Institution: University of Bath

Unit of Assessment: 3. Allied Health Professions, Dentistry, Nursing and Pharmacy

Title of case study: Teenagers in chronic pain - Innovation in assessment and treatment

1. Summary of the impact

Adolescents (and their families) in the UK and around the world are now better able to cope with chronic pain because of the unique work carried out at the University of Bath Centre for Pain Research (BCPR), directed by Professor Christopher Eccleston.

The BCPR produced the first multidimensional 'one-stop' tool to assess the impact of pain on children's lives, which has now been adopted in at least 12 countries. Pioneering treatments from Bath have influenced therapeutic approaches worldwide.

The Bath team also manage the evidence base for chronic pain, giving access through the Cochrane Library, advising internationally on clinical service development and improvement.

2. Underpinning research

Chronic pain causes significant problems in the lives of many adolescents, negatively affecting their physical, psychological and social functioning. Prevalence studies of persistent chronic pain in childhood demonstrate that 12% of adolescents have a severe episode of pain and 2% have persistent stubborn pain. Descriptive data show that 20% of adults with chronic pain reported untreated pain in adolescence. The assessment of the impact of chronic pain and its subsequent treatment is therefore an essential clinical task.

The BCPR team (Eccleston (1994-) Keogh (2004-) and ~55 PhD students, postdoctoral research fellows, and clinical collaborators) established a specific research programme on the assessment and treatment of adolescent chronic pain**.** Foundational research was absent: the evidence for psychological interventions was unknown, and little assessment and treatment technology existed.

Assessment. This work involved systematic reviews of the existing measurement tools used to assess the impact of untreated pain on adolescents, and on their parents. This showed that no specific multidimensional tools existed. The team won two research grants, one from the BUPA foundation and one from the PPP Healthcare Medical Trust, to create optimal assessment technology, and published these tools as the Bath Adolescent Pain Questionnaire (BAPQ) [1] and the Bath Adolescent Pain – Parent Impact Questionnaire (BAP-PIQ) [2]. They also developed a version of the BAPQ for non-communicating children. The BAPQ offers a comprehensive way of assessing the widespread deleterious impact of adolescent chronic pain in both a research and clinical setting. The tools are available at: http://www.bath.ac.uk/pain/assessment-tools/.

Evidence. In 2002, the BCPR undertook the first systematic review with the Cochrane Collaboration. This analysed the world's existing data on treatment effectiveness. The results were widely disseminated and extensively commented upon. The review was updated in 2009 and again in 2012 [3]. The team also undertook a companion Cochrane Collaboration systematic review of the evidence for parent-focused treatments produced in 2012 [4]. The BCPR has published extensively, including a BMJ editorial [5] on the need for evidence in paediatric chronic pain, and consulted widely on the optimal methods of trial design.

Treatment. In 2003, the team developed the first multidisciplinary intensive rehabilitation programme for adolescents in association with its principal clinical stakeholder, the Royal National Hospital for Rheumatic Diseases in Bath: a three-week, residential treatment for the severely disabled. More recently, the team has developed computerised versions of treatments (EPSRC EP/F001916) and is exploring how to use the internet to improve access to treatments. With colleagues in the USA, the BCPR is also developing a parent-only treatment (funded by NIH 5-R21-HD065180), a randomized controlled trial of a problem solving treatment for parents versus wait list control.

Mechanisms. The BCPR has a strong research programme aimed at discovering the mechanisms of disability in chronic adolescent pain, in particular, the role of anxiety processes in driving maladaptive behavioural responses. This research stream provides the basis for the development

and targeting of treatment.

Advocacy and influence. The existence of adolescent chronic pain still surprises people. Part of the BCPR's role is to serve as an advocate, and in particular to educate scientists, policymakers, governments and health-care professionals. This included the first and only cost of illness study of adolescent chronic pain [6].

