Making sense of aches and pains

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**Background.** The uncertainty about the status of upper limb disorders (ULDs), particularly the non-specific conditions, is believed to have consequences for clinical management and patient care.

**Objective.** This paper presents evidence about how sufferers with ULDs respond to their pain, how their pain is managed, when and who they go to for formal help and how sufferers evaluate the care they receive.

**Methods.** The data analysis is derived from face-to-face, informal interviews with sufferers with a broad spectrum of upper limb disorders (*n* = 47). These informants were selected according to strict criteria from a ‘screening’ postal survey of the working population (25–64 years) in south-west England (*n* = 2781).

**Results.** Ideas about causation were crucial to understanding patterns of illness action and help seeking behaviour. The common strategy was to wait and see what happens as the pain was believed to be a natural part of the ageing process. Explanations invoking psychosocial and work related causes were less common and tended to be used when biomechanical explanations were no longer appropriate. Self-management was the preferred strategy but orthodox practitioners were usually the first choice for formal care. Complementary and alternative medicines (CAM) were popular but were used to complement orthodox care. Practitioners were evaluated mainly in terms of their ability to alleviate pain.

**Conclusion.** There is a need for orthodox and non-orthodox care to be closely integrated in primary care and GPs should not depend on orthodox medications alone when caring for patients with upper limb pain.

**Keywords.** Health service use, illness behaviour, lay beliefs, upper limb disorders.

**Introduction**

Upper limb disorders (ULDs) are a major source of morbidity, are relatively common,1,2 and can often lead to lost time from work and significant use of health services.3,4 They consist of soft tissue rheumatic disorders that fall into two broad clinical categories:4 specific disorders (such as carpal tunnel syndrome) and non-specific (often chronic and troublesome) pain. However, these conditions are heterogenous by nature and casual use of terminology has fostered confusion. For example, a variety of labels such as ‘repetitive strain injury’ (RSI), ‘cumulative trauma disorder’ (CTD) and ‘work related upper limb disorder’ (WRULD) have been employed, in particular, when a causal relationship between symptoms and work activities has been suspected. These labels are seen to be unsatisfactory5 for a number of reasons, not least because clinically indistinguishable disorders may arise for non-occupational reasons. Also, labels like RSI and CTD assume a particular causal mechanism, but repetitive movement and cumulative trauma may not necessarily be causal.

This uncertainty about the status of ULDs, most notably the non-specific conditions, has consequences for management and treatment and understanding causation.6,7 This uncertainty may also present a challenge to the patient and their sense of identity.8

The bulk of the research into ULDs has focused on identifying ‘scientific’ explanations of cause. The ‘scientific’ discourse on upper limb disorders has identified a range of possible causes of upper limb disorders. One of the most common has been the working environment either directly causing or aggravating the problem.9 High levels of exposure to physical factors (e.g. repetitive lifting of heavy objects, in extreme or awkward postures) are the most common

Received 10 December 2004; Accepted 6 July 2005.
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explanation for work-related upper limb disorders.\textsuperscript{9,10} More recent research argues against over-reliance on physical or biomechanical explanations for upper limb disorders and for the need to take into account the psychosocial make up of the individual, their ability to cope with their working environment and the importance of the role of job stress and psychosocial demands.\textsuperscript{11,4} Some researchers have argued that the effects of these conditions are exacerbated or even caused by job dissatisfaction and anxiety, or that workers with boring, repetitive and low paid jobs convert psychosocial dissatisfaction into physical experiences of pain.\textsuperscript{7}

There is little understanding, however, of how sufferers with upper limb pain manage their problem, when and where they go for help and how they evaluate the care they receive. The little research that has been carried out into sufferers’ experiences has involved those at the end of the continuum with non-specific labels such as RSI.\textsuperscript{12,13} The study presented here examines the broad spectrum of upper limb pain, including those with specific and non-specific pain. More specifically it explores the pathways through healthcare followed by ULD sufferers and how they negotiate them.

Methods

As it was proposed to obtain information from a broad range of informants and to compare the experiences of sufferers at different points in the course of management, diagnosis and treatment the design consisted of a community screening survey followed by face-to-face, informal interviews with a purposive maximum variation sample of ULD sufferers.

The community-based screening survey was carried out on a random sample from the working population of patients registered with a sample of five general practices on the list of one primary care trust in south-west England. Practices were purposively selected for maximum variation, including practices with both large and small partnerships, practices serving both deprived and affluent patient populations, training and non-training practices and those based in rural and urban areas. A random sample of 5000, aged 25–64, was selected and the probability of selection was constant across the practices. Of the original 5000, 75 were excluded because of death, moved away etc. The final response rate after four mailings (the initial mailing plus three reminders) was 56\% (2781). The survey was carried out in the winter of 2002–2003.\textsuperscript{14}

The aim was to select informants at different points in the pathway from initial awareness of symptoms, through to consultation, diagnosis and treatment. Thus, the sample included ‘new’ cases as well as those which were more long-standing. However, the pilot study ($n = 16$) revealed that informants with relatively severe and long-standing upper limb problems reported information which was more relevant to the studies aims and objectives than those with comparatively minor complaints. The purposive sample thus was weighted in favour of those with more severe and long-standing problems. Patients who had consulted health care practitioners and patients whose difficulties might be work related were also of specific interest and the sample was also weighted to include those who consulted a health care practitioner and those who are in paid employment.

