

This is the accepted version of the following article:

Gauntlett-Gilbert, J. and Rodham, K. and Jordan, A. and Brook, P. (2015) 'Emergency department staff attitudes toward people presenting in chronic pain: a qualitative study.' *Pain Medicine*, 16 (11): 2065-2074.

which has been published in final form at http://dx.doi.org/10.1111/pme.12844.

ResearchSPAce

http://researchspace.bathspa.ac.uk/

This version is made available in accordance with publisher policies. Please cite only the published version using the reference above.

Your access and use of this document is based on your acceptance of the ResearchSPAce Metadata and Data Policies, as well as applicable law:https://researchspace.bathspa.ac.uk/policies.html

Unless you accept the terms of these Policies in full, you do not have permission to download this document.

This cover sheet may not be removed from the document.

Please scroll down to view the document.

Emergency Department staff attitudes towards people presenting in chronic

pain: a qualitative study

Gauntlett-Gilbert, J. (PhD)^{1,3}, Rodham, K. (PhD)², Jordan, A. (PhD)³ & Brook, P.

(FFPMRCA)¹.

¹ Royal National Hospital for Rheumatic Diseases

² Staffordshire University

³ University of Bath

Running Title: Staff attitudes towards chronic pain

Corresponding Author:

Prof Karen Rodham,

School of Psychology, Sport and Exercise,

Staffordshire University,

Science Centre,

Leek Road,

Stoke-on-Trent

ST4 2DF

Email: karen.rodham@staffs.ac.uk

Disclosure & Conflict of Interest

The Authors were supported by the Royal National Hospital for Rheumatic Diseases Donated Funds

and Charitable Trustees Committee. The Authors declare that there are no conflicts of interest.

1

2

Emergency Department staff attitudes towards people presenting in chronic pain: a qualitative

study

Abstract

Objective: Patients who experience their non-malignant chronic pain as intolerable sometimes

present at Emergency Departments (EDs). However, since emergency medical services are set up to

provide rapid treatment for acute injury or illness; there is potential for misunderstanding and

disappointment. Literature on the topic of ED staff attitudes towards chronic pain patients is

minimal, USA-based and methodologically unsatisfying. We carried out an in-depth, qualitative

study identifying the attitudes and narratives of ED staff around people in chronic pain.

Design: Focus groups with ED staff; qualitative analysis of the group transcripts

Setting: Regional trauma centre in the UK

Subjects: Three focus groups, 20 ED clinicians, mean ED experience 8.1 years

Results: The clinical challenge of treating patients in the ED stemmed from a mismatch between

patients' needs and what the setting can deliver. Participants reported frustration with the system

and with chronic pain patients' perceived inconsistencies and requirements. However, they also

highlighted good practice and acknowledged their frustration around not being able to help this

group.

Conclusions: ED staff found people presenting at ED with chronic pain to be a challenging and

frustrating population to treat. Staff were constrained by the fast-paced nature of their jobs as well

as the need to prioritise emergency cases, and so were unable to spend the time needed by chronic

pain patients. This was seen as being bad for staff, and for the patient experience. Staff suggested

that care could be improved by appropriate information, signposting and with time invested in

communication with the patient.

Key Words: Chronic pain, Staff attitudes, Emergency Department

2

Background

Chronic, non-malignant pain is common, with prevalence estimates ranging from 11% to 64% [1], and is hard to treat. Analgesics are often only partially effective, and patients often do not always have access to non-medical pain management treatments. Thus, around 20% of patients attending a pain clinic have previously attended an Emergency Department (ED) due to their pain [1].

EDs are not an ideal context to manage chronic pain. Standard investigations can be inconclusive and routine analgesics can be counterproductive. In chronic pain conditions, pain levels are poorly correlated with findings on investigation. For example, back pain researchers have largely abandoned the attempt to connect specific spinal pathologies to pain levels [2]. Also, medication that might be appropriate for acute pain may be ineffective or harmful when prescribed in the long term. In the USA, the prescription of opioids for non-malignant pain is now regarded as a public health problem, with prescription opioids leading to over 15,000 deaths per year [3].

Patients can sometimes attend the ED repeatedly, and a small number of repeat attenders can use substantial time and resources. For example, in the USA, Jorgenson (2007) found that 3% of ED attenders with chronic pain accounted for 12% of ED expenditure [4]. It has been established that ED clinicians 'prefer' some clinical presentations over others. For example, fractures or dislocations are preferred to presentations around dizziness or pain [5]. Sometimes, ED clinicians under pressure can form negative attitudes towards patients with particular presentations; for example, repeat attenders have been termed 'pain recidivists' in peer reviewed journals [6]. There is no justification for this. Although patients with pain can become 'catastrophic' and frightened of their symptoms [7], chronic pain is a legitimate and disabling complaint; researchers have abandoned simplistic attempts to label chronic pain as 'psychosomatic' [8].

There are few studies of ED clinicians' attitudes towards patients with chronic pain. Wilsey et al used questionnaires and semi-structured interviews to establish that emergency physicians found treating people in chronic pain to be irritating and of low priority [9]. They found conflicts in approach between patients and staff; patients felt that inadequate attention was paid to locating a cause for their pain, whereas staff were more preoccupied with the danger of problematic use of analgesics [9]. However, staff denied holding stigmatising attitudes towards patients with chronic pain. The authors of this study noted that 'social desirability' may have affected these results, and reported an opposing finding in another study they conducted that used almost identical wording and concepts. In this other study, 85% of emergency physicians interviewed suggested that there were negative or stigmatising attitudes towards people with chronic pain [10]. Thus, clinicians acknowledged that such attitudes are widespread but denied them in their own practice. Wilsey et al.'s (2008) findings are a helpful and suggestive beginning; however, their interview study focused on practical barriers to treatment, did not explore staff attitudes explicitly, and did not use an in-depth qualitative analytical technique [10].

