpToDate*, an online clinical resource accessed by more than 1.9 million clinicians in over 190 countries, supporting their understanding of contemporary standards and care decisions. The findings in relation to fibromyalgia treatment were also recommended in the *Journal of Lancaster General Hospital*, distributed to over 7,000 physicians and nursing leaders in Pennsylvania [5.10].

Impact on public health resources

Elander's sickle cell research was translated into open access public health and educational materials for the SCOTER (Sickle Cell Open Education Resources) project [5.10], and Van Gordon's research influenced health resources for the public including a wellness resource compiled by the goop PhD team on the lifestyle and wellbeing website, goop, which has a very wide international reach. Based on the research findings, this resource highlights the benefits of Mindfulness Awareness Training (MAT) in significantly reducing pain and fibromyalgia symptoms [5.10]. Other online public health resources for advice/ information about managing and treating fibromyalgia where Van Gordon's research has provided the evidence on which advice has been based include *VeryWellHealth*, *Coping.US*, and the *Natural Health Research Institute* [5.10].

5. Sources to corroborate the impact (indicative maximum of 10 references)

5.1 Sickle Cell Society. (2018) *Standards for the Clinical Care of Adults with Sickle Cell Disease in the UK* (2nd Ed). London, UK: Sickle Cell Society. Please see the section on chronic pain. Available at: <https://www.sicklecellsociety.org/sicklecellstandards/> (Accessed: 03-02-2021).

5.2 James, C.V. and Wilson-Frederick, S. (2018) *The Invisible Crisis: Understanding Pain Management in Medicare Beneficiaries with Sickle Cell Disease*. Centers for Medicare and Medicaid Services Office of Minority Health, USA. Available at: <https://www.cms.gov/About-CMS/Agency-Information/OMH/Downloads/CMS-OMH-September2018-Sickle-Cell-Data-Highlight.pdf> (Accessed: 03-02-2021).

5.3 National Academies of Sciences, Engineering, and Medicine. (2020) *Framing Opioid Prescribing Guidelines for Acute Pain: Developing the Evidence*. Washington, DC: The National Academies Press. DOI: <https://doi.org/10.17226/25555>

5.4 Smith, W.R. and Alsalman, A.J. (2013) 'Methadone Prescribing in the Sickle Cell Patient' in Cruciani, R. and Knotkova, H. (eds.) *Handbook of Methadone Prescribing and Buprenorphine Therapy*. New York: Springer, 263-276. Book downloads are available at: <https://link.springer.com/book/10.1007/978-1-4614-6974-2> (Accessed: 03-02-2021).

5.5 Shapiro, H. (2015) *Opioid Painkiller Dependency: An Overview. Report Written for the All-Party Parliamentary Group on Prescribed Medicine Dependency*.

5.6 Alam, F., D'Agnone, O., Bremner, D., Tuckey, G., Abbasi, Y., and Littlewood, R. (2017) 'Towards best practice: trends in the management of opioid analgesic dependence', *Heroin Addiction and Related Clinical Problems*, 19(1), 55-62.

5.7 Group of evidence on Van Gordon's impact on treatment guidance for fibromyalgia:

- a) Cited in Wilson, J. et al. (2018) 'Medical Family Therapy in Spiritual Care', in Mendenhall, T. et al. (eds.) *Clinical Methods in Medical Family Therapy*. Cham: Springer, pp. 463-95.
- b) Cited in chapter 14 on pain in McClafferty, H. (2018) *Mind-body Medicine in Clinical Practice*. Oxford; New York: Routledge, pp. 175-195.
- c) Cited in chapter 13 on meditation in Everly, G.S. and Lating, J.M. (2019) *A Clinical Guide to the Treatment of the Human Stress Response* (4th Ed). New York: Springer, pp. 289-314.

5.8 Evidence group of correspondence from clinical care providers (2019–2020):

- a) Haemophilia (correspondence from 2 representatives from US Clinical Care Providers).
- b) Sickle Cell Disease (correspondence from 3 representatives from US Clinical Care Providers and correspondence from 7 representatives of UK Clinical Care Providers).

5.9 Elander, J., Bij, D., Kapadi, R., Schofield, M.B., Osias, A., Khalid, N., Kaya, B. and Telfer, P. (2019) 'Development and validation of the Satisfaction with Treatment for Pain Questionnaire (STPQ) among people with sickle cell disease', *British Journal of Haematology*, 187, 105-116. DOI: <https://doi.org/10.1111/bjh.16015>

5.10 Evidence group demonstrating influence via online health resources (all resources were available before 31-12-2020 and were accessible online on 02-02-2021):

- a) *UpToDate* (topic last updated 14-01-2020): <https://www.uptodate.com/contents/treatment-of-fibromyalgia-in-adults-not-responsive-to-initial-therapies>
- b) Coleman and Ton-That in *The Journal of Lancaster General Hospital* (Spring 2020): http://www.jlgh.org/Past-Issues/Volume-15-Issue-1/Coleman_Fibromyalgia-Treatment.aspx
- c) The SCOOTER Project (archive from 01-2014–09-2018): <http://sicklecellanaemia.org/health-studies/sickle-cell-patient-hospital-experiences-by-james-elander/>
- d) *goop* (topic last updated November 2019): <https://goop.com/wellness/health/understanding-fibromyalgia/>
- e) *verywellhealth* (published 09-08-2020): <https://www.verywellhealth.com/mindfulness-for-fibromyalgia-4147054>
- f) *Coping.US* (1999-2020): <http://coping.us/mindfulnessneurobiology/painmanagement.html>
- g) Natural Health Research Institute website (published 14-12-2017): <https://www.naturalhealthresearch.org/meditation-awareness-training-improves-fibromyalgia-symptoms-directors-choice/>