

Airing Pain Programme 36: Societal Impact of Pain

Evaluating the cost of chronic pain to society and improving public health policy on pain.

In this programme we explore issues affecting the management of chronic pain across the diverse societies of Europe.

*In May 2012 over 400 delegates representing 35 European countries met in Copenhagen at the third Societal Impact of Pain conference organised by EFIC (the European Federation of the International Association for the Study of Pain Chapters). **Airing Pain** was there to listen in and speak to patient groups and leading experts on pain and public health policy from across the continent. We hear how chronic pain accounts for 500 million lost working days in the European Union every year, costing the EU economy over 34 billion Euros.*

Interviewees talk about the strengths and weaknesses of pain management in their part of the continent, including Italian successes in raising political interest in pain treatment and a shining example of good practice in Kirklees, Yorkshire.

Paul Evans: Hello, I'm Paul Evans and welcome to **Airing Pain**, a programme brought to you by Pain Concern, the UK charity providing information and support for those of us living with pain. This edition is financed by Grünenthal.

John Lindsay: If you have cancer, cystic fibrosis, multiple sclerosis, motor neurone disease you are diagnosed by the physician. Chronic pain is the only one where you go into your physician, your GP or your consultant and say, 'I have chronic pain, can you help me?'

Evans: In May 2012 over 400 delegates representing 35 European countries met in Copenhagen at the third Societal Impact of Pain conference organised by EFIC, that's the European Federation of the International Association for the Study of Pain Chapters. Chronic pain accounts for 500 *million* lost working days in the EU every year, costing the EU economy over 34 *billion* Euros. Janet Graves covered the event for Pain Concern. She started by speaking with Professor Hans Kress from Vienna. He's President of EFIC.

Kress: In the minds of many people, of politicians in particular, pain is just a symptom, a symptom of another disease and they have the misconception that also chronic pain is just a symptom of another chronic disease that must be treated and when it's treated it's fine and the chronic pain

disappears. We know from our many, many chronic pain sufferers that that is not the case. It may develop into a disease in its own right and therefore we have already, many years ago in 2001, proclaimed, stated that chronic pain in many cases must be considered a disease.

Unfortunately, chronic pain does not exist in the classical systems that are used around the world for coding of diseases; for also reimbursement purposes and so on. One typical example is the so-called ICD, that is, the International Classification of Diseases. It's published and developed by the WHO in Geneva and there you will not find the diagnosis, chronic disease. What cannot be found is not diagnosed and does also not appear in our official statistics; and what is not in the official statistics doesn't play a role for political decisions. So one step is the result of another, and what we must reach – and we are discussing that during our symposium – is that at least in the ICD 11, that is, in the new version which is in the pipeline of WHO some category of 'chronic' appears.

Evans: Professor Hans Kress, president of EFIC. Dr Beverley Collett is a consultant in pain medicine and chair of the chronic pain policy coalition in the UK.

Collett: The Department of Health have said that they would find it conceptually easier to prioritise pain if chronic pain was called a disease in its own right. But pain is very complex and it's also a continuum. And so you have acute pain after an operation or an accident and that is obviously due to tissue damage and that is not a disease in its own right. If somebody, for example, who has an osteoarthritic hip, they have that hip replaced and the pain goes, so the pain for them was not a disease in its own right. So whilst I think conceptually we know that in some patients you get 'central sensitization' and you get changes going on in the spinal chord that are common to many different causes of pain, I think it's a route which needs to be taken with caution, because otherwise you may get doctors not looking for ways to totally change pain but actually just looking for ways to manage pain.

And so I think it's something that needs to be viewed with caution. And I think also you need to remember that, as pain specialists in England, we manage acute pain, we manage cancer pain and we manage non-cancer pain and I think dividing it up is actually going to make things much more difficult for us to manage. So I think we need to view that by looking at the patient as an individual and really managing the individual patient in front of us in the best possible way. And I think that that is how we will manage patients with pain to the best of our ability.

Evans: Dr Beverley Collett, Chair of the Chronic Pain Policy Coalition in the UK.

So what is the picture across Europe? Can patients expect the same level of treatment in whatever country they may be? John Lindsay is vice president of Pain Alliance Europe which is a relatively new umbrella organisation representing patients and patient advocacy groups.