Patients with chronic pain report being affected by healthcare staff's attitudes. For example, patients report feeling that they are being told that their pain is psychological, or that they are being labelled as a 'difficult patient'. They struggle with the 'invisibility' of their condition and with the absence of straightforward therapeutic options [11]. Thus, rushed or dismissive responses from ED staff can cause distress and further sour patients' relationship with health care. ED staff are often aware of this and wish to handle this problem better [9].

Our study explored ED clinicians' attitudes to patients with chronic pain in depth. In contrast to previous research, it used an in-depth qualitative approach to exploring clinicians' attitudes and narratives, and, to the authors' knowledge, is the first study on a sample outside North America. In this exploratory study, we aimed to clarify the difficulties and challenges of treating patients with chronic pain, and sought examples of pro-therapeutic approaches and good practice.

Method

The study was conducted in an ED based in the Southwest of England. Three focus groups with ED staff were conducted. Focus group interviews were performed to get a broad and rich insight into the participants' experiences of treating chronic pain patients in the ED setting. Interaction in a group context was chosen as a means of gaining a broader perspective, as participants are more likely to express their views after listening to others in a similar situation [12]. All ED staff were invited to take part in the focus groups. Focus groups were scheduled to run on three different dates, each of which immediately followed staff training. The dates were advertised in advance. The research team provided a sandwich lunch for participants. The number of staff on each occasion who chose or were able to take part was therefore somewhat dependant on the work flow in the ED at that time. As such, the sample was opportunistic. The numbers of participants ranged from three to nine. The groups lasted between sixty to ninety minutes, were audio-recorded and subsequently transcribed. Groups had a mix of ED staff (physicians and nurses, novice and experienced). Group size ranged from 3 to 9 participants. Groups were conducted in a separate room at the ED site.

Participants

Twenty members of staff participated in the focus groups, mean age 38.0 years (SD 7.9), 70% female. Participants had been qualified for 14.7 years (range 2 - 30) and had worked in ED for 8.1 years (range <1 - 30). They had worked in an average of 3.1 different EDs (range 1 - 8). Ten nurses participated, as well as eight physicians, one physiotherapist and one ward manager.

Focus groups

A topic guide was used by the focus group convenors (JGG, KR and AJ), but flexibility was built into the schedule which also allowed the focus group members to introduce topics that they felt were of importance. Topics covered included:

- Are there challenges around treating people who present to ED in chronic pain?
- How do ED staff feel about people who present repeatedly in chronic pain?
- What do people in chronic pain expect from ED?
- Do people with chronic pain impact on the regular functioning of ED?
- What might be the best approach for this issue/these patients?
- Are there examples of best practice?
- Are there any actions or approaches that have made the patient, or the interaction, worse?

We adopted a number of 'shame reduction' techniques, taken from psychiatric interviewing, to

encourage candid reporting [13]. These included (1) establishing group rules about confidentiality,

(2) encouraging anonymous attribution of statements or attitudes (i.e. "I have heard some people say..."), (3) clarifying that the interviewers appreciated the potentially challenging aspects of treating

people with chronic pain

Analysis: Inductive Thematic Analysis [14] was employed to analyse the focus group transcripts. This is an established qualitative technique that allows in-depth exploration across a data set to find repeated patterns of meaning. Such an approach is grounded in, but goes beyond, the 'surface' of the data to facilitate, in this case, the development of an in-depth understanding of the attitudes of ED staff towards patients presenting with chronic pain. The key steps of Thematic Analysis include extensive familiarisation with the data, generation of initial codes, and then the search for overarching themes. These are then reviewed for coherence and distinctiveness, before being

closely defined and named (See Braun and Clarke, 2013 for detail [14]).

KR and AJ independently analysed the three focus group transcripts. In line with recent recommendations [15:p3-4] they maintained a curious stance and actively engaged in reflexivity throughout the period of analysis. Once their respective analyses were complete, they met with JGG (who had read the transcripts) in order to reach agreement about the themes. KR and AJ presented their analysis and responded to JGG who actively questioned the underlying assumptions. It was apparent that although they had used different names for some of the themes identified, the definition of the themes generated was similar. They repeated steps four and five and agreed on the final themes¹.

Ethics: The proposed research was approved by the University of Bath Department of Psychology Research Ethics Committee and the relevant NHS Research and Development committee.

Results

Running through all the focus groups was the notion of system failure. This in turn fed a mismatch between the individual and situational needs, which then created clinical challenges. Figure 1 shows the inter-relationship between these three key themes. We have used the term ED throughout, whilst some of the participants use the older term A&E (which stands for Accident and Emergency). Please note that [...] denotes data that has been removed from the quote for lack of relevance to the point being made and underlined words, are those that participants' emphasised.

******* Insert Figure 1 about here, please ********

System Failures

A key example of system failure is that of the generation of false hope being created when patients are signposted to ED through out-of-hours primary care services².

(9/10/13: p8) "And they might have been pinpointed to us because often [...] they might have already <u>tried</u> to get a GPs [primary care doctor] appointment, <u>not</u> been able to get one,

directed to us by <u>them</u>, they come to <u>us</u>, we're <u>busy</u>, they <u>don't</u> get prioritised, we don't do much for them. And we've wasted ...six hours of their time" [A].

Patients are often rapidly disappointed on arrival at ED and it is therefore perhaps unsurprising that patients with chronic pain sometimes file formal complaints. There is anger at a service that can't deliver what they want (even though it is not designed to deliver what they want). ED staff believe that patients with chronic pain should never have been there in the first place, and that patients wanted the impossible, and then complained when they didn't get it.

