ESRC End of Award Report: Exploring justice issues in chronic pain: sufferer and partner perspectives (RES-000-22-2381)

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Background
Chronic pain is a multifaceted condition that is now established as a health care problem in its own right. Given the high prevalence of chronic pain in the British population (Bowsher et al, 1991; Elliot et al, 1999) and its high economic cost (Maniadakis and Gray, 2000) there is a need to understand more about this condition, from not only a medical but also a psychological perspective. There is a literature on the impact of specific pain-related beliefs on coping and adjustment. However, neglected is the role other, more socially-focussed beliefs, may occupy in this context. Specifically, since chronic pain is experienced in a complex social and cultural context, principles of justice and injustice that guide everyday social behaviour are potentially salient here, particularly because chronic pain provides many opportunities to experience injustice. Early ideas of justice beliefs emerged from Just World Theory (Lerner, 1980), particularly the belief in a just world which holds that individuals have a need to believe that they live in a world in which we generally get what we deserve. Research in chronic illness quite consistently reports benefits of justice beliefs for psychological adjustment. Recently our own quantitative research found that perceiving justice in one’s own life, but particularly in the world in general is important for psychological well-being in chronic pain (McParland and Knussen, in press). Other work has also found that perceiving injustice is associated with poor physical and psychological outcomes in chronic pain (Sullivan et al, 2008). What has not been investigated is the phenomenology of justice and injustice in the everyday context of chronic pain. This is a critical omission because it is suggested that perceptions of unfairness can impact negatively upon physical health (Jackson et al, 2006), which in chronic pain may serve to worsen an already insufferable condition. The primary aim of our study was to explore the nature and constructions of justice and injustice in chronic pain, in the context of everyday life. To be as inclusive as possible, and to account for societal variations in the chronic pain experience, the study aimed to recruit chronic pain sufferers from different socioeconomic areas, through General Practice, where pain is most often treated. Given the social context of pain, a secondary aim of the research was to consider spouse/partner perspectives of justice and injustice in the context of living with someone who has chronic pain. The justification for this is that pain brings changes in roles, responsibilities, boundaries and expectations within the relationship that may create many opportunities for perceiving injustice from a spouse perspective.

Objectives
An innovative mixed quantitative and qualitative methodology in this field was adopted to explore conceptions of justice and injustice, in two phases of research. Phase 1 adopted a focus group methodology to capture the lived experience of chronic pain within a social framework. Phase 2 adopted a Q-methodological framework to examine meanings of justice and injustice in the context of British culture, from a within and between subjects perspective. The research objectives were as follows.

1. To identify key justice issues within the social context of chronic pain using focus group methodology
2. To determine whether justice issues may vary as a function of status, namely the person with chronic pain and their significant other
3. To develop a novel Q-sample of justice items that represent the issues raised in the focus groups
4. To conduct a pilot Q-sort study to examine individual and group justice issues
5. To examine the relationship between justice issues, demographic variables and psychological variables.

Objectives 1 and 2 were met through phase 1 focus group discussions. Objective 2 was also explored in study phase 2. There was an extension of this objective in phase 2 to include other groups of individuals. Low phase 1 response rates prompted an extension in recruitment, both of chronic pain and spouse samples into regional hospital Pain Clinics and support groups, and also the addition of health professional and member of the public groups to enhance diversity of opinion in phase 2. This extension has significantly contributed to the results and added much value to the research (phase 2). Objective 3 was addressed in an interim period between study phases 1 and 2 when a novel Q-sample of justice-related chronic pain items was developed. Objective 4 was met with the Q-methodology study in phase 2. Objective 5 was also addressed in phase 2 with a battery of questionnaires. However, low questionnaire return rates prevented a meaningful statistical analysis. Instead, some descriptive statistics are presented to understand the characteristics of the sample.

Methods and Results
Both study phases are reported here separately. Glasgow Caledonian University and National Health Service (NHS) ethical approval for the study were obtained for the research and their rules of ethics and conduct followed throughout, as were British Psychological Society ethical guidelines. Study information sheets were distributed and consent forms signed in both phases of the research.

**Study Phase One**

1.1 Recruitment and method
Four, two and three General Practices from upper, middle and lower socioeconomic areas in Glasgow, consecutively, participated in the study (9% response rate). The Scottish Primary Care Research Network (SPCRN) facilitated recruitment through General Practice using medication criteria (Smith et al, 2005), to identify eligible chronic pain sufferers in a stratified random sampling technique. Letters were sent by practices to chronic pain sufferers inviting them and their spouses/partners (if appropriate) to participate. In total, 44 chronic pain sufferers and 13 spouses/partners expressed an interest in the study (10% response rate).