3. References to the research

1. Eccleston C, Jordan A, McCracken L, Sleed, M, Connell, H, Clinch, J. (2005) The Bath Adolescent Pain Questionnaire (BAPQ): Development and preliminary psychometric evaluation of an instrument to assess the impact of chronic pain on adolescents. Pain, 118, 263-270. DOI: 10.1016/j.pain.2005.08.025
2. Eccleston C, McCracken L M, Jordan, A, Sleed, M. (2007) Development and preliminary psychometric evaluation of the parent report version of the Bath Adolescent Pain Questionnaire (BAPQ-P): a multidimensional parent report instrument to assess the impact of chronic pain on adolescents. Pain, 131; 48-56. DOI: 10.1016/j.pain.2006.12.010
3. Eccleston C, Palermo TM, Williams AC de C, Lewandowski A, Morley S, Fisher E, Law E. (2012). Psychological therapies for the management of chronic and recurrent pain in children and adolescents. Cochrane Database of Systematic Reviews, Issue 12. Art.No.: CD003968. DOI: 10.1002/14651858.CD003968.pub3.
4. Eccleston C, Palermo TM, Fisher E, Law E. (2012) Psychological interventions for parents of children and adolescents with chronic illness. Cochrane Database of Systematic Reviews, Issue 8. Art. No.: CD009660. DOI: 10.1002/14651858.CD009660.pub2.
5. Eccleston, C & Malleson, P M. (2003) Management of chronic pain in children and adolescents (Editorial). British Medical Journal, 326, 1408-1409. DOI: 10.1136/bmj.326.7404.1408
6. Sleed M, Eccleston, C, Beecham J, Knapp M, Jordan, A. (2005) The economic impact of chronic pain in adolescence: Methodological considerations and a preliminary costs of illness study. Pain, 119, 183-190. DOI: 10.1016/j.pain.2005.09.028

4. Details of the impact

Assessment. A challenge for pain clinicians is to determine the aspect of a complex clinical presentation for treatment targeting. The BAPQ, BAPQ-P (parent-completed version for non-communicating adolescents) and BAPQ-PIQ (parent impact version) provided the first tools designed and validated with the patients (and families) to enable that targeting. They have been translated into French, Spanish, Dutch and Thai, and have been, and continue to be, used in the USA, Canada, Europe and Australia [1].

Affirmation of the value of these tools may be illustrated by comments from the Director of Psychology Services in Pain Medicine at Boston's Children Hospital (Harvard Medical School) [2]: *"… the Bath Centre for Pain Research has also been the leading center in the development and dissemination of focused outcome assessment tools to inform our understanding of the impact of pediatric pain on the child and family. The Bath Adolescent Pain Questionnaire (BAPQ) and its companion BAPQ Parental Impact Questionnaire (PIQ) are the first well validated tools specifically focused on providing a broad based assessment of the functional impact of pediatric pain, encompassing physical, emotional and social domains in both children with pain and their parents."*

Similarly, a Professor of Pediatrics at the Connecticut Children's Medical Center (CCMC) attests [3], *"… we are expanding our program and resources for treating chronic pediatric pain and currently utilize a multidisciplinary assessment process that includes standardized questionnaires. As we continue to refine our assessment process and services at CCMC, I take comfort in knowing that we can rely on [the BCPR's] validated assessment tools and treatment program as a model."*

Further examples of the reach and significance of the assessment tools come from (a) the Director of the German Paediatric Pain Centre, who said [1], *"The BCPR measures are carefully developed, scientifically sound and essential for good clinical practice. In addition they deliver important data for the understanding and treatment of paediatric chronic pain... We constantly follow the output of*

the Bath research group, given the high scientific standard and the clinical importance of their research", and (b) from the Seattle Children's Hospital (with which Bath is collaborating on a U.S. NIH funded grant to evaluate the feasibility and acceptability of problem-solving skills training as an intervention in parent caregivers of youth with chronic pain, and to conduct a preliminary efficacy trial in parents of youth with chronic pain) [1]: *"The BCPR tools provide unique information regarding the impact of pain on child and parent emotional and physical functioning."*

Treatment. The treatment developed in Bath has proven highly effective in spreading best practice, and has led to foundational research on the patterns and predictors of disability in adolescents, and to new service provision in chronic pain for adolescents, all over the world. It continues to attract a great deal of attention – for example, approximately five international visitors a year observe at least a week of the treatment programme.

Professor Eccleston has lectured internationally on treatment content, development and effectiveness, and his award of the Pfizer Visiting Fellowship in Paediatric Pain in 2007 to visit New England and Connecticut as the guest of the CMCC [4] led to their implementation of the BCPR assessment tools and treatment developments during the REF period.

Significantly, the programme has been replicated, *inter alia*, at the Institute for Rehabilitation in Chicago [1], in the Pediatric Complex Pain Service of Dalhousie University (Canada) [1], at the CCMC [3], and at Harvard Medical School [2], where the Director of Psychology Services in Pain Medicine at Boston's Children Hospital states, *"Unequivocally, the Bath Centre for Pain Research and its clinical partners set and continue to represent the gold standard for intensive inter-disciplinary treatment programs in the field of pediatric pain management. The [BCPR] was the first successful program developed for children and adolescents with complex, intractable chronic pain conditions. In the past decade, numerous top academic medical institutions in both Europe and North America have sought to create programs following the model of care established at the [BCPR]. As a co-creator of our own such program here at Boston Children's Hospital, the Mayo Family Pediatric Pain Rehabilitation Center (opened in 2008), I can attest that our program is closely based upon this model. The [BCPR's] clinical program has become the model to emulate in the field due to their highly successful outcomes and international reputation for providing excellent clinical care."*