Fifty informants were selected for follow-up according to these criteria based on questions used in the screening questionnaire: ‘experienced arm pain during previous 12 months’ (50\% of postal sample); ‘duration of arm pain’ (a month or less or more than a month); ‘disabled or not’; ‘consulted a health care practitioner or not’; ‘in paid employment or not’. ‘Disabled or not’ was scored on the basis of responses to questions about level of difficulty in carrying out five activities of daily living. Figure 1 shows the different characteristics of the sample selected for follow-up interview and the number of informants in each category. The informants were randomly selected for each category from the sub-sample identified through the screening questionnaire. All the informants also reported that follow-up was acceptable. It was only possible to interview 47 of the 50 who were contacted, of whom 32 were women and 15 were men and the age range was from 27–64 with the majority (31) being aged between 40 and 59.

Interviews were carried out by the researchers in the informants’ homes and were audio taped and transcribed. The interviewer was guided by a list of topics and questions which were derived from different cognitive stages in the illness action process\textsuperscript{15,16} and pathways through health care e.g. initial recognition and interpretation of the problem, decisions about what to do about the problematic experience, self management and when, where and why help was sought, experience of the consultation with a health care practitioner, management and treatment and their consequences. However, the interview was flexible and informal in order to reveal essential themes of the individual’s experience.\textsuperscript{17}

The interviews were independently analysed by two of the authors and initially involved the examination of a sample of transcripts to identify the principal themes. Coding schemes were then compared and common category and theme definitions agreed. The transcripts were coded by the researcher using the constant comparison approach, comparing interview text with agreed theme and category definitions, with close collaboration over subsequent revisions of the coding scheme.\textsuperscript{18} Atlas.ti software was used to facilitate a
systematic inspection of text coded under each category. Exceptions to the framework were sought and the framework was modified to take account of them where appropriate.

Data was also collected from the practitioners (both orthodox and non-orthodox) who managed and treated the patients, their medical records and from a physical examination of the informant’s condition after the interview. This data, along with information collected from the informant, was used to construct case studies of the pathways followed by patients through healthcare.

Results

The uncertain and non-linear character of lay experiences of illness posed a problem for the presentation of empirical data; should the perceived causes of upper limb pain which may change over time or the experiences of the first clinical consultation, which may come quite late in the course of an illness, be discussed initially? To overcome this difficulty the natural history of the illness was followed, but the shifting conceptions of aetiology, diagnosis etc was examined at each point in the pathway. The presentation of the data thus began with the point at which the informant decided that something was wrong, i.e. the subjective interpretation of the problematic experience (see Fig. 2).

Interpreting symptoms and making sense of what is wrong

Informants who reported arm pain tended to recall that something was wrong in terms of the sudden onset of physical pain. This recognition of the problem usually occurred once the pain had actually prevented them doing something routine at work or around the house. The informant’s theory of onset was frequently that it was sudden and unexpected:

“No, don’t remember doing anything, I just got this very severe pain and I couldn’t lift my arm. It lasted for two or three days and then I went to see the doctor.” (B2052)

The onset of symptoms was often linked to a very specific activity, for example:

“Well it was at work actually, we were moving a patient, and I felt and I thought, oh gosh that hurt a bit, the hoist wasn’t working at the time and I just thought, oh I’ve done something with my shoulder and it just got worse and went on really. I guess cos I didn’t rest it, it just aggravated it really.” (A1018)

But the informants themselves also kept in reserve a number of other possible explanations and if the sudden over-exertion theory no longer made sense as the
symptoms persisted they resorted to recalling the condition gradually building up over time:

“My aches and pains started after it . . . I was very ill with a high fever and shortly afterwards I started experiencing these aches and pains. But then the symptoms went away and the pain started.”

Interviewer: “Do you think they are related?”