(9/10/13: p12/13) "If we're honest, it slows it down, because a lot of these people are not-some of them are <u>not</u> very mobile, at <u>all</u>, [...] if they actually <u>bring</u> the person in to you, that's a trolley³, and you think 'right, that person's on that trolley and I <u>can't</u> really do very much for them, I'm going to have to spend this <u>time</u>, or put in a quick, sharp intervention that might not be doing- might not be in their best interests, and <u>then</u> you've blocked a trolley. Because then you're stuck with this person and you end up putting them onto EDA, REACT⁴, um, and ongoing care and everything else, so they <u>slow</u>...A service- I'm not, I'm not being nasty. Well I <u>am</u> being nasty-" [Q]

[...]

"I do quite a lot of, complaint responses, and several of those are around experiences for people with chronic illness and chronic pain where our service couldn't deliver what they wanted, and then there comes this whole <u>raft</u> of <u>anger</u>... And historical stuff [murmurs of agreement] that pinpoints into what their experience was in ED. And they're particularly, <u>tricky</u>, complaint responses to write as well, and to know what we could have done differently and to learn the right lessons. But. Sometimes the reason that that happens is that they come in out of hours, exactly as 'A' describes, we end up in- in the end, giving people Entonox⁵ initially which you then can't remove, or we um, or we give people morphine

9

in the end, or we give them intravenous morphine which, settles people temporarily, but then we can't get them home. and they came in an ambulance and the ambulance won't take-.

We get this sort of //cycle//" [F]

[...]

"And then of course, they quite rightly say y'know 'I stayed in your department for eighteen hours' or however long it ends up being 'and you did <u>nothing</u> for me'. And then we look, and we look at the complaint response and we did <u>this</u>, <u>this</u> this <u>this</u>, this is what we did, we tried to, but- but you- you understand <u>completely</u> what they mean. What they mean is that you didn't actually stop this from being a cycle for me." [F]

This suggests that the wider system may be failing ED staff and chronic pain patients, with both parties reporting dissatisfaction with the clinical encounter and related outcomes.

Mismatch between institutional and individual needs

The idea of 'mismatch' or discordance was often mentioned. Part of this sense of staff dissatisfaction seemed to stem from the constraints of the ED setting; it is an acute environment and not set up for dealing with chronic conditions. Chronic pain patients are not typical of the patients seen in an ED setting and there is a mismatch between the remit of the ED and the individual requirements of the patient with chronic pain.

(9/10/13: p6) "Because we're kind of focusing on, y'know, we're used to dealing with people who can't breathe" [Q]

Staff spoke of feeling unprepared, 'useless' and disempowered, even though they were absolutely clear that ED was not a place that this group of patients should turn to. Staff felt they should be able

to do more. It was hard to deal with the conflict of having a role that required them to act fast and decisively to solve a person's acute health problems and then be faced with someone who does not have a life threatening issue, who is taking time away from others who do. The kind of compassion required in an ED is very different to that needed by a person with chronic pain. Chronic pain patients' need to feel listened to, but the consensus was that the ED is not the right place for this.

(4/9/13: p3) "... I think we feel. . . just unprepared to add anything in to that, especially when we have the time management issues as well, that we don't really have as much time as we ought to for <u>listening</u> to these people. That's probably what they are here for. Is to sit down in a quiet place and to be <u>listened</u> to and <u>empathised</u> with, which is <u>not</u> what they get in our triage room or our "seat-and—treat" cubicle where there's nowhere to lie them down when they're in pain and they feel . . . unwelcome." [N]

In short, ED staff felt that chronic pain patients have a false impression of what ED can do; one that is at odds with the reality of what can be done. ED staff felt that when patients' expectations are contested, patients can feel like they are being 'fobbed off' (something the staff themselves fear they are doing). The tension experienced as a result of this mismatch is reflected in four sub-themes: 'panacea', 'fixers who can't fix', 'behavioural inconsistency' and 'best for whom'.

A panacea: Staff members commonly reported patients misunderstanding of what can be achieved in the ED. Specifically, talk focused around patients believing that an ED visit may facilitate a final diagnosis, referral to a pain clinic or 'cure' for their ongoing pain condition, none of which are usually possible. Chronic pain patients can feel like they are at the end of the line; most often their primary care doctor has exhausted possibilities and advised them to learn to live with their condition. They then come to ED with the underlying expectation that ED is a means of accessing more specialists:

(4/9/13: p4) "I think they've seen their GP four, five times already. And the GP has done the things that they think they need to do to exclude something serious. And so they feel that they're no longer being listened to, because the GP's sending them away. And yeah, they have nowhere else, they can't, the GP is their main port of call, they don't know where else to go, so they just rock up in A&E" [J]

"I guess it's like their <u>last ditch</u> hope that there <u>will be a cure</u> and someone has a <u>magic</u> wand, but that they just kind of haven't found that yet maybe" [N]

"There's also the perception that this is the <u>hospital</u> so we must have more specialists" [F]
"We can do <u>everything</u>" [N]

It was felt that chronic pain patients mistakenly thought that ED staff could expedite referrals and bring forward existing appointments.