Lindsay: They are not vastly different. If we take the country we're in at present, which is Denmark, everybody would say that generally the health services in Denmark are superb, but I just heard a representative of a Danish organisation who support people with chronic pain say that they had the same issues and problems in Denmark as they do all around Europe. And it would appear to be the same everywhere. Some countries may be slightly more advanced, such as Norway, Portugal, Scotland, Wales; Ireland is doing reasonably well, Germany is doing reasonably well.

But still, on the whole, with 20% of people in Europe living with chronic pain, access to services is very, very limited and correct diagnosis can be a huge issue, which can lead in turn to an incorrect referral, so that one ends up going round the houses before they eventually get to the pain consultant. And waiting times vary considerably. I know, I think, in Denmark they have managed to get it down to nine weeks to see a pain consultant. In the west of Ireland it's three years to see a pain consultant and you're just left in pain for three years which is horrendous.

But generally, no-one has ever looked and said 'What is best practice, all around Europe? Where can we identify best practice? Who is giving those living with chronic pain the best care and management? It is part of the work we will do with the Pain Alliance Europe – we will ask all the national organisations to try and make even initially a rough assessment of what services are available and then compare them. I know recently I was in Northern Ireland and their services were quite good, although they themselves would not think they were good, but they would have access to multi-disciplinary teams, which is absolutely essential.'

Evans: John Lindsay, Vice President of Pain Alliance Europe.

Justino Marasi manages a public company providing health care services for a population of about 350,000 people in central Italy.

Marasi: Unfortunately progress cannot be the same all around Europe for many different reasons. Basically it depends on the background in the different regions of Europe, and also, it depends on the charisma of the different people working in that specific area. The influence we can have from the central action to the local action is extremely important, of course, but is not everything. We can give guidelines, like the one we tried to give with the Roadmap for Action, but at the same time we cannot influence at the local level, because the local level is done by, especially for health care

services, it is done via the organisation of patients and especially of politicians. But again it depends also from the influence of local people.

For example I think the action that has been made in Italy is really important because we have succeeded at the political level, obtaining many different advantages for the pain patients, and of course maybe the organisation of the health care is also influenced by the local ability of the different doctors, all in the same country. And this is of course the same for all the countries in Europe and I think in some countries there are spots where the pain patients are treated better, in some others there are spots where pain patients are not cared for at all.

But what we obtained for sure in the last few years is that at least the politicians have started to discuss about pain patients. Now they are more sensitive – pain is on the agenda of a lot of politicians and this is very important, because this is the beginning of the change we can have. ‘

Anne Lloyd: The map of progress in Europe is indeed very patchy and I’m afraid to say that the UK is not doing well at all.

Evans: Anne Lloyd is a trustee of the Patients’ Association in the UK.

Lloyd: That is not to say there isn’t really excellent work going on in the UK. We do research into who’s making the most progress in the Patients’ Association in these areas and there has been some really excellent work done in Sheffield, done in NHS Easton, done in Kirklees and the Kent coast. And again this is an issue of ‘Why is not everybody adopting this good practice, opening up the care pathway and working with local government colleagues to ensure that the services are working more seamlessly together? (And haven’t we been talking about *that* for years!) And to ensure that the commissioners can have the evidence on which to start to commission a totally different type of pain programme, for which they will then pay, rather than the traditional surgical intervention. That is still necessary in a small proportion of patients but certainly not in 90% of people who refer for back pain and other things.

Evans: That was Anne Lloyd of the Patient’s Association. One of the areas she singled out for praise was Kirklees in West Yorkshire. Now, Dr Judith Hooper is the Director of Public Health for NHS Kirklees and Kirklees council.

Hooper: West Yorkshire’s legacy is of (obviously) mill-working, so there are a lot of low-skilled, low-paid jobs. Some of it was very badly hit by the 80’s recession and it is very much a land of small businesses, so income levels are relatively low, education, relatively low. It’s also got a very high

proportion of people from the South Asian subcontinent, particularly Pakistan, where the understanding of pain is significantly different to the indigenous population.

There's a lot of deprivation, of people on low income, people with low use of resources, and one of the things we've tried to do is get people to understand what they can do to help themselves. Encourage things like expert patient programmes, get the right tools – CDs, DVDs from the local libraries – get the librarians trained up to know how to guide people to the right things, whatever they're coming for, as well as get information out to people, so they're not dependent on their GP, or they're not dependent on the system to actually point them in the right direction.