“Yes, well the doctor did say that sometimes that’s how these things start. That’s why I think it. He said did you have any severe and sort of happening a traumatic happening in the last six months and I said the only think I could think of that was unusual was the symptoms of the virus.” (N2119)

Wait and see: ‘it’s natural wear and tear’
Deciding to ignore the early stages of the pain experience on the assumption that it would pass was the most common response, unless the informant had some reason to suspect a definite pathology. Informants who associated their pain symptoms with a family history of MSDs like arthritis, or with a heart condition like angina wanted to rule that out quickly:

“The reason I was concerned about angina, was because my father when he was in his fifties started to suffer from angina, and my mother died when she was 77, and I thought oh dear is the something that I have got to look forward to as I get older.” (G2248)

Other informants with arm pain were, on the whole, not unduly worried by their symptoms and were generally more likely to adopt a ‘wait and see’ approach and attach a great deal of value to ‘working through the pain’ at least in the early stages:

“I thought it was all muscle pain that I would have to wait to recover from.” (N2119)

The decision to adopt a ‘wait and see’ approach was most commonly used by informants who would not consult their GP at least until they had allowed what they saw as a normal amount of time for natural healing to occur, i.e. they believed that the symptoms were temporary and would pass, and also that the symptoms were a natural part of the ageing process:

“I try to only go when I am bad. I usually wait a while and see if it wears off but you get aches and pains at my age. Basically I work with the rule that what can clear up by itself isn’t serious so I wait but if it is something specific I don’t go until I have condition, and my father died when he was 64, and my mother died when she was 77, and I thought oh dear is the something that I have got to look forward to as I get older.” (G2248)
tried simply waiting it out and treating myself.” (A2954)

Informants also invoked a ‘moral’ dimension to the decision in that those who waited to see what happened presented themselves as stoical and strong and regarded persistent help seeking as a weakness:

“I would rather not make a meal of it . . . I think that if I stick my head in the sand, then perhaps I can manage . . . I am pretty bloody-minded and I am not going to let it beat me . . . Yes I could indulge and feel sorry for myself and sit around all day and do nothing and probably create a lot more health problems for myself.” (A4324)

The ‘wait and see’ strategy was also used by informants who were reluctant to visit health care professionals. Most instances of reluctance to consult were based on the assumption that the GP was a very busy person and arm pain was something that, at least until it has become persistent and disabling, was not a priority. Informants attempted to work out when something was a legitimate complaint worth bothering the doctor with. In addition, they were more likely to be able to access other sources of information and saw self-treatment as a more legitimate approach:

“I mean generally being a sort of proactive person if there is something I want to find out about I will go and look myself, knowing how busy doctors are, I would rather go and look on the internet that’s probably the primary source as far as I am concerned rather than go and bother them.” (A3033)

Informants were also concerned about wasting the doctor’s time:

“Yes because as I said it is an ache more than a pain. Like most men I don’t have a low pain threshold. I try and keep away from the doctor because I know they have got enough to do. I try and work on the principle that if I go to the doctor there is something wrong.” (I3994)

Of course, there were informants who did not want to consult because of previous experiences with the medical profession and were unwilling to expose themselves to what they expected would be poor treatment:

“I suppose it’s personal reasons really it’s a lot to do with the fact that I lost both my parents quite close together and I became sceptical about going to the doctor’s. That’s why.” (I3127)

But other informants preferred not to consult about their arm pain on the assumption that nothing could be done about it:

“I can’t remember discussing it with Dr X because mmm I may have mentioned it at sometime but it’s just something that seems to go on and em I just work with it I suppose. I don’t really expect anything to be done about it to be honest. I expect he’d give me some more pills or something but its not as if, its not like you need to take painkillers its just annoying . . .” (N935)

Self-management: the preferred strategy

Most informants tended to have at least tried some self-treatment before approaching health care practitioners for help. The self-treatment adopted tended to involve the use of creams and pills as well as lifestyle changes. The common explanations for the pain that were considered by most of the informants, prior to visiting the health care provider, were their posture and ergonomic factors at work. Thus they tried out new grips on sporting equipment, lightweight kitchen utensils as well as wrist supports for typing:

“Yes. I bought a specially designed mouse mat, which is quite good as it supports the wrist. If I had more room on my desk I would get one of those things that would support your wrists as well when you are typing.” (I3127)

For the most part though the pain was not perceived to be bad enough to warrant a major change in lifestyle and none of the informants here recalled giving up anything completely because of pain in the upper limb. Many had designed their own system of exercises to get the blood circulating again since the pain was often seen to act like cramp:

“Nothing to moan about. Each time it has been after I’ve been lifting and working like this [raise arms above head] doing fitting and things in someone’s house and then I might get a twinge. But I have learned by now just to swing my arm around. Sit down have a cup of coffee and I’m all right.” (M980)

Most were just resigned to getting on with it and rather than pay too much attention to it they preferred to self-treat with painkillers:

“Only when it gets bad, because I know how to deal with it, I take the tablets and I take the Ibuprofen if things are a bit sore, I put Ibuleve on the left elbow, so I haven’t bothered to see the doctor, because I know there is not really a lot they will do, except perhaps give me another injection.” (A3033)