(4/9/13: p5) "We can do all the scans that they've ever heard of immediately and obviously we'll be able to refer them to this pain clinic that they've heard of but not been to yet, and if they've got an appointment, we should be able to bring that forward, because they're in more pain than anybody else...When in actual fact we have no. access. Whatsoever." [N]

(4/9/13: p6) "I think they don't understand the <u>pathways</u>. No. They assume that if the <u>clinic</u> is at the hospital, y'know, you're in the very next <u>building</u>, then why can't you... Why can't you contact them and make the appointment <u>earlier</u>? Y'know, I think they don't understand that we don't have that <u>ability</u>." [N]

Others think that staff in ED can prescribe other drugs, this is not the case:

(9/10/13: p8) "And y'know, as a nurse prescriber, they're way out of our league. They're on gabapentin, amitriptyline, and I wouldn't even <u>begin</u> to <u>know</u> what else would, would ease their pain. And it's, they're <u>frustrated</u>, they've come to us on a Saturday night, and we can't, y'know, almost- it's really <u>difficult</u> because we're actually almost probably fobbing them off, we're probably not the service that they <u>want</u> really, or <u>need</u>. [J]

Fixers who can't fix: The attraction of working in the ED for staff was the opportunity to fix things and more specifically, to fix people:

(4/9/13:p28) "That's why we do A&E, to make things better" [K]

ED staff reported feeling inadequate when they could not 'fix' their patient. As 'N' suggests below; such feelings of inadequacy can have an impact on staff-patient relations:

(4/9/13: p27) "I think patients like that make you as a clinician feel <u>inadequate</u>. Because I already <u>know</u> that before I walk in there that I'm not going to solve it or anything, because I can't cure what they've got, and that makes me feel – I think that's why chronic back pains and things <u>are</u> such a heartsink, not necessarily because of the <u>patient</u>. You feel that <u>you</u> don't have the answer to this, and that the time you are going to <u>spend</u>, to you feels <u>wasted</u> because you're <u>not</u> making a brilliant medical diagnosis, you're not coming up with a treatment nobody else <u>knows</u> you're...It is just another patient that <u>you</u> feel you can't do anything <u>for</u> and I think if you <u>let that</u> get to you...Then you transfer some of that. If <u>you</u> feel disheartened and <u>fed up</u> that, then you can make them feel like it, like it's <u>them</u> that you're fed up with rather than the situation, and sometimes you just have to be very honest and say 'look, the ED is <u>really bad</u> at chronic pain and I'm not going to be able to sort you out. And take it from there. 'What <u>can</u> I do for you, you've been here before, what helped out last time?" [N]

Being unable to 'fix' chronic pain not only results in a sense of disempowerment for staff, but it also is felt to impact on patients who can feel that they have been side-lined and that ED staff are ill-informed about their particular form of chronic pain:

(9/10/13: p18) "Depending on what the condition is we we-, it makes you feel quite disempowered, but also perpetuates what patients think, which is that we don't have the knowledge that the patient has about their own underlying chronic condition. And they know everything about it, of course they do, but we don't. And they'll come in and they'll mention a long name and if you say 'I'm really sorry, I don't know what that is', already you'll get that '(sighs loudly)'. [crosstalk] And then we get letters about 'you must educate the A&E staff, how can you be nurses if you don't know!' y'know? We've had several letters like that about how useless the A&E nurses were and when you look it up it affects one in X number of million patients, but to that patient, it's really frustrating that we don't know what that is!"

Behavioural inconsistency: Not knowing a person's history meant that the ED staff had to rely on observation of the patient's behaviour:

(4/9/13: p7) "And we judge them by the way they are behaving in front of us" [G]

Staff made assumptions about the behaviour of patients in their home setting, compared to how they presented in the clinical ED setting. They felt that patients were coping (however badly) at home, but that as soon as they were in the hospital, they became passive, and embraced the sick role. Staff felt that the system contributed to this behaviour:

(4/9/13: p10) "The thing I find difficult is the patient who's been coping at home in their own environment and they call an ambulance. They get on a trolley, then they get on a bed. And when they come on the bed they are completely incapacitated, lose every ability to, sit forward, stand up. And that's very difficult because we put them into a very sick role then,

haven't we? By giving them a bed and saying 'Oh there's something <u>wrong</u>' And then trying to persuade to them that <u>actually</u>, you've been walking around like this for the last few weeks, you <u>can</u> walk, you can manage, even though, you know, it's difficult." [K]

Staff in this study also felt that patients behaved differently when they were not being watched:

(4/9/13: p7) "The more you're <u>there</u>, the more they are being like, what we call <u>dramatic</u>. But when you walk away and no-one's around, they're <u>fine</u>." [G]

[...]

"And just <u>rolling like mad</u> on the floor with their back pain, on the floor, back to the trolley.

And if you are in pain really, any movement's not gonna do that so, it's like <u>sliding</u> down the trolley like that. Like very <u>dramatic</u>. And we see that quite a <u>lot</u> and it's quite <u>bad</u> really that we become <u>judgemental</u>, but we've seen some of them, they're all coming back here like, for being here really, so" [G]

[.]

"(laughs) Yeah, and their heart rate is sixty and they're texting on their mobile phone – "[N]

"<u>Texting</u> whilst you walk in! That's a good sign [group laughter] that they are <u>not</u> requiring of morphine!" [K]

So, staff observed the behaviour displayed by the patient at the same time as they searched for consistency in story, symptoms explained/displayed and behaviour displayed:

(4/9/13: p11) "Like the lady the other day who was in a <u>closed</u> cubicle with a <u>door</u>. Somebody had taken the Entonox bottle from her, and she was in a bed with two bed rails up, and she was in so much <u>pain</u> that she couldn't possibly <u>walk</u>. The Entonox was over the other side of the cubicle. And then ten minutes later she was <u>using</u> the Entonox back in bed. So obviously she <u>had</u> gotten out of bed [group laughter], retrieved the Entonox bottle from across the-"[N]

What's best and for whom?: Staff strove to find an approach that would be considered appropriate by the patient with chronic pain. Sometimes staff reported offering patients a 'placebo':

(4/9/13: p 13) "You know it is how you deliver it. This is, you know, this is a wonder drug. I call it wonder drug, and then we give it to the patient [who asks] 'how long will I, y'know it work?' and we say 'straight away'. And then I say 'in twenty minutes I'll come back', I always make a deal, but you must go back. And to say 'in twenty minutes it'll work and I'll come back.' And then sometimes it work" [G]

There was recognition behind this example that talking to, and reassuring someone who is frightened is often the best medicine in these situations. However, staff are aware that they may well be feeding misconceptions about appropriate treatment – they know that different pain killers are unlikely to make a difference, but because they don't have time to explain this, they end up giving the patient something, possibly to appease their own sense of helplessness as well as allowing the patient the perception that 'something is being done'.

