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Explaining unexplained pain to fibromyalgia patients: finding a narrative that is acceptable to patients and provides a rationale for evidence based interventions

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Running title: explaining fibromyalgia to patients

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### Abstract

As the cause of fibromyalgia is controversial, communicating with patients can be challenging, particularly if the patient adopts the narrative 'I am damaged and so I need a more powerful pain killer.' Research shows that providing patients with alternative narratives can be helpful, but it remains unclear what particular narratives are most acceptable to patients and at the same time provide a rationale for evidence-based psychological and exercise interventions. This paper described the development of a new narrative and the written comments made about the narrative by fibromyalgia patients. The narrative derives from a complexity theory model and provides an alternative to biogenic and psychogenic models. The model was presented to 15 patients whose comments about comprehensibility led to the final format of the narrative. In the final form, the body is presented as 'a very, very clever computer' where fibromyalgia is caused by a software rather than a hardware problem. The software problem is caused by the body adapting when people have to 'keep going' despite 'stop signals', such as pain and fatigue. The narrative provides a rationale for engaging in psychological and exercise interventions as a way of correcting the body's software. This way of explaining fibromyalgia was evaluated by a further 25 patients attending a 7-week 'body reprogramming' intervention, where the therapy was presented as correcting the body's software, and included both exercise and psychological components. Attendance at the course was 85%. Thematic analysis of written patient feedback collected after each session showed that patients found the model believable and informative, it provided hope and was empowering. Patients also indicated that they had started to implement lifestyle change with perceived benefit. Conclusion: fibromyalgia patients appear to respond positively to a technology-derived narrative based on the analogy of the body as a computer.

Keywords: Fibromyalgia, communication, adherence, empowerment, medically unexplained symptoms, illness model, qualitative, pain

Fibromyalgia (FM) is a potentially disabling condition characterised by symptoms of pain and variable other symptoms but commonly including fatigue, sleep disturbance, dizziness and gastric problems. Outcome is improved by evidence based interventions that have included individualised exercise and psychological components [1]. A recurring obstacle facing clinicians is that patients appear unwilling to adopt the recommended lifestyle interventions because they fail to comprehend the rationale for why such interventions should be helpful. The Explaining Pain approach[2-5] is based on the premise that if patients are provided with a narrative that explains their pain in terms of a perceived need to protect the body rather than a marker of tissue damage, then this story provides a rationale for patients to engage in the recommended interventions. There is evidence that using the Explaining Pain approach within a therapeutic framework improves outcome[2-5]. While research within the Explaining Pain framework is specifically associated with the treatment of pain, there is a wider body of literature showing that the patient's conceptual understanding or insight into the problem is a critical part of therapeutic outcome across all types of psychotherapy[6], and that the reason may be due to common factor mechanisms, now referred to as the 'contextual model'[7].

Any pain story needs to be acceptable to both patients and clinicians if it is to act as an effective way of communicating between the two. Research has shown a consistent divergence between patients and clinicians in the underlying conceptual of fibromyalgia, with patients[8-11], and this divergence contributes to non-adherence[12]. Whereas patients favour a biogenic model, they are often presented with a psychogenic model. Kenny[13] writes "Potentially healing interactions between doctors and their patients that do not rely on the biogenic model of the visible body or the psychogenic model of invisible pain are needed to assist the communication between chronic pain patients and their doctors" p. 297. The aim of this paper is present a model that satisfies Kenny's recommendation.

Any narrative also needs to be acceptable to clinicians. Few clinicians would be happy telling a pain story based on fairies, evil spirits, or the five element theory of Traditional Chinese medicine, not necessarily because of lack of evidence, but because the theories are inconsistent with modern scientific thought. A conceptual model needs scientific plausibility or clinicians will either not use it or their lack of confidence in the model will communicate to patients.

### **Scientific basis of the model**

The model is based on the assumption that complex, parallel distributed processing (PDP) systems have emergent properties that cannot be explained in terms of sequential causality of biological events. Instead, these emergent properties require explanation in terms of rules or algorithms that describe the functioning of the system as a whole in relation to its inputs and outputs. Complexity or PDP theory has been applied mathematically to biology[14] and forms the basis artificial intelligence particularly as applied to robotics[15]. If complexity theory is applied to pathologies such as fibromyalgia, then the explanation takes the form of algorithms that explain the formation and removal of distributed error that occurs over the whole network. The idea that functional disorders, such as fibromyalgia, represent a distributed error has been suggested over a period of time[16-23], and is consistent with the principles of systems biology that "The ultimate goal in Systems Biomedicine is to apply mechanistic insights to clinical application and to improve patients' quality of life", p.1 [24].