Everyone was invited to participate in a focus group discussion. Groups were arranged according to majority consensus in timing. Accounting for some non-attendance at each group, five, four and six chronic pain sufferers from upper, middle and lower socioeconomic areas consecutively attended separate focus groups. Although groups of around eight individuals are ideal (Kitzinger, 2005), these numbers are satisfactory for interaction. Eight (53.5%) of the total chronic pain sample were female (mean age = 51.64 years (SD = 12.56), mean pain duration = 15.1 years (SD = 10.48); mean current pain intensity = 5.2 (SD 2.04). Participants reported upper (n = 3, 6.7%), middle (n = 5, 33.3%), lower (n = 5, 33.3%) and all over body pain (n = 2, 13.3%). Fewer individuals were available for the spouse/partner focus groups. Here, some non-attendance at the group resulted in one interview being conducted and separate groups of four spouses from upper and middle socioeconomic areas combined, and two spouses from lower.
socioeconomic areas. Although not ideal, small numbers can still provide useful data. Four (57%) of the total spouses were male (mean age = 55.4 years (SD = 6.18).

Semi-structured interview schedules were developed to facilitate focus groups. Questions encompassing everyday understandings of justice-related concepts: fairness and unfairness, deservingness and entitlement were developed in consultation with academic literature, colleagues and target group members. A structured questioning route was adopted (Krueger and Casey, 2000) and the final schedule was piloted on student groups. Group discussions were audio-recorded and were attended by a facilitator and an observer.

Discussions were transcribed verbatim and checked for accuracy. Given the richness of the data, analysis of the transcripts continues. However, data pertaining to the research questions are presented here. As planned, interpretational phenomenological analysis is being used to analyse the data, following a pattern of exploratory coding, development of emergent themes, the identification of patterns and connections in themes within, and then across transcripts. Here there is an additional dynamic of positionality and roles and relationships in groups. Experts in the field of IPA are being consulted in the analysis process.

1.2 Results
1.2.1 Chronic pain sufferer focus groups
Across groups, the discussion of justice-related concepts focuses more on what is unjust rather than just. Decisions about and constructions of justice or injustice are largely dominated by (1) self-interests (wants and desires, or perceived needs) (2) downward social comparison processes (3) the need for status and inclusion and (4) perceived distributive, procedural or interpersonal justice or injustice. There are key differences in conceptions of justice and injustice across social and cultural contexts.

Focus group one participants from upper socioeconomic areas often disengage themselves psychologically from justice-related concepts. The world is viewed as a place in which “shit happens” i.e. suffering comes to everyone and so is normalised. Pain is no more unjust than everyday “hassles”. The group disengage their identity from that of “others” who are considered likely to entertain unfairness, namely those who worry or who suffer depression. Consistent with the disengagement from injustice, coping and acceptance is important to the group. Justice-related concepts aren’t entirely rejected but are secondary to a life with pain. Central here is that no one in particular to blame for any reported unfairness. There is a timeline of injustice, from the evaluation of “Why me?” at pain onset, to more outwardly fussed social constructions of unfairness as pain continues. These constructions are episodic in nature and are triggered by the group. Unfairness is most often reported through a perceived “lack of humanity” in the failure to acknowledge pain and its suffering as an individual lives with pain in society. Discrimination is at the core of this disregard. Unfairness here isn’t driven by self-interest. Nothing is specifically owed to this group. Outcomes do not need to be favourable in order to be considered fair. Instead, what appears to be sought is fair opportunity and equality.

For the participants of focus group two, from middle socioeconomic areas, pain exists in an unfair world. Conceptions of injustice are often oblique. A concern to present a public persona of the self as a positive person who is coping, at times precludes any direct reporting of what is unfair. To complain is weak. There is vulnerability to harsh and
unfair judgement. There is a perception that chronic pain does not fit into a time-hurried society, which brings intolerance, stigma and disrespect. The group agrees with the principles on which they are judged by others i.e. that to appear not to cope is weak and unacceptable. In turn, they also judge others unknown to them using the same moral principle. Justice-related concepts are often discussed within the context of the medical and financial “systems” in which participants appear to have “locked” themselves. There is a complicated relationship with healthcare professionals, involving some history of blame for negligence which, in the current situation breeds a sense both of role violation, and that it is unforgivable that doctors should make mistakes. This manifests itself in a lack of trust, suspicion and questioning of medical decisions. There is also a perception of a flawed financial benefits system in which chronic pain sufferers lose their “right” to entitlements both through the invisibility of pain which often precludes the demonstration of physical need and also as a penalty for having their own financial means of living. A “gatekeeper” to entitlements is needed, who can provide knowledge, “fight” for entitlements and provide a voice for the chronic pain sufferer.