So we're working with social care workers, we're working with housing officers and we're even working with dustmen, in terms of, when they have conversations with the people they're coming into interaction with, to just give them some ideas about things they could do, even if it's just becoming more physically active like going for longer walks. So it's very much about working with people, particularly on the front-line to get them to think differently and get them to be able to point patients in the right direction when they come across them.

So, for example in Kirklees we've got a website which is called Kirklees Self-care, so if people just Googled that, that would bring up a whole load of resources and opportunities, not just for people who live in Kirklees but other people can access [it] elsewhere on the internet, or even buy stuff off Amazon. So it's kind of a quality assured resource inventory of stuff that you can do to help yourself.

Evans: Dr Judith Hooper.

Patients in England will see changes as a result of the controversial Health and Social Care bill of 2012. Now, you may not find many people these days who'll use the words 'exciting' and 'economic struggle' in the same context, but...

Hooper: One of the exciting things about the economic struggle that we're all in is there is no more money. There's a lot of money already in the system, so actually it's how do we make best use of this. One of the things that actually I have managed to get over to both social workers and local clinicians, is you don't have to do everything. Just get your sign-posting systems in your clinics, or when you're seeing your clients, sorted out, so you can actually point the clients in the right direction.

But it's actually trying to get the system to think about the person in the context that they're living; that it is not just someone coming with pain in their knee but actually what is the impact of that pain

on how they are coping with their work; how they are coping with their relationships within their family; how they get out of bed in the morning – all those basic things in terms of living.

As a result of the Health and Social Care Bill the NHS reforms are actually in three ways. One is around increasing the variety of providers of health care subject to strict regulation. Another one is putting GPs in charge of commissioning instead of primary care trusts and the third thing is that my world, which is public health, is moving to local government where it should have been years ago.

Now what's that doing? In the short term it's pretty chaotic as this change goes through. But after about next spring when things will start settling down, I think we have got a real good opportunity here. Because it's GPs who actually understand that pain is actually probably the biggest thing alongside mental distress that they deal with *and* they are not very good at doing it and they know that. So if there are things that they can see that will help improve pain management, whether the patients are doing it or there is different ways the health care system can do it, I think they will be really interested in it because it will also save them a lot of money both on prescribing and hospital, both admission and use. And that's one of the things we've been doing in Kirklees and why we have sold it to the GP commissioners in terms of putting in this, what's called a 'step two service'.

I think the other bit that's really exciting and really is positive, is that the NHS reforms are bringing local government, i.e. local councillors together with GPs in this thing called a 'health and wellbeing board' which is overseeing both the commissioning of social care and health care together with public health services. The advantage of that is, in my dealings — I brought in councillors ages ago to look at what was happening in pain management to give it some clout —and the councillors are fantastic because they are in touch with their constituents; they know what's going on in their own surgeries, so they've been really helpful in terms of saying to the clinicians: 'Hey! Why aren't you doing this? Why haven't you thought about the patient in this way?' And I am hoping that in the dialogue between councillors and GPs, we've got two sets of people who deal with the public in quite different ways that actually can gel and work well together; and in Kirklees they already do and that feels really positive.

Lloyd: I think the way in which she described how she went about engaging with local authorities and other stakeholders, charities etc. and their expert patients in trying to change the commissioning framework was most encouraging. But in Germany it seems that they are really, really trying to push the societal costs argument to ensure that their governments start to change the way in which they commission and they have had remarkable results about the huge amount of money they have saved in their pilots from treating people completely differently, enabling self-care

to take place and getting really, really good at patient and carer satisfaction results, so improved quality of life. That has been very encouraging.

Evans: Anne Lloyd of the Patients' Association.

Improved quality of life for the elderly is one of the bullet points for this conference on the Societal Impact of Pain in Copenhagen. Dr Chris Wells is president elect of conference organisers, EFIC:

Wells: At the moment 15 % of the population of Europe are over sixty-five, by 2020 that will be over 20%; and by 2030 it will be over 25%, so over a quarter of us will be over 65.