(4/9/13: p 14) "If you are <u>aware</u> that it's a non-organic pain, then you are also aware that the painkillers you're giving aren't going to make a <u>difference</u>, that's <u>not</u> the answer. And yet the whole large amount of that patient's time in the department revolves around different painkillers and what can – and I think it's a cliché- I know that's <u>not</u> the answer and I know that's not going to make any difference to their symptoms [...] But I don't have <u>time</u> to spend an <u>hour</u> sitting down talking around <u>why</u> painkillers aren't going to help, and I think

the nurses have the same...None of us actually <u>expect</u> the treatment we're giving to be the answer to that patient's problem" [N]

Participants often showed clear awareness that resource limitations contributed to the problem. The angst this participant experiences as she tells us how disempowering this whole issue is, is clear; as is her awareness of how she is in effect also contributing to the problem. There is a discordance between what she feels is the most clinically appropriate treatment and the reality of what she can actually deliver. There was also a huge sense of frustration that so much time was taken up exploring options that ED staff knew would not help. The combination of system failures and the mismatch of individual versus institutional needs leads to a range of clinical challenges.

Clinical challenges

Health professionals working in the ED face a number of challenges when dealing with patients with chronic pain. Such challenges are typically very different to those faced by ED staff when dealing with patients with acute problems. They include 'managing the chronic in an acute setting', 'heart-sink patients' and balancing an already difficult situation'.

Managing the chronic in an acute setting: It is the 'chronic' nature of pain that is problematic for staff. Patients arriving at ED have a complex history, of which very little, or none, is known. Staff are essentially reliant on the patient to be honest, informed and capable of sharing key information. What ED staff said tended to happen was that although the patient was usually well-informed, they were not capable of giving a short and clear summary; patients needed to 'tell their story' in full:

(9/10/13: p17) "Particularly, I think is we get a history from the paramedics, or they've come in through triage and it's quite a <u>long</u> history. And we're very quick to take that down to the bare bones as much as possible and they sometimes. I'm sure they must hear their history

changing <u>slightly</u>; they <u>live</u> and they <u>breathe</u> their history and everything that has gone wrong with them and they think if you've got it <u>slightly</u> the wrong story or the wrong end of the stick or <u>something</u>, even if it's not going to make a big difference to them, they can get quite frustrated quite <u>quickly</u>, and very quick to <u>judge</u> the service and, and think 'actually, you know [quietly] you're useless" [A]

"That's really true though isn't it? Because we're often saying to ambulance crews that are queuing 'you don't know what's behind them on these trolleys' and they say 'Oh, I'll just give you the history' and you're often saying 'the very <u>succinct</u> one! Like <u>two</u> words. <u>Chest. Pain...</u>

<u>Lovely.</u> There'. Because you haven't got time to be listening to this <u>convoluted</u> story, and then you're looking at everything that's behind, and if you are honest. . . You shut off. And you're just kind of picking out the things that are relevant" [Q]

It can be difficult for ED staff to discern whether there are new acute issues that are mixed in with the ongoing chronic ones:

(25/09/13: p 2) "Because you've got people who come in with their pain and people that it's not mutually exclusive, they can have their chronic pain and another problem on top. So often it's quite difficult to separate out what is a component of the chronic pain, and what is the new component, um." [E]

Although ED staff have to clarify whether there are new symptoms in case treatment is required, their dominant impression was that people in chronic pain simply needed empathy, understanding and support. Staff were not suggesting that chronic pain was psychogenic; indeed they were quick to highlight the importance (and difficulty) of identifying emergent and/or acute pain amidst the ongoing chronic pain. In contrast, this perception stemmed from the recognition that since there was little that could be done practically, emotional support was of greater import. This is not

something which is easy to provide in a fast paced setting such as the ED and is further compounded because ED staff need to make judgements and prioritise the needs of individuals. As such, a chronic pain patient who has been assessed as not having emergent or acute pain on admission to the ED is never going to be top of the list because other patients who *are* emergencies take precedence. Although there was empathy for the predicament of the person in chronic pain, there was also a sense of frustration

(4/9/13: p23) "And that's the last thing that somebody like that wants to hear, when they say why have they not been seen yet? Well, because there's more unwell – do they hear that as more deserving patients? Or patients that we're more interested in? And of course they feel like they have been left at the end of the queue. Which they have. Unfortunately [group laughter] because you know that you are unlikely to make them worse because you are more or less sure that there isn't anything organically wrong with them to start with" [N]

"So especially on a night shift, they get bumped down the list as sick, as sicker people come in. And that's another bone of contention isn't it? 'Cause they feel as though they've been bunged in a cubicle, the curtain's been pulled and everyone else is being seen first. Which unfortunately at times is true." [K]

'Heart sink' patients: The complexity of chronic pain patients makes them a 'heartsink' on arrival, because the staff know that they are unlikely to be able to 'fix' them.