Focus group 3 participants from lower socioeconomic areas are also “locked” into medical and financial “systems” where they predominantly relate experiences of injustice. Here, however, there is a stronger sense of this. Participants more consistently identify themselves as patients living with pain. There is victimisation by pain and a continued sense of “Why me?” Pain is perceived as unfair from the time of its onset. What are dominant are the downward social comparison processes that are used to highlight their own disadvantage in life. There is a perception that other, marginalised groups receive unfair advantages over them. What is most unfair about this is that many of these groups are perceived to be responsible for their predicament, whilst chronic pain patients are innocent victims of pain. There is a concern with perceived “malingers” who threaten to de-legitimise the experience of chronic pain and threaten ones own identity as a chronic pain patient. This brings a fear of not being believed by healthcare “gatekeepers” who are essential for access to medical and financial aid upon which the group are dependent. Linked to this is a benefits “culture” where there is envy that perceived malingerers and others are able to afford a better quality of life than them, and who threaten to compromise their own entitlements. At the same time there is a sense of perceived shame in receiving “charity” that is buffered by a perception that one’s financial gains are somehow earned. Rejection by the benefits system brings the perception of procedural unfairness as well as feelings of being disrespected and fraudulent. Ultimately, the group seek to feel valued, respected and, most of all, believed about their suffering.

1.2.2 Spouse focus groups

Across all discussions, justice-related concepts are discussed in a relational context, in which the spouses are embedded in the suffering of their chronic pain partner. Chronic pain is a barrier to the marital relationship. Traditional roles are lost and the spouse becomes the carer. There is a fleeting reference to “Why me?” and also a perception that no one deserves to live with a spouse who suffers chronic pain. Equally, however, there is some adjustment, acceptance and a commitment to the meaning of the marriage vows. There is a broad perspective that what is considered unfair in life is subject to individual perspective, effort and balance, whereby what is fair is an equal balance of positive and negative life experiences. Here, there is an imbalanced relationship. What is unfair is reported not only in relation to the spouse perspective, but also the chronic pain partner perspective where there is some discrimination. From the spouse perspective, unfairness at times arises from feelings of personal deprivation and a sense of loss which results
from the limited commitment to activities that chronic pain can bring. To commit to activities alone would bring guilt and a sense of abandoning one's chronic pain spouse. In order to avoid this, the needs of the spouse are often neglected. What is most unfair to the spouse is that they should suffer psychologically at the hands of their chronic pain counterpart. There is some understanding and a perception that their chronic pain spouse is absolved from any accountability for their somewhat cruel and verbally abusive complaining behaviour during episodes of pain. What are described during pain are multiple personalities. There is a breakdown in communication. Key here is that there is meaningless blame of spouses by chronic pain partners that is accompanied by withdrawal, anguish, helplessness and fear on the part of the spouse, in an ongoing cycle. There is also guilt that one does not suffer chronic pain and some self-limitation in being careful not to “flaunt” one's abilities to the chronic pain spouse. Support is sometimes needed but spouses are often neglected in a flawed medical system. However, gaining spouse support is not a priority. Instead, there is a sense of “mulling along” with the chronic pain predicament in silence.

2. Development of Q-sample items
Quotations and ideas across all six chronic pain and spouse transcripts were used to generate a Q-sample of justice-related items in chronic pain. Additional sources were also drawn upon to generate a diverse sample of items, including consultations with colleagues, target groups, relevant research literature, chronic pain datasets and popular media. There was an original pool of 182 statements that was edited by the research team using criteria of eligibility, diversity, duplication and balance. A final set of 47 statements was reached and was successfully piloted with five target group participants. The 47 items form a new Q-sample of justice-related items in the context of chronic pain.