The problem is, we know from this survey, and from other surveys, between 20% to 50% of people over sixty-five have chronic pain, so it has a major impact on their quality of life. Some of them have mild pain which they could manage usually very well, but the most common pain is moderate pain and a very significant number have severe pain.

The cost is in quality of life because most people over 65 aren't working, but with the aging population of course it is envisaged that people over 65, some of them are going to have to work, because we can't afford to pay the pensions of everybody over 65 with a longer life expectancy.

So I think, yes, in the future people will have to work on longer, so that there is an economic impact to being over 65 and having pain, but most important is the quality of life. After years and years of working hard, bringing up a family, earning a living, then you get some peace and quiet and retirement and it's blighted because you have chronic pain. Most people over 65 have more than one chronic illness. High blood pressure, depression, as well as pain, and that makes the treatment of pain even more difficult because some of the treatments that we want to use, some of the drugs we want to use we can't because of the other conditions.

The problem being that the multi-morbidity prevents adequate treatment because there aren't any special systems set up to deal with people like that. Most healthcare systems only deal with one problem. Pain clinics are used to dealing with people with multi-morbidity, with the elderly patients with pain with all of the problems and what we need is more access to qualified doctors, staff, nurses, psychologists who know how to manage chronic pain in the elderly.

Evans: Dr Chris Wells, president elect of EFIC.

Here's John Lindsay of Pain Alliance Europe once again.

Lindsay: One of the things about chronic pain when I think of it: it is the only condition that I'm aware of where you the patient tell your medical consultant that you have this condition. You're diagnosed with other conditions. If you have cancer, cystic fibrosis, multiple sclerosis, motor neurone disease, you are diagnosed by the physician.

Chronic pain is the only one where you go into your physician, your GP or your consultant and say, 'I have chronic pain, can you help me?' There are no diagnostic tools, so the medical profession just have to accept that what the patient is saying is 100% correct.

I was speaking to a consultant last night who specialises in the treatment or management of pain. He said in twenty years treating people with chronic pain, he has come across two people who, if you like, were 'con artists' who pulled the wool over his eyes. He said that's all, because people in pain are not going to wait six months for an appointment, are not going to go to pain management programmes, are not going to pain management clinics, are not going to attend workshops in self-management techniques. So generally for the person complaining, who says 'I have severe chronic pain', they have chronic pain and have to be believed.

Lisa Mickenan: I am Lisa Mickenan I come from Finland. I got a slipped disc in '98. I was just doing my thesis at Plymouth University and I didn't understand the problem was so serious and I didn't go and see the doctor in England, because I couldn't tell or say the names of the medicines which I'm allergic too. So I went to see the doctor in Finland and on that part I was using my own pain killers which affected my stomach and the doctor in Finland just tried to heal my stomach. And he didn't believe me when I said that there's a problem at my back – that something is wrong.

Finally, he gave me a paper to hospital, and on that paper he writes after: 'a little bit angry young woman wants to be referred to consultant.' I caused problems at the hospital again because the doctor didn't believe that the pain is as it is. The doctor just said that the pain can't be as bad as I said it is. Finally when they took magnetic pictures they found out there is a massive collapse between the vertebrae and they operated but the damage had already happened and I lost some nerves from my leg and also some muscles from my leg.

Lindsay: I think one of the biggest issues facing all people with chronic pain is not being believed: not being believed by your physician is very disappointing but not being believed by your spouse, your partner, your loved one, family, friends is really devastating and leads to isolation, loneliness and I know very recently there was a survey carried out in Australia where they have concluded that possibly as high as 21% of all suicides have a pain element related to them; that the person can no

longer live with the pain, so the whole area of not being believed, the isolation, the loneliness, family not believing is a really serious issue that needs to be dealt with.

Mickenan: I have lived with the pain now for 14 years, I would say I have lost everything I used to work hard and now I have no possibilities to work. I am a graduate from university but there is no use for my education. I can't have children, so I can't have family. I lost my income because I can't work, but I am one of the lucky ones: I haven't lost even one friend during these years, they are still there, good friends.

Evans: Lisa Mickenan of the Finish Pain Association. The issue of employment is one that was addressed by Stephen Bevan at the Societal Impact of Pain conference. He's director of work force effectiveness at the Work Foundation. It's a research and policy organisation based in London. And one of their projects, 'Fit for Work', looks at how musculoskeletal pain affects the health of the European workforce.