(4/9/13: p2) "And um, it's a heartsink"[F]

Staff did not like having to assess these kinds of patients, indeed, some mentioned how they had seen colleagues actively avoiding doing so:

(9/10/13: p25) "I think, um, because they <u>are</u>, or can be quite difficult to manage I think sometimes there's staff avoidance looking after this group of patients. It might be because

you've looked after them <u>before</u>, it might be because they've looked after patients who've presented <u>similarly</u> before, it might be because you know you have not patience because you've had all these other things happening, and you know damn well that they're just going to put in a complaint and you'll have to deal with that, on top of everything else, when you've tried your <u>hardest</u> and you've got to deal with <u>this</u>, and so I think maybe there is some staff avoidance." [F]

Balancing an already difficult situation: Staff were concerned with ensuring that they didn't make a difficult and complicated situation even worse; both in terms of patient outcomes but also in terms of inadvertently creating future work for other professionals involved in the patient's care.

(9/10/13: p7) "We have to be pretty careful because, we, we like to <u>fix</u> people in, in A&E.

Um, and so we like to fix people and we like to fix people quite <u>quickly</u>. Or certainly be able to have a plan for <u>imminent</u> fixing if we can't do it ourselves. [. . .] And some of the things that we might put in as a quick <u>fix</u> may, and somebody else may have to <u>unpick</u>. It's very conscious about that as well..." [Cy]

However, with little or no history, staff felt that they had no choice but to undertake a number of tests to rule out particular issues. This in itself was problematic for it fed the false expectation that tests could be fast-tracked:

(4/9/13: p7) "But as nurses, because we can see the patients first, like rolling on on the trolley, so we go <u>beyond</u> by doing <u>all</u>, every single blood test, bladder scan and everything, because we don't know what's the history" [G]

A number of the participants spoke about how their behaviours fed the problem because they <u>did</u> end up ordering more tests etc. This feeds the perception that an ED visit will facilitate access to further investigations, a catch-22 scenario.

(9/10/13: p5) "So we're <u>perpetuating</u> a little bit of a situation where, where we are doing increasing numbers of scans and you, you go to your GP and you're told 'we'll book you in for an MRI' and then you get your appointment and it's for <u>three</u> months later, and you're in chronic pain. So people come to A&E very regularly, either with a <u>genuine</u> or a <u>perceived</u> or an... absolutely <u>fabricated</u> flare up...in order to expedite the investigation and that's completely understandable." [Cy]

As is hinted at in the quote above, staff spoke about patients knowing the system and the symptoms to report in order to access the tests they wanted. This was a difficult situation for staff to deal with, because they are reliant on self-report as part of the diagnostic process and even if they suspect someone of fabricating symptoms, they are still duty bound to explore and rule out anything sinister.

Whilst much discussion focused on the challenges of working with patients with chronic pain in an ED setting, we asked staff to describe positive strategies for managing these encounters. Perhaps the simplest strategy mentioned was to adopt, or at least outwardly portray, a positive attitude towards the patient.

(4/9/13: p 26) "You know, you are tired, it is 3am, you've met them six times before, they were rude to you last time, you're not in the mood, and to walk in there with that attitude is just going to go wrong from the start, isn't it?...So...Deep breath before you go in!" [N]

Being open and honest was something that ED staff members perceived to be important in managing the clinical encounter satisfactorily.

(4/9/13:p18) "I think the only thing that has <u>any</u> effect on some people is just being very honest and just saying to them 'you have this pain. You've had this pain y'know, for many <u>weeks, months, years</u>, y'know. My job is to rule out anything that's y'know, an <u>emergency</u> that's changed today. I've examined you and I can't find anything that I'm worried about. I'm

very <u>sorry</u>, there's nothing else that we can <u>do</u>. Y'know, you need to go back to your GP, pain clinic, whatever else' And I think that there are a group of people that are very receptive to that and say 'Oh thank you, I feel much better now that you have looked at me and listened to me' [K]

Thinking carefully about useful strategies to work collaboratively with patients in the ED setting was of particular importance for managing the most frequently attending patients. Indeed, some of the most frequently attending chronic pain patients had been given clinically developed plans for managing ED visits. Such plans provided clear direction to staff and outlined expectations clearly for both patients and staff:

(4/9/13: p18) "I've seen some departments have a <u>plan</u> for patients. But that plan comes about literally for the patients who've been in fifty, eighty, maybe even a <u>hundred</u> times. They have been <u>thoroughly</u> investigated and it's multidisciplinary, so you've got, y'know, the team from the emergency department that sit down, you've got the psychologist, psychiatrist, their GP, social workers, y'know. Everybody sits down and has a series of mass meetings which must <u>cost</u>... which must take so much time to organise. And then there's a co-ordinated plan of 'when this patient comes in, <u>complaining</u> of their chest pain, we <u>don't</u> do an ECG, we <u>don't</u> give them anything – unless there is something <u>different</u> about them you know? Then on those situations <u>yes</u>, we investigate and manage. Cause he could still have a heart attack. But I've seen that work and dramatically reduce a few patients' attendances. But that's such a huge investment not just for an emergency department, but for the whole Trust." [J]

Discussion

Staff working in Emergency Departments regularly encounter patients with chronic pain, and they have clear opinions about the patients, their treatment and how well EDs meet their needs. This study is the first to use careful, in-depth focus group methods to elicit staff attitudes and summarise experiences. Staff felt that there was a clear mismatch between what patients wanted and what their clinical systems could deliver; they acknowledged the frustration of dealing with patients in chronic pain, but did not locate blame entirely within the patient; they detailed a series of accounts of good practice.