The algorithm that predicts fibromyalgia is called the *compensation rule*, the rule that the body adapts to (i.e., compensates for) its inputs – drug tolerance effects provide an example of compensation or adaptation[21]. The theory predicts that when pain or fatigue

symptoms fail to have their normally adaptive effect of behavioural inhibition, the body adapts by potentiating the non-responded to symptoms.

### **Explaining the model to patients**

The explanation of the model to patients was developed with the help of 15 FM patients, recruited through a pain management service, who contributed to the research as part of Patient Public Involvement (PPI). Patients varied in educational attainment and socio-economic background. During initial explanations of the model, it became clear that explaining the model to patients in terms of complexity theory worked poorly for the majority of patients. Feedback from the PPI patients led to modifications in the way the model was presented through a series of iterations, so that the model is now explained in terms of a hardware-software analogy. Whilst this is not strictly accurate it communicates far better with patients. Patients find it an acceptable analogy that the body is ‘a very clever, super-complex computer’. They are taught that bodies, like computers, can have two kinds of problem: a hardware problem or a software problem. Modern medicine is very successful at detecting and correcting hardware problems (examples are provided). Fibromyalgia is a software problem and to get better the patients need to change their body’s software. Patients are taught that their body’s software adapts to things that happen – both to make them ill and to make them better.

A simplified version of the explanation for fibromyalgia given to patients is as follows. Under certain identifiable conditions, the body creates ‘stop signals’ that prevent damage and promote recovery. These stop signals include pain, fatigue, nausea and dizziness. If, for whatever reason, the person is unable to respond to those stop signals – i.e., they don’t stop what they are doing - then over time the stop signals increase and become fixed, and the body is sensitised to anything that creates a stop signal (which includes but is not limited to being sensitised to stressors). An important part of communicating this idea to patients is to show that FM creates not ‘only’ pain but also creates many other symptoms, all of which are the body’s way of trying to stop them from doing things. The idea that FM is distributed over the whole body is demonstrated by using a patient symptom questionnaire with an emphasis on showing how the whole body has adapted to a challenging lifestyle.

Lifestyle advice is then linked to the predictions from the model as to how the body’s software can be changed so that the body self-heals. The underlying rationale is to do things that do not create stop signals. Patients are told that they should think of FM in terms of their bodies having ‘put the brakes on’. If they push too hard, the brakes just come on tighter. If they do nothing, then the brakes stay on. The narrative presents FM as being an active process as opposed to an analogy consistent with ‘the battery being flat’.

The term ‘body reprogramming’ is applied to any psychoeducational intervention based on the complexity theory model above. The intervention will differ slightly depending on the presenting symptoms as different kinds of life circumstance are predicted to lead different patterns of symptoms. In the case of FM, the aim of the ‘body reprogramming’ psychoeducational group programme is to empower patients to teach their bodies messages that can be learned only through experience. The two principal messages are:

- The world they live in is a safe place – where actions never lead to stop signals and in particular the stop signal of danger (e.g., movement does not equate to danger). Interventions include relaxation (e.g., mindfulness) and slow graded exercise, but with an emphasis on combining physical movement with a positive mental state.
- The world they live in is a good place – where actions are rewarding as well as being health promoting. Interventions include strategies for reducing negative cognitions and promoting positive cognitions, with an emphasis on behaviour change so as to produce a more rewarding and health promoting lifestyle.

The body ‘learns’ these therapeutic messages through a combination of physical exercise and psychological techniques that are individualised and consistent with evidence based techniques[1]. Patients are also taught about healthy eating and reduction in analgesics. Body reprogramming can be considered a large step in understanding but a small step in practice: neither the psychological or exercise components are entirely novel.