Reluctance to draw attention to the problem was often motivated by fear of being seen as a problem employee, particularly among the older women in the sample. For example, this woman had so far resisted her doctor’s advice to take time off work because of the pain, and in fact admitted that her initial reluctance to consult was
partly due to her expectation that that was exactly what he would advise:

“No, just in the end I knew I had to do something. I know it sounds daft but I don’t want to have time off work, and I was frightened he was going to say I’d have to have time off, and because of my age I don’t want that label of oh she’s getting old.” (A1217)

**Pain management rather than diagnosis**

The most common reasons for consultation cited were the exhaustion of self-treatment options with the pain getting worse and the perception that this pain was different to more common ailments like a pulled muscle, and needed to be treated in a different way. The first port of call for these informants tended to be the GP’s surgery.

It was common for informants to report that they had not received a diagnostic label for their upper limb problems. However, failure to get a diagnosis did not usually cause too many problems for informants because it did not preclude the possibility of treatment. There was an awareness that pain conditions could be very difficult to diagnose and in fact this was often what discouraged them from seeking medical advice in the first place. A diagnosis, where one is given, was often perceived to be based on cursory examinations and discussions with medical practitioners:

“I said I had dreadful pains in both my shoulders I said it was hard to move my head and my hands and he just said: ‘Can you fasten your bra?’ I said no. He said: ‘Can you put your hands above your head?’ I said no. He said I think you’ve got this myalgia and that was it. It was as simple as that.” (N2119)

Different types of problems arose when the informant adopted the ‘shopping around’ approach, visiting a number of different practitioners who offered different diagnoses or different treatments. Sometimes this arose where the informant was referred to another specialist by their GP:

“So I go there and they X-rayed it and they came up with osteo-spondylitis. That’s when they put me in the collar and in about a week or less my neck had frozen solid, so my doctor got me back into the hospital to see the physio. And the first thing they said was, you shouldn’t be wearing that collar. So there is a conflict in there of information.” (B3577)

This caused problems for informants who were then unsure about what treatment regimen to follow or who to believe:

“The trouble is I found with the, I forget whether it is the physio or the osteopath and they explain exactly what is wrong and they say this will hurt, and it sounds so logical that you come away thinking that that is definitely the problem. And they give you a set of exercises and then maybe a year later you go to somebody else who give you a completely different diagnosis, and it sounds equally plausible and so one of them says to cure it you should twist that way and the other one says to cure it you should twist that way and you believe them both.” (K4825)

Most informants ended up adopting the explanation for what is wrong that was associated with the most successful alleviation of symptoms.

If the informant attended the surgery with recurrent symptoms then they were likely to be offered x-rays in the first instance and then either steroid injections or physiotherapy. To some extent this depended on the informant’s preference and in all cases where steroid injections were used informants were given a choice. Although a number of GPs seemed to prefer steroid injections as a quick solution and for pain-relief especially where the waiting times for physiotherapy appointments were long and the informant did not have the resources to see one privately:

“I saw the GP that gave me a hydrocortisone, and he said oh we have found it very successful but we have found it can take a month to work, but actually it was about three months so I didn’t really think that it had made any difference at all.” (A1422)

Although it was often the first type of treatment to be offered, the injection of steroids was not always successful as the above quotation shows, and informants also expressed a certain amount of ambivalence about taking steroids if they think there was an alternative:

“And so eventually I went to the doctor’s surgery and they offered an injection, a cortisone injection, I didn’t really want to have that because they said it wasn’t always that successful, and so I asked if I could have some, well they suggested physio as well, so, but then the waiting weeks for the physio was quite a long time, so I suggested that I might perhaps go privately so I went up to the BUPA hospital quite honestly it didn’t improve at all really, I didn’t find it improve.” (M1775)

On the whole most informants were happy to follow the GPs advice about steroid injections or other forms of treatment and would have the injection at least once. When this treatment was deemed to have been unsuccessful physiotherapy was often tried. Most informants who received NHS physiotherapy only had access to two or three sessions and then had to either continue the prescribed exercises at home or continue to see a physiotherapist privately. The priority
for this group of informants was symptom alleviation so when physiotherapy proved “unsuccessful” they were often quick to seek out a chiropractor or other complementary therapist.