Previous research has suggested that staff find patients with chronic pain to be somewhat frustrating, and a low clinical priority [9, 10]. It also established the paradoxical finding that staff identified a good deal of stigma towards patients with pain in their clinical environment, whilst denying any stigmatising attitudes personally [9, 10]. Our study was designed on the premise that indepth group discussions, carefully conducted and using 'shame attenuation' techniques, would stimulate more candid reporting. Participants acknowledged the existence of some stigmatising attitudes and clinical avoidance openly, using the phrase 'heart-sink patient'. Some negative discourse was also evident in the incredulous / humorous description of patients' behavioural inconsistencies. However, data from this study extends previous findings by showing that ED staff did not view the problem of chronic pain as solely present in the patient. They were clear that many of the clinical frustrations arose from the fact that the clinical needs of people in chronic pain simply could not be met within the ED. They acknowledged that the ED has a limited range of clinical goals, which does not involve the conclusive investigations, rapid referrals and effective 'cures' that patients were hoping for. They also gave clear accounts of how the ED context might increase patient frustration. Thus, staff had a more reflective and nuanced understanding of their clinical challenges than previous research has implied. The perception of a 'gap' between patient

expectation and physician response has been explored in many studies, for example, Kravitz and Callaghan's work on perceptions of medical investigations and tests [16].

Previous research, based on US samples, has also emphasised staff concern about the prescription of potentially addictive medication [9]. In contrast, this was not an issue that was consistently raised in our focus groups, despite medication being mentioned and the existence of prompt questions about this in the focus group schedule. Staff did report being concerned about making changes to existing complex analgesic regimes, or about taking action that might cause more problems for other clinicians in the future. However, it seemed that fears of drug-seeking were less of a pressing issue for British clinicians.

Wilsey et al.'s (2008) study investigated 'barriers to accessing care' for patients with pain [10]. In this study, clinicians clarified a number of ways in which the ED setting could make the clinical encounter difficult or the patient's experience worse. Clinicians regularly raised the issue of unrealistic patient hopes for investigations, medication, or access to specialists. This was often contrasted with the patient's experience of waiting for a long time, not being seen as a clinical priority, and being seen by staff who did not have the time to listen to the patient's full story, or to carefully explain why the ED may not be able to help. Participants felt that patients did not realise the narrow range of analgesic options that ED staff felt comfortable with, and staff were quite clear that they felt that prompt, rapidly accessible pain services did not exist in the healthcare system. They contrasted this with how they could expedite access to some other medical or surgical specialties. Staff consistently noted the challenge of working without the benefit of understanding the patient's history, prior treatments and investigations, and without any access to notes. They appreciated that the rapid and

blunt information handovers they usually received from paramedics could not do justice to the patients' clinical histories.

Thus, it seems that both patients and staff are uncomfortably caught in the space between patient needs and expectations, versus what EDs can deliver. This was described as having a toll on staff, as well as patients. Staff were worried about how their services were affected by beds 'blocked' by people with pain. They were concerned about patients' willingness to make a complaint, and also by the potential of missing an acute problem that might exist against the backdrop of chronic symptoms. ED staff derive satisfaction from being able to provide a rapid 'fix' for presenting problems; not being able to achieve this, led both to frustration and also a sense of helplessness. Some staff were aware of the hazards of allowing this emotion to become apparent in the clinical consultation.

Alongside helplessness and frustration, staff also expressed a good deal of sympathy for people in chronic pain, and regret that they could not provide a 'better service'. Staff were clearly unhappy that patients with chronic pain could, in perception and in reality, receive brief and uncommitted treatment in their ED encounters. However, they also described some clear examples of positive, reflective approaches to frustrating encounters with individuals with chronic pain. For example, one staff member cited 'taking a deep breath' outside a patient's cubicle, thereby refusing to allow their impatience and sense of pressure to colour the clinical interaction. Others took a clearly validating approach to people's pain – overtly acknowledging the reality and difficulty of the condition – whilst also taking the time to explain how the ED could offer few useful responses to the problem. The possibility of coordinated multidisciplinary care plans for people with pain was raised, but was also seen as resource-intensive and expensive.

This study emphasised depth and detail, both in its approach to data collection and analysis. This was a clear contrast to the previous literature. However, our convenience sample of 20 staff, whilst entirely adequate for qualitative purposes, should not be seen as descriptive of British ED clinician's attitudes overall. All staff were taken from one unit, a regional specialist trauma centre, and it may be that they had a particularly reflective team culture. However, we also note that we sampled a total of over 160 years of combined ED clinical experience, and most participants had worked in multiple ED settings. We also achieved a good mix of disciplines and clinical seniority. However, although we used 'shame attenuation techniques', it could be argued that some participants were reluctant to acknowledge stigmatising attitudes in front of their peers or seniors. Whilst we cannot discount this, it is clear from the quotes that our focus groups included some candid and blunt discussions.

There are a range of clinical implications from this study, from provision of information to staff training and support. For example, it seems clear that those who refer people with chronic pain to the ED, for example, out-of-hours primary care services, could also usefully educate the patient about the likely outcome of ED attendance. For example, they could clarify that ED staff could rule out potentially hazardous conditions, but that they would be unlikely to achieve new diagnoses or therapeutic options. With regard to ED staff, in this study it seems that they tempered their frustration and sense of helplessness around pain by appreciating the patient's hopes and needs, however unrealistic, and by being aware of the nature of the ED as a limited setting devoted solely to the rapid detection and treatment of urgent problems. ED staff might usefully consider the successful strategies cited, for example, using reflective self-regulation (a "deep breath") to avoid frustration being evident in the clinical encounter, as well as finding time to validate the patient's problem whilst clarifying the limited role of the ED.