### **Methods**

Ethical approval (NRES committee South West, ref. 14/SW/040) and institutional approval (ref. 14/P/086) was obtained to run three pilot body reprogramming courses, and obtain data on the experience of patients. Patients attending the pain management clinic for the first time were provided with information about the course during an assessment interview with a psychologist. Inclusion required patients to be willing to experience an intervention other than that of medication. There was no attempt to recruit patients specifically by gender or age, and recruitment reflected the type of patient normally attending the clinic. The course was structured to run over seven weeks (two hours per week). The sessions were: (1) explanation of the model, (2) relaxation techniques, (3) mood enhancing techniques, (4) exercise, (5) diet and medication, and two sessions on individualised implementation using patient-specific insights from the model. During the first two courses patient attended without family support, but due to patient request, significant others (family or friends with a maximum of 2 per patient) attended the sixth session in the third course. Twenty five patients started the programme (22 female, 3 male); one patient withdrew after the first session due to discomfort with the group setting. The remaining patients attended all sessions except where illness prevented attendance, with an overall attendance rate of 85%.

Patients were invited to provide ratings and provide written comments after each session and from significant others for the session they attended. These written reports were anonymous. The ratings included an evaluation of the usefulness of each session, based on the scale 1 = not useful and 7 = very useful.

The written reports were transcribed verbatim, and after thematic analysis, the WORD file was searched for key words pertaining to the themes relevant to the patient’s response to the model. Sentences containing these key words are reported.

### **Results**

The conceptual model was presented in the first session and the usefulness of this first session was evaluated by 25 patients: one gave a rating of 3, three gave a rating of 5, three gave a rating of 6 and eighteen gave a rating of 7 (1 = not useful, 7 = very useful). The patient who rated the usefulness of the first session as 3 wrote in the comments section ‘a few overpowering others’ and it is possible that this patient was the one that withdrew and the comments relate to discomfort with a group situation.

Patients commented on a number of aspects of the course, but the principal themes were that the model was informative and believable, that the model provided hope and that the course was empowering. A final theme concerned implementation.

*Comments relating to information and belief:*

Patient: Very informative. I’ve learned so much in such a short time, thank you.

Patient: Very informative and so refreshing to find answers to problems I’ve had for over 14 years and wonderful to be able to self believe “It’s not in my head” as I’ve self doubted so many times. I was even questioned why I had a walking stick, which I personally found incredibly hard.

Patient: So I am so glad to have had this opportunity to learn about the Hyland model. Thank you.

Patient: Helped with the understanding of the symptoms and medication usage.

Relative: Informative treatment that combines natural chemicals in the body and the mind. Interesting! Recognises that modern living is a construct that can have unforeseen consequences for health.

Relative: There has been a lot of useful information that will assist in my partner's recovery. Previous medical interaction has led to a lot of dead ends; this has been the first truly positive and progressive interaction.

*Comments relating to Hope*

Patient: And is a little hope that maybe one day I could be pain free.

Patient: Helping us on a hopeful journey for a great future with dealing with a condition that's not very nice.

Patient: It gave me hope and improved my understanding

Relative: This has been a revelation and has given our family 'hope' where we thought there was none. This illness has not only affected my daughter but the whole of our family. We have spent years trying self help, but it felt like we were just stabbing in the dark.

*Comments relating to Empowerment*

Patient: Although I felt unwell I felt empowered after the first session.

Patient: I felt very empowered after these techniques as I am putting into practise what I have learned.

Patient: The group has empowered me to do this. I feel I am no longer alone

Patient: Coming to these group session has empowered me to have a REAL understanding of my illness and it is an illness that maybe invisible but I have to live with it and my family and friends have learnt to understand me, it is real.

*Implementation*

Patient: I have implemented changes already, such as drug reduction, and more exercise. Also, I have also learned about relaxation and meditation. Meditation has now become an everyday part of my life.

Patient: Was a good session having my partner here to learn about what we have done so far. He has already thought about ways to implement at home.

Patient: I've spoken to my husband and he has a little understanding of the group and what the changes we as a family need to implement.

Patient: Others are need(sic) to implement changes.

Patient: I listed my daily routine and also what is important to me and I found that although there problems there were also ways of implementing what was important to me.

Patient: From previous sessions I was able to tell my partner and express when I need to implement to make ME feel better.

Patient: This session has helped me to see how much I am already doing to implement change without actually realised it.