The attraction of CAM: a pragmatic approach

Complementary therapies were not usually the first port of call for treatment by informants, unless they had had previous experience of their successful treatment of an earlier problem or their use was a result of lay referral. Informants who used complementary therapies tended to adopt a pragmatic approach to their use and it was sometimes the result of dissatisfaction with the medical care on offer:

“I had a chiropractor. A friend of mine a boyfriend of hers was a chiropractor and at one point I was in so much pain I couldn’t do anything. It was straight across my shoulders and it even affected my breathing my chest felt really tight I really was in a very bad way so that time he rubbed my shoulders and my back and the pain just went away it was incredible. It just really was so I would go and do that again but I certainly wouldn’t go to the doctor [again]. I don’t think the doctor could help or would help.” (I3127)

Most informants who tried complementary therapies do so by combining them with more conventional approaches i.e. taking painkillers and attending for massage, reflexology or osteopathy. In these cases informants were searching around for the approach that could best alleviate their pain:

“I have tried every treatment that is going bar going under the knife, which I don’t really wanna have to do if I can get away with not going under the knife then I will try anything, and I tried acupuncture a little while ago.” (I2007)

There was no sense in which a complementary approach was favoured on philosophical grounds or in terms of the holistic nature of the care process and there were factors that boosted the position of orthodox medicine over CAM, particularly their accessibility to technology such as x-ray and MRI scans. However, informants saw no harm in dipping in and out of a variety of approaches:

“I had just heard that it [a copper bracelet] was supposed to be good for, I don’t know if there is some property in copper whether they can seep into the skin and radiate, but I just read that it’s, and you see people with them and I thought I will give them a try.” (C293)

and

“I have had acupuncture, I have had aromatherapy too, but it doesn’t work on me, I went to two aromatherapists and they said they had never met somebody so resistant, which I can understand because I don’t believe in it. I mean I know it works for other people.” (A4324)

As these two quotations show, many sufferers did not understand what was involved or even believed in them, they were nevertheless willing to try them. This was perhaps one of the most striking things—the lengths to which informants would go in search of a cure. One woman who was an amateur musician in a local orchestra even talked of seeing a faith healer although she had no personal religious beliefs:

“I’d only go to him if I was in really serious pain and nothing else was helping, because I have a great belief in doctors and medicine . . . The reason I used it that one time was that you know, was that I just wanted to get through that particular performance and I wasn’t bothered.” (F2865)

Some informants who had not tried complementary medicine would be willing to do so if they felt that practitioners were regulated in some way or even if they felt their GP advised it. These informants did not want to risk doing something that might later prove dangerous:

“I would actually like to look at alternative therapies, complementary therapies, I guess the difficulty is finding a practitioner who had a reputation, than look for something in the Yellow Pages because I do see the standards of education and the level of student competence in some of the complementary therapies is more variable . . . I am more concerned that there might be a greater chance that there is somebody that is less well qualified, or less competent . . . And there is no question about it that would make a difference to me, between going with confidence and going with apprehension.” (A3200)

The financial outlay involved in seeing an alternative practitioner means that it was only when the pain has become quite bad that the cost could be borne:

“Yes, be guided by the doctor or however for the best possible option, if it is recommended that I visit a chiropractor and it might cost a bit, I do have some health care insurance that does pay a proportion of the fee.” (A1262)

and

“No, oh, I went to see an osteopath and I explained my financial situation as well, and then when he looked at me like this, he said oh sorry I can’t do nothing for you, thirty pounds please, so it put me off going to these people.” (B3577)
Informants who had seen a complementary therapist were generally satisfied with the care they received and saw it as a useful addition to their health care regimen. The most popular practitioners were chiropractors and acupuncturists. Chiropractors were seen to have a specialist insight into the bones and joints that a GP, as a generalist, did not have:

“Anything to do with my back or anything like that I don’t consider the doctor. I don’t think to be quite honest they have had the training in back pain. I mean the don’t how can I see, they don’t treat the symptom—take painkillers and rest—with chiropractor will actually treat your injury, whereas a GP doesn’t treat your injury, it is just oh yeah you have got this or you have got that.” (E4556)

They also offered more time and were easier to access than Rheumatologists and other hospital specialists. Acupuncturists were particularly popular because they provide pain relief without drugs.

The risks of orthodox medicines
Informants who suffer with upper limb problems were unhappy about the long-term use of painkillers and tried to avoid their use where possible. The fear of painkillers was based on the belief that they could be addictive:

“Some of the painkillers that I take are very, very strong and I only take them as and when I really, really need to because I just don’t wanna get hooked on them, and then get addicted to them, but I try to manage without but then when it gets that bad I can’t.” (I2007)

There was also the assumption that if the informant used analgesics too often in the early stages when the symptoms got worse they would have nowhere left to turn. They would have become immune to painkillers and there would be no other treatment available to them:

“I won’t take more painkillers, I could ask for more if I wanted but I don’t, I take one Ibuprofen a day because I have noticed that after a while they no longer work, the more you take the more you need and I don’t want to go down that road. . . . If I have got to be together I will take them if I have got something important to do. But the rest of the time I just live with it. I did have a TENS machine but I don’t think that that works terribly well, not for me anyway.” (A4324)

Another major reason for trying to avoid painkillers was the fear that masking the pain would do more harm in the long term. This was where the problems caused by lack of a clear diagnosis became most obvious. A number of informants did not know what was causing their upper limb problems but were fearful that their problems were possibly a sign of serious pathology. To take painkillers that would enable them to carry on as normal might have meant that they were simply storing up trouble for themselves or even making things worse:

“Well I was wondering if it was anything more sinister than just an ache, and whether or not there was a diagnosis that could be made . . . I was seeking treatment in that respect, rather than just having pain control. I wanted to know the reason before I started taking the painkillers, it is all very well taking painkillers, but in the end you have got to treat the cause and not the symptoms.” (G2248)

Another common response to upper limb pain was to start using dietary supplements. The most commonly used supplements were cod liver oil and glucosamine. Most informants had tried both of these at some point in time although none had any clear ideas about the way in which these supplements might work yet many continued to take them on a regular basis:

“I was doing those capsules for yonks, like. Because those things are long term anyway, and I didn’t feel any benefits from it to be quite honest.” (B3577)

Some informants even said that although they took these supplements they did not believe in the explanations about how they worked:

“I don’t believe in it . . . you shouldn’t have to, not if it actually works. I mean I take Aloe Vera, you know I will take it but I haven’t noticed any difference.” (A4324)

The supplement glucosamine is held in a different regard by informants and was considered by everyone who tried it to have given them some relief from pain. Although again they could not explain why they thought it worked:

“I was just out and about delivering flowers and I was delivering to this lady in this flat and I used to ask her how she was and she had just had a knee operation and a friend of hers took these tablets and she said if she had heard of them before she would have tried them before. So I asked her the name and I tried them although they are expensive to buy they are brilliant.” (E2833)

Many of the informants who took glucosamine did so on the advice of friends and thus based their decision to use it on anecdotal evidence. However, there was some evidence that glucosamine in particular had taken on the status of a prescribed drug. In some cases informants said that their GP had recommended it and others cited ‘scientific’ evidence:

“Eventually I happened to read an article in the Mail on Sunday on the health page about
glucosamine sulphate and I thought, nothing ventured nothing gained you know. And I started doing that and at the time I did have a little pain in my knee, nothing much and a little twinge in my ankle – nothing much, and literally within weeks that just went, and but it took about a year before I had any real improvement in the arms, and since them it has been fine . . . as little ago as three or four years ago they were saying what a load of rubbish, they are not saying that anymore, there has even been a write up in the Lancet about it and there is real proof now that it really is helpful, and it is regenerating worn out muscle tissue, and they are no longer dismissing it.” (E2389)

Redefining the problem: invoking psycho-social explanations
Initially the pain and other symptoms including swelling and tingling were understood by informants as the result of some transitory biomechanical dysfunction which primarily resulted from wear and tear. When the symptoms failed to respond to treatment and persisted or even got worse then this understanding was called into question. The informant had to redefine their health problem from one that was transitory to one that was probably permanent. Once the condition becomes persistent and entered into a chronic state the informants displayed a greater willingness to explore other explanations such as stress as a psychological factor in causing pain although they tended to begin with an understanding of the physical aspects of stress:

“Well, yes, I think it does because your neck bunches up and the muscles tighten and I don’t think that helps. And yes any stress will exacerbate any sort of condition.” (A4324)

Later on a more psychosocial understanding of stress was often introduced and informants who had been dealing with their condition for some time prior to interview suggested that pain could be psychosomatic and realised that being anxious could make things worse:

“I had just sold my own cottage and it was just hideous what I went through, it took me about three years really, to even begin to even feel emotionally better. But as I got emotionally better, some of my aches and pains got much better as well. It’s only recently that I’m aware that it was a lot to do with stress. Its almost as if it ate away at me. And being shouted at was like being physically slapped.” (B3590)

Informants who invoked stress as an explanation tended to do so as a result of a suggestion by the doctor or other health care worker:

“They always ask about stress, and I was with a very difficult partner I was stressed most of the time, in fact when I went to the specialist he was asking about the stress in my life, and he sort of questioned me a wee bit, and he said I’m not a psychiatrist Mrs X but really this does not help your situation, and people said you’re so stressed all the time you need to get away . . . I wasn’t aware that stress could affect the body in that way.” (B3590)

More commonly informants were forced to come to terms with the impairment and the need to adapt to it by invoking the inevitability of ageing and the degeneration of the body that was expected to go with it. These informants eventually gave up “bothering the doctor” because they were convinced that there was nothing more that could be done for them:

“Well they are not miracle workers, I mean yes I think they probably could have done more, but the state of the NHS, what I have got is not life threatening, it is very uncomfortable, but at the end of the day you have to accept that sometimes there are no cures. And they haven’t managed to do anything yet, I mean yes possibly one day something will come up and yes they will be able to sort it out.” (A4324)