3. Study Phase Two
3.1 Recruitment and method
Multiple recruitment methods, including stratified random sampling, a limited snowballing technique, general advertisement and word of mouth was used to recruit chronic pain sufferers from primary and secondary care and a support group, spouses, health professional lecturers and members of the public. In all, 229 people expressed an interest in the study after contact, among which 80 responded with completed packs by the deadline. Given the demanding nature of this methodology, low numbers are to be expected. The mean age of the sample was 48.61 years (SD = 14.1); 50 (62.5%) of the sample were female. Participants were instructed to indicate their level of agreement or disagreement with each justice-related statement whilst ‘adopting the view of someone who suffers from chronic pain’. Level of agreement was indicated on a grid containing 47 boxes with response options ranging from -5 to +5, in the shape of a quasi-normal distribution. Participants were also invited to offer comments regarding the justice-related statements. Q-sorts were entered into PQ Method v2.11 (Schmolck, 2002), a programme which uses principal components analysis to examine data by person. An expert in Q-methodology was consulted in the process of analysis. For analysis purposes the sample was split into a chronic pain sufferer (insider) perspective and a non chronic pain sufferer (outsider) perspective. The unique features of each account are summarised here. Open-ended responses to the items for exemplificatory sorts (> .6 loading on a factor) were used to aid interpretation of the data.
3.2 Results
3.2.1 Chronic pain sufferer (‘insider’) results
Thirty three chronic pain sufferers were recruited into the study: 17 (51.5%) from General Practice, 13 (39%) from Pain Clinic and 3 (9%) from a support group. Twenty (60%) of the sample were female. The mean age of the sample was 54.67 years (SD = 10.85) and the mean pain duration was 16.12 years with an average current pain intensity of 6.30 (SD = 2.09). Thirteen participants (39%) reported pain in the middle body (e.g. abdomen), 10 participants (30%) reported pain associated with specific conditions (e.g. arthritis), 7 participants (21%) reported lower body pain (e.g. legs) and 3 participants (9%) reported upper body pain (e.g. neck). Within Q factor analysis, six factors emerged with eigenvalues >1.

Account one: pain is normal. It is not about injustice
Twelve participants’ Q-sorts exemplified this factor. There is a rejection of any idea that pain and its experience are a unique injustice. There is no basis for perceiving injustice. No one is to blame for pain. It can happen to anyone. Although not unjust pain isn’t easy and requires active attempts to cope, including acceptance.

Account two: pain is awful. It is society’s fault
Eleven participants’ Q-sorts exemplified this factor. There is primary victimisation at the hands of pain and secondary victimisation at the hands of society for a failure to appropriately acknowledge pain. Embedded here is a medical “rights” theme. Pain control is a basic human right and medical treatment should be provided unconditionally. However, the right to treatment isn’t being met by the current limited medical system.

Account three: chronic pain is not your fault, but it is your responsibility to address it
One participant Q-sort exemplified this factor. Pain is inevitable suffering. It is more predetermined than random. Although unfair, everyone suffers pain eventually. Chronic pain sufferers are responsible for their reaction to the injustice of pain. Depression isn’t the answer. Instead, a sufferer should become self-reliant. This isn’t necessarily about medical treatment. Instead, pain can be addressed in other, psychological ways to free oneself from pain.

Account four: it’s not fair, there should be a cure for pain
One participant Q-sort exemplified this factor. Within the account, pain itself is unfair. Pain is needless suffering. There is enough knowledge about the body in pain to alleviate it. That pain continues suggests conventional medical treatment is unsatisfactory. Managing pain is not at issue here. Pain should not be accepted. Instead, one should hope to be free of pain and independent, not because pain is difficult to cope with, but because pain should be curable and so there is no reason for this suffering.

Account five: if you are unlucky enough to suffer chronic pain, you deserve help
One participant Q-sort exemplified this factor. Those who suffer pain deserve more than others because, in addition to being challenging, sufferers aren’t culpable for their pain. It is bad luck. Individuals are treated unfairly because of their pain. However, despite this they don’t react badly to others. This increases a sense of deserving, perhaps as a reward. Pain gives no reason to be positive. However, there is a perspective that things could be worse. Help is justified, not because something is owed, but because it would make life easier. Although fortunate for the National Health Service, receiving unconditional medical help is deserved, although financial benefits would be better.
Account six: there is hope that the injustice of chronic pain will be redressed

One participant Q-sort exemplified this factor. Pain is useless suffering. It is inhumane. This suffering does not come to everyone. There is a perspective that justice will prevail in suffering. It is important to hope that pain will end and suffering will stop. When and how justice will prevail is not clear, but this life offers some temporary relief from suffering. There is a sense that medication can bring a sense of normality and clarity to realise what is important in life, while one waits to have the injustice of chronic pain redressed.