Bevan: Chronic low back pain is one of the biggest causes of sickness absences from work. It has a massive economic impact about £12 billion a year in terms of the wider European economy and it can also affect people's psychological well-being, their mental health and its one of those areas where physical and psychological health combine together and so chronic pain associated with things like fatigue have a big impact not just on and sickness absence from work but the speed with which people return to work. We've seen from some pan European surveys recently, for example, that the proportion of European workers who report that they are in jobs that require repetitive movements or require difficult postures, after a long period of decline, is now going up again in some occupations and so I think there are things about working conditions and the design of jobs and the design of the working environment that could still be improved to make sure that people are at lower risk of developing chronic pain caused by their work.

Most employers are very reluctant to think creatively about how they can make adjustments to the workplace to accommodate people with long term and chronic conditions and yet the evidence is that the cost of doing so is very, very small. I have to say that, if you are an employer and one of your existing staff has a new diagnosis, it's more likely that you are going to be more sympathetic and make changes to their working environment. But if you are recruiting and one of your candidates happens to have a long term condition that involves chronic pain it is quite unlikely that you will recruit them in the first place. So for me, the big challenge is to get employers with staff that already have these conditions to recognise the skills and attributes these individuals bring to the business and make very tiny adjustments – often that's all that's needed – and they are often very

inexpensive, and so the more we can do that, the more we can allow people to stay in work much longer.

Evans: Stephen Bevan of the Work Foundation.

I'll just remind you of Pain Concern's usual words of caution that whilst we believe the information and opinions on ***Airing Pain*** are accurate and sound, based on the best judgements available, you should always consult *your* health professional on any matter relating to your health and well being. He or she is the only person who knows you and your circumstances and therefore the appropriate action to take on your behalf.

Don't forget that you can download all editions of ***Airing Pain*** from www.painconcern.org.uk. You can also get CD copies direct from Pain Concern. All the contact details are at the web site including those to put a question to our panel of experts, or just to make a comment about the programmes via our blog, message board, email, Facebook, Twitter or pen and paper.

The last words from the 2012 Societal Impact of Pain conference go to Professor Hans Kress, President of the European Federation of the International Association for the Study of Pain Chapters, and, representing the host nation, Pia Frederiksen of the Danish Association of Chronic Pain Patients.

Frederiksen: I am so grateful; it's very important that such a big event as the Societal Impact of Pain is here in Copenhagen and also because our society in Denmark is far behind in this pain issue. So, we do hope that it will increase some inspiration for the politicians so they can see that it's a very big effort. We do have problems. It's not ok that so many of us are outside the labour market; it's not ok that so many of us end up on benefits or sick leave or early retirement. We really do want to contribute to society, but society has failed to help us.

Kress: We have been very proud that the European Commission for Health and Consumer Protection has taken patronage of our initiative, which shows that now we are also existing in the minds of our politicians. And we have at least achieved that not only the media but also the politicians have recognised that chronic pain is a problem for the future development in our societies and something that has to be solved by our national healthcare systems, and something that has also to be taken into consideration when we are talking about our strategic plans for 2020 for all our European countries.

Contributors

- * Professor Hans Kress, President of EFIC
- * Dr Beverly Collett Chair of the Chronic Pain Policy Coalition in the UK
- * John Lindsay, Vice President of Pain Alliance Europe
- * Justino Marasi, Manager of a company providing health care services in Italy
- * Anne Lloyd, trustee of the Patients' Association, UK
- * Dr Judith Hooper, Director of Public Health for NHS Kirklees and Kirklees Council
- * Dr Chris Wells is president elect of EFIC
- * Liisa Mikkonen, Finish Pain Association
- * Prof Stephen Bevan, Director of Work Force Effectiveness, the Work Foundation
- * Pia Frederiksen, the Danish Association of Chronic Pain Patients

Contact

Pain Concern, Unit 1-3, 62-66 Newcraighall Road,
Fort Kinnaird, Edinburgh, EH15 3HS
Telephone: 0131 669 5951 Email: info@painconcern.org.uk

Helpline: 0300 123 0789
Open from 10am-4pm on weekdays.
Email: helpline@painconcern.org.uk

To make a suggestion for a topic to be covered in *Airing Pain*, email suggestions@painconcern.org.uk

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