For informants who reached this stage the most common response was to undertake some programme of lifestyle change, usually involving stress management, dietary supplements and exercise. The changes that these informants made were usually relatively minor and were intended to enable them to continue living as normally as possible. When describing these changes no one described feeling particularly disturbed by them, instead their attitude was that anything that enabled them to live normally could be accommodated:

“I just put up with the pain, you know when I went shopping, I just came back with an aching arm. It doesn’t exactly stop me, I mean its only an ache it didn’t stop me shopping, or it made me get my granny trolley, but I suppose in that way it changed my life, when I got my granny trolley.” (F2865)

Claims making and the role of work
Informants rarely invoked work and its effect on them as a cause of their problems and as a consequence did not always feel it is necessary or possible to alert their work colleagues and employers to their condition. Some of this reticence stemmed from a fear of being seen as a complainer. The informants who felt unable to discuss their condition at work were more likely to feel this way because of the ‘age factor’:

“I’m just very conscious of my age and I work with a lot of young people, and I just don’t take time off of work . . . I’ve got a TENS machine for my back
and I sit and work with my TENS machine on.”
(A1217)

Where work was invoked it was more often cited as an aggravating factor rather than the primary cause of their condition and sometimes accounted for the recurrent nature of their condition rather than the cumulative effect of the work that they did:

“...I actually fell through a roof when I was 11 and I suppose I have had problems ever since then really. Nothing drastic, nothing too bad ... I think that’s sort of followed on from that too ... I think my job has aggravated it. I think if I wasn’t doing so much typing I wouldn’t sit so much but I think that obviously there is a problem there that’s never been sorted out and I think that combined with the job I do that over the years its made it worse.”
(I3127)

There were people who realised that their work had caused their problems and understood that if they were able to change jobs things would improve. Certainly, people who had changed jobs or whose work situation had improved had seen an improvement in their symptoms:

“As my wife always used to say as a bull at a gate. I don’t do that no more I just plod along nice and slow.”
(M980)

Similarly, for those whose job had changed and for instance were now using computers more, there had been an increase in pain:

“I’d had it before. The work I do know is totally different. I used to be a typist, but the type of work I do now, I have to use the mouse a lot, so that is why I have sort of noticed it more. Because it was not using my arm, but keeping it in one position. And I play skittles, and I find after an evening of playing skittles, the next day my arm is just, I wish I could rip it off sometimes.”
(A1217)

Some informants directly related their condition to the work that they did or had done in the past but again they did not place the blame directly at the feet of their employers:

“If you had a bit of common sense you would try to find the quickest way of doing your job, so you could leave those pieces on the side of the cutting board until you got a certain amount and then you would turn left and lay them out. You could cut the corners that way and do things more efficiently ... So the faster people were the ones who were more perceptive than others ... if you were much cleverer you would earn more ...”
(B3577)

This person had retired from his job on health grounds, after a long period of rigorous testing and evaluation by company doctors it was decided that indeed he had been made ill by his work. Although he realised his work contributed to his problems he also placed some of the blame on non-work experiences and himself in that he could have earned more money by working more quickly and less carefully.

Other informants who felt sure their condition was caused or made worse by work tried to continue to work even when the pain had become quite debilitating as the money they earned from working was necessary and they had to keep going or they were doubtful they would receive compensation:

“...it is definitely linked to my work, but I think they are reluctant as well, because I think they didn’t want to commit themselves to backing me if I tried to make a claim, everything is money related.”
(A1217)

Case studies
The four case studies constructed from the interviews with patients and health care practitioners typify the different patterns and pathways experienced by sufferers with upper limb disorders (Figs 3–6). They show the non-linear nature of the process and also highlight the points of agreement and divergence between the health care practitioners and the patients as well as the negotiation process that is engaged in to try to resolve these differences.

Case study A shows the uncertainty about the diagnosis, the perceived ineffectiveness of some treatments, the benefits of a chiropractor and the acceptance that such a condition may be part of the ageing process and the management of pain is all that can be expected. This can highlight the pragmatic use of health care and shows that the main priority is symptom alleviation. The informant is willing to accept that the ageing process means that a cure might never be possible. On the other hand Case B provides a typical example of the use of psycho-social explanations when the conventional treatments and biomechanical approach fails. It clearly illustrates different perceptions of outcome. The GP felt that the musculo-skeletal problems had been sorted out but the sufferer felt medicine had little to offer for older people and has used self-medication to control the pain. In this case the patient and the doctor were both operating with entirely different models of her condition, the GP highlights psychosocial aspects of the patients condition and believed that a referral to the CPN has resolved her psychological problems and interpreted the fact that she had not been back to the surgery complaining of arm pain as a sign that this intervention was fully successful. The patient on the other hand was left with the impression that her arm pain could not be resolved via conventional medicine and persists with self-treatment in the form of
supplements. The patient is not unaware of her history of depression etc but understands this as entirely separate from her arm pain.