3.2.2 Questionnaire results

In addition to the Q-sort task, questionnaires were administered to the chronic pain sample. Specifically, The Roland and Morris Disability Questionnaire (Roland and Morris, 1983), The Beck Depression Inventory (BDI-II) (Beck et al, 1996), 20-item Chronic Pain Acceptance Questionnaire (CPAQ) (McCracken et al, 2004), Pain Solutions Questionnaire (PASOL) (De Vlieger et al, 2006), and Acceptance and Action Questionnaire (AAQ-II) (Hayes et al, 2004). The PASOL measures responses to the problem of pain: efforts to change or solve pain, or efforts to accept the insolubility of pain and change life goals. The AAQ-II measures psychological flexibility (willingness to accept negative thoughts and take action consistent with personal goals). The BDI and AAQ-II were also distributed to spouses. Forty chronic pain questionnaire packs and nine spouse packs were returned (19% response rate). Given the low number, spouse data is not presented here. Table 1 summarises the mean scores for the chronic pain sample on each measure. There is a moderate level of depression and disability and a measure of overall acceptance and psychological flexibility, as well as efforts to modify or accept the pain problem.

Table 1: Chronic pain scores on study measures

<table>
<thead>
<tr>
<th>Measure</th>
<th>Mean (SD)</th>
<th>Range</th>
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<tbody>
<tr>
<td>Disability</td>
<td>16.15 (5.83)</td>
<td>0-24</td>
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<tr>
<td>Depression</td>
<td>21.50 (12.70)</td>
<td>3-48</td>
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<tr>
<td>Acceptance (total)</td>
<td>50.31 (21.84)</td>
<td>17-113</td>
</tr>
<tr>
<td>PASOL Solving pain</td>
<td>17.94 (5.97)</td>
<td>6-27</td>
</tr>
<tr>
<td>PASOL Meaningfulness of life despite pain</td>
<td>20.36 (6.550)</td>
<td>6-30</td>
</tr>
<tr>
<td>PASOL Acceptance of the insolubility of pain</td>
<td>9.78 (5.50)</td>
<td>0-18</td>
</tr>
<tr>
<td>PASOL Belief in a solution</td>
<td>6.39 (4.20)</td>
<td>0-20</td>
</tr>
<tr>
<td>Acceptance and Action</td>
<td>31.28 (14.00)</td>
<td>5-60</td>
</tr>
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Although the low return rate precluded detailed statistical analyses, spearman’s rho correlations were conducted to explore relationships among variables. Depression correlated with disability ($r = 0.49$, $p = 0.002$), acceptance ($r = -0.52$, $p = 0.001$) and psychological flexibility ($r = -0.47$, $p = 0.003$). Thus depressed individuals were more disabled, displayed less psychological flexibility and were less accepting of their pain. Acceptance also correlated with psychological flexibility, ($r = 0.58$, $p = 0.000$), solving pain ($r = -0.34$, $p = 0.04$) and the meaningfulness of life despite pain ($r = 0.48$, $p = 0.002$). Thus, those who accepted their pain also displayed greater psychological flexibility, less persistence in actions to solve pain, and were more likely to find meaning in life despite pain. There was also a positive relationship between meaningfulness of life despite pain and acceptance of the insolubility of pain ($r = 0.39$, $p = 0.02$). We continue to collect data on these measures in Pain Clinic samples in order to determine relationships among them, and justice beliefs.
3.2.3 Non chronic pain sufferer ‘Outsider’ results
Forty seven ‘outsiders’ were recruited into the study: 23 (48.9%) members of the public (lay), 15 (31.9%) health professional lecturers and 9 (19%) spouses. Thirty (64%) of the sample were female. The mean age of the sample was 45.34 years (SD = 14.24). Within Q factor analysis, eight factors emerged with eigenvalues >1.

Account one: an added injustice is being ignored
One health professional lecturer Q-sort exemplified this factor. Here, individuals develop chronic pain because doctors don’t listen to them. So doctors are to blame for pain. This is one of the most frustrating aspects of pain. When pain does happen, doctors still don’t listen. This is cruel because there is nothing worse than pain. There is a lack of empathy and listening skills. In this context, independence is important. Patient should rely more on themselves than on health professionals in the management of their pain.

Account two: pain just happens. You should get on with it
Two lay participants’ Q-sorts exemplified this factor. Pain comes to us all. No one is to blame, specifically not doctors. There is, however, sufferer fault for self-pity in the chronic pain predicament. Chronic pain is associated with character weakness. That is not to say that there are no grounds to complain. However, pain is an important lesson. Sufferers should accept their lot and count themselves lucky for the medical treatment they receive when pain does happen.

Account three: pain is part of life. Sufferers