Patient: I feel now that I have all the tools I need in order to put in the work to change.

There were no negative comments about the model, but there was one negative comment on the group situation.

## Discussion

Pre-selected patients referred to a pain management clinic found a computer based conceptual interpretation of their illness to be believable and informative, and that it provided hope. Additionally, patients reported the body reprogramming course to be empowering.

One of the striking features of the way patients respond to the model is how many immediately feel that the model is true. It would appear that technological analogies are just as acceptable as a form of explanation to patients as biological ones. Of course there has always been a link between the biological and technology in medicine – at least, since Harvey made the radical suggestion that the heart was a kind of pump. However, the suggestion that ‘the body is a clever kind of computer’ seems to resonate in some way with the way people conceptualise the body. Another reason why the model may be so readily believed is that it is empowering since it portrays the patient in a positive light, for example, someone who has managed to keep going despite challenging circumstances. Finally, the demonstration that patients have multiple symptoms which can then be explained by the model may have provided additional support for the model.

One of the challenges facing health professionals in communicating with patients is that the illness is often perceived as diagnosed by exclusion. When doctors say ‘I can find nothing wrong with you’ patients can interpret this as ‘You are not really ill’. Thus, the model not only provides an explanation of why the patient is ill, but at the same time explains why the doctor has not been able to ‘find anything wrong’ or a ‘broken component’ – because the problem is a software problem rather than a broken component. It is interesting to note that earlier doubt about the ‘reality’ of the illness was reported by one of the patients. Providing an appropriate conceptual model makes the illness ‘real’. Making the illness real is important to patients which may explain why patients reported that they found the model informative.

Hope is an important facet in the experience of chronic pain[25]. When patients have no explanation of their illness, they do not have a conceptual model of how and whether they will ever get better. Thus, providing patients with an illness narrative provides information not only about the route into the illness but also the route out.

Patients found the course to empowering. During the course, patients are provided with a rationale for the lifestyle modifications that could help, but they are not given specific instructions about what to do. Instead, the patient uses the narrative of their illness and recovery to individualise their own route out of the illness. Individualisation is known to be important feature of recovery in fibromyalgia[26]. It would appear therefore that providing patients with a conceptual understanding is an important route to empowering patients to make their own decisions. Rather than empowering patients by giving them choices, the use of a conceptual model provides patients with a way of individualising those choices to their own particular circumstances.

Finally, patients reported that they were implementing the changes that promote recovery, but there was reference to the importance of others in implementation. The need to include relatives as part of the course was reported in the first two courses and led to the change where they were included in the final course. The family is an important component in lifestyle change for FM patients.

### *Limitations*

Patient reaction to the conceptual model was limited to those who had expressed a willingness to engage with a non-biologically mediated intervention. It remains unclear to what extent the technological analogy is accepted by patients who have well established views that their symptoms relate in some way to damage. This is a single centre study and the model was explained by clinicians with enthusiasm for this approach.



### Conclusions

The patient's conceptual model of what is causing their illness is important to the clinical outcome of the patient[2-7]. The need for an alternative to the biogenic and psychogenic models has been identified[13]. This study provides evidence that a framework incorporating a computer based analogy provides an acceptable story that helps FM patients understand their illness and motivates them to engage in evidence-based lifestyle adaptations that enhance recovery.

Body reprogramming is an intervention based on the conceptual model above. Several existing therapies are consistent with and can be used as part of body reprogramming, in particular third wave CBT, acceptance and commitment therapy, compassion focused therapy, and mindfulness, as well as individualised graded exercise. The model provides a single, holistic framework for understanding why multiple lifestyle changes are needed to promote recovery, rather than having different rationales for, for example, psychological and exercise techniques.

In addition to providing the conceptual model, body reprogramming empowers patients by providing choice. For example, although patients are introduced to mindfulness, they are also introduced to other relaxation techniques and advised to select the technique that suits them best. The model provides a guide as to how lifestyle changes can be individualised depending on the particular circumstances of the patient. Body reprogramming can be applied to other functional disorders, which, according to the model, also result from a distributed pathophysiology[22] and are therefore best understood in terms of a complex system. Whatever its application, body reprogramming should be individualised as it is based on the premise that lifestyle and life circumstances (which differ between people) play a major role in the formation and recovery of functional disorders.

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