26

Looking at the wider literature, there may be other ways to support people with chronic pain to

avoid emergency admissions. For example, ED clinicians in this study did not reference the many

different strategies used to reduce admissions in other chronic conditions. Chronic disease

management programs (CDMPs) have been shown to reduce admissions in populations with heart

disease or diabetes, and analogous approaches may be applicable to people with chronic pain [17].

Conclusion

This study extends previous findings by showing that although ED clinicians can find the treatment of

chronic pain frustrating, they can also be reflective about this and appreciate that this arises from

the mismatch between patient expectations and what the ED can deliver. There was clearly room for

better information about what is possible in the ED, and for referring clinicians to foster realism

when recommending ED attendance. Concern about medication seeking was not prominent, in

contrast to previous research in the USA, indicating that this issue may be culturally specific. Staff

were capable of recognising their professional preference to 'fix' patients with more classically acute

problems. However, some also adopted clear self-management and communication techniques

when approaching difficult clinical encounters, indicating areas of good practice that might be

disseminated.

Notes

¹ Readers unfamiliar with qualitative research could read Richards, L. (2009) Handling Qualitative

Data. London: Sage

26

² Out-of-Hours: In this context, refers to the hours when a primary care service is closed. Referrals are often made via a phoneline (NHS 111) which is free and available 24 hours a day, ie accessible when doctors surgeries are closed.

³ Trolley= a wheeled stretcher. In USA this is known as a gurney.

⁴ EDA = Emergency Department Assistant REACT = Rapid Emergency Assessment and Care Team

⁵ Entonox is a brand name for the blend of Nitrous Oxide (50%) and Oxygen (50%)

⁶ 'Fobbed Off' in this context means giving the patient substantially less than what they want

References

- Hauser, W., Wolfe, F., Henningsen, P., Schmutzer, G., Brahler, E., Hinz, A. Untying chronic pain:
 Prevalence and societal burden of chronic pain stages in the general population-a cross-sectional survey. BMC Public Health 14, 352.
- Shambrook J, McNee P, Harris EC, Kim M, Sampson M, Palmer KT, Coggon D. Clinical presentation of low back pain and association with risk factors according to findings on magnetic resonance imaging. *Pain* 2011; 152: 1659–1665.
- Warner M, Chen L, Makuc D. Increase in fatal poisonings involving opioid analgesics in the United States, 1999–2006. NCHS data brief number 22. http://www.cdc.gov/nchs/data/databriefs/db22.htm (accessed 10.6.2014).
- 4. Jorgenson DJ Fiscal Analysis of Emergency Admissions for Chronic Back Pain: A Pilot Study from a Maine Hospital. *Pain Med* 2007: **8**; 354-35.
- Dutch MJ, Taylor D, Dent AW. Presenting Complaint Descriptions Bias Emergency Department Waiting Times Acad Emerg Med 2008; 15:731–735.
- 6. Dixon WJ, Fry KA. Pain recidivists in the emergency department. *J Emerg Nursing* 2011: **37**; 350 356.
- 7. Sullivan, MTC, Thorn, B, Haythornthwaite, JA, Keefe, F, Martin, M, Bradley, LA, Lefebvre, JC.

 Theoretical perspectives on the relation between catastrophizing and pain. *Clin J Pain*, *17*, *52-64*.
- 8. Crombez, G., Beirens, K., Van Damme. S., Eccleston, C., Fontaine, J. The unbearable lightness of somatisation: A systematic review of the concept of somatisation in empirical studies of pain.

 Pain 2009; 145: 31-35.
- 9. Wilsey BL, Fishman SM, Ogden C, Tsodikov A, Bertakis, KD. Chronic pain management in the emergency department: a survey of beliefs and attitudes. *Pain Med* 2008: **9**; 1073-1080.
- 10. Wilsey BL, Fishman SM, Crandall M, Casamalhuapa C, Bertakis KD. A qualitative study of the barriers to chronic pain management in the ED. *Am J Emerg Med* 2008: **26**; 255 263.

- 11. Dow CM, Roche PA, Ziebland S. Talk of frustration in the narratives of people with chronic pain.

 Chronic Illness 2012: 8; 176-191.
- 12. Krueger RA. *Focus groups. A practical guide for applied research.* 4th ed. London: Sage Publications, 2009.
- 13. Shea SC. *Psychiatric interviewing: The Art of Understanding*, 2nd edn. Philadelphia: W.B. Saunders, 1998.
- 14. Braun V, Clarke V. Successful Qualitative Research: A Practical Guide for Beginners. London: Sage, 2013.
- 15. Rodham, K., Fox, F., Doran, N. Exploring analytical trustworthiness and the process of reaching consensus in interpretative phenomenological analysis: Lost in translation. *International Journal of Social Research Methodology*, 2015, 18(1), 59-71.
- 16. Kravitz, R.L., Callahan, E.J. Patients perceptions of omitted examinations and tests: a qualitative analysis. J Gen Intern Med 2000; 15: 38-45.
- 17. Hamar, G.B., Rula, E.Y., Wells, A., Coberley, C., Pope, J.E., Larkin, S. Impact of a chronic disease management program on hospital admissions and readmissions in an Australian population with heart disease or diabetes. Population Health Management 2013; 16: 125-131.

Acknowledgements

The team wish to thank Dr Steven Meek for helping us to access ED staff. We thank the participants for giving up their precious time to talk with us, to Sarah Bennett for transcribing the three focus groups. The study was funded by the Royal National Hospital for Rheumatic Diseases Donated Funds and Charitable Trustees Committee. Finally, we thank the reviewers for their helpful and constructive feedback.

Figure 1: Summary of the focus group themes