The Professor of Pediatrics at the Connecticut Children's Medical Center (CCMC) is equally enthusiastic [3]: *"[The BCPR's] ground-breaking work to assess, understand and effectively treat these most complex pediatric patients with chronic pain has been a steadfast beacon of light in the often murky trenches that make up the day to day work of intensive rehabilitation treatment programs for pediatric pain... I have found your program's emphasis on addressing psychological wellbeing, in balance with goals for improved physical functioning, to resonate widely across treatment settings specializing in pediatric chronic pain."*

Policy and advocacy. The BCPR authored and maintain the two key Cochrane Library Systematic Reviews (see Section 2 and references in Section 3), one on parent treatments, the other on those for adolescents. Both are updated biannually and provide the evidence for policy and clinical development. Although the international workforce in paediatric pain is small, it has been able to significantly increase its impact and scope through a special interest group of the International Association for the Study of Pain. In 2010, Professor Eccleston was chair of the scientific programme committee for the International Symposium on Paediatric Pain, which attracted 550 of the world's top scientists and lead clinicians in the field [5].

In addition, Bath supported a grant to develop Pain in Child Health (PICH) [6], an international programme, which has to-date produced a community of more than 40 postgraduates with formal and informal training in the assessment and treatment of paediatric pain. PICH operates on a policy level to influence paediatric pain practice worldwide, and the Bath group are the only behavioural science group in the UK to be involved in, and have impact on, the training of new paediatric pain researchers.

The BCPR has contributed to a number of policy initiatives, including (a) supporting the UK Chronic Pain Policy Coalition, (b) co-chairing the expert group writing the American Pain Society Guidelines on the treatment and assessment of chronic pain [7], and (c) agreeing the consensus

statement on core outcome domains and measures for all new randomized controlled trials in pain [8] (which include the Bath instruments).

In the last two years, the UK has moved to specialized national commissioning of services for patients with severe and disabling conditions like chronic pain, and the Bath Service is included, as are the use of specific measures (BAPQ and BAPQ-PIQ) [9]. The move to specialized services is a major advance and is the culmination of much work to promote the needs of young people. The BCPR is now in discussion with NICE on planned guidance in pain related topics, specifically in how to inform new guidance, including that planned on children and young people in pain [10].

5. Sources to corroborate the impact

1. Examples of responses to recent requests from the BCPR for information about how the assessment tools are used, received from: Director of the UCLA Paediatric Pain Program, USA; Professor of Anaesthesiology & Pain Medicine, Seattle Children's Research Institute, USA; Professor and Canada Research Chair, Centre for Paediatric Pain, Research, Dalhousie University, Canada; Director, German Paediatric Pain Centre, Datteln, Germany; Professor of Experimental, Clinical and Health Psychology, Ghent University, Belgium; Professor of Anaesthesia and Pain Medicine, Sydney Children's Hospital, Australia.
2. Letter from the Director of Psychology Services in Pain Medicine, Children's Hospital, Harvard Medical School, Boston, USA.
3. Letter from a Pediatric Psychologist and Clinical Investigator, Division of Pain & Palliative Medicine, Connecticut Children's Medical Center, Hartford, USA.
4. http://www.bath.ac.uk/news/2007/9/26/ecclestonpfizer.html
5. http://childpain.org/. Hosting arrangements for this important committee are also being managed by the Bath Team (see invitation to host http://childpain.org/ispp.shtml). For information about the MayDay Fund, which supports Bath graduate students, see http://www.maydayfund.org/.
6. http://paininchildhealth.dal.ca
7. http://www.americanpainsociety.org/uploads/pdfs/aps12-pcp.pdf
8. http://www.immpact.org/static/publications/McGrath%20et%20al.,%202008.pdf
   McGrath PJ, Walco G, Turk DC, Dworkin RH, Brown MT, Davidson K, Eccleston C, Finley AG, Goldschneider K, Haverkos L, Hertz SH, Ljungman G, Palermo T, Rappaport BA, Rhodes T, Schechter N, Scott, J, Sethna N, Svensson OK, Stinson J, von Baeyer C, Walker L, Weisman S, White RE, Zajicek A, Zeltzer L. (2008). Core outcome domains and measures for pediatric acute and chronic/recurrent pain clinical trials: PedIMMPACT recommendations. Journal of Pain, 9: 771-783. DOI: 10.1016/j.jpain.2008.04.007
9. http://www.england.nhs.uk/wp-content/uploads/2013/06/e02-paedi-surg-chronic-pain.pdf (see page 9).
10. Email correspondence demonstrating the involvement of the BCPR (via its Director, Prof. C. Eccleston) in the development of NICE's 5-year work plan to develop a number of guidances (involving, self-evidently, one on children and young people in pain).