Case C illustrates the different opinions of doctors about what is wrong and the use of different diagnostic labels. It clearly shows how sufferers use a range of different practitioners and regulates the treatment which finally leads to improvement. The lack of further use of a GP led the doctor to suggest the patient’s condition had improved which in this case was an accurate assumption. A similar approach was used by the GP in Case D although in this instance it was not accurate as the sufferer, a reluctant consulter, adopted a strategy of accommodating the problem through the use of physical support and medication. The patient and the doctor clearly differed in their assessment of the encounter in that patient felt the doctor was hinting at the label ‘RSI’ and the doctor wanted to attribute a diagnosis of ‘irritated elbow’. It is interesting that the possible role of work in causation was raised by the doctor but resisted by the patient. Again there is disagreement about outcome with the patient still feeling incapacitated and the GP suggesting that not consulting is a sign that things have improved. For the informant
the most important thing is to maintain a sense of normality by adapting their behaviour at work to accommodate the pain she feels is unavoidable.

Discussion

Ideas about causation are crucial, as others have consistently shown, to understanding the patterns of action and decisions to consult, and the lay response to upper limb pain was no exception. The common strategy was to wait and see what happens, as the pain was commonly believed to be due to wear and tear and the condition would heal naturally or could be managed through self-remedies. Informants tended to view their condition as a transitory departure from ‘normality’ that will quickly be resolved but later on if treatments had not been successful then the inevitability of ageing may be invoked as the patient came to adapt to their condition. Hence, a biomechanical
explanation was common and preferred, at least in the early stages, but when the condition and the pain persisted other, psychosocial explanations may be selectively invoked.

This lay discourse of physiological ‘wear and tear’ and the ageing body was based on a machine metaphor of the body in which it was assumed that greater use of the arm is likely to make its mechanical components wear out more quickly. Most of the informants were middle aged and were coming to terms with the ageing process and the physical impairments that were seen as a part of this. This is a common finding in studies of musculo-skeletal conditions amongst older people and while such ideas appear firmly embedded in current popular thinking they may reflect the influence of medical, scientific ideas from previous generations. This stands in contrast to the scientific discourse on upper limb pain where work is identified as a major cause or exacerbating factor. When work was invoked it was mainly seen in terms of exacerbating the condition.

FIGURE 5 Case study C
and informants tended to take on the responsibility for their problem rather than placing the blame on their employers. Certainly, there was little evidence of claims making. However, it might be possible that this is a ‘generational’ rather than an ageing effect. Younger informants might be more aware of the influence of the working environment on their health than previous generations because of changes in the working environment such as the more recent increase in health and safety regulations.

Similarly, while the scientific discourse emphasised the possible influence of stress and psychosocial factors in upper limb pain these elements were not evident in lay discourse. Stress tended to be invoked when biomechanical and physical explanations and the treatment linked with such explanations were seen to have little to offer and thus were no longer acceptable. Certainly, sufferers favoured biomechanical and physical explanations (as opposed to psychological explanations) in that problems arising from physical
traumas are considered more ‘legitimate’ than those arising from psychological causes.

Studies of ‘RSI’ sufferers\(^ {13}\) suggested that one of their reasons for seeking help was to obtain validation from their health care practitioner for their condition. There was little evidence of ULD sufferers ‘searching’ for an acceptable diagnostic label and many did not receive a diagnosis. Failure to get a diagnosis did not appear to be problematic for most informants mainly because it did not preclude the possibility of treatment. Hence, the search focussed on the treatment that might alleviate pain. This search regularly involved the use of CAM practitioners,\(^ {22,23}\) although there was little evidence that sufferers believed CAM was more effective than orthodox practice and a pluralistic approach with dual usage was the norm.\(^ {24}\) Certainly, there was ambivalence about orthodox medical treatments and particularly about the long-term use of painkillers (believed to be addictive). However, osteopathy and chiropractitioners, and the other CAM practitioners that provided care tended to be evaluated in terms of a biomechanical model of the body rather than an holistic centred approach.

In conclusion, upper limb disorders exemplify the large numbers of ill-defined conditions that are presented in primary care. The evidence clearly shows that sufferers opt for or end up with using a mixture of treatments and care from the popular, orthodox and complementary sectors. They tend to evaluate them pragmatically, mainly in terms of pain management and whether they were safe. This suggests the need for orthodox and non-orthodox care to be closely integrated in primary care and that GPs should not depend on orthodox medications alone when caring for patients with upper limb pain.

Acknowledgements

We are grateful to Keith Palmer and David Coggon at the MRC Epidemiology Unit at Southampton for use of their screening questions on upper limb pain.

Declaration

Funding: this study was funded by a grant from the MRC HSRC.

Ethical approval: ethical approval was sought and given for the study from two local research ethic committees. Conflicts of interest: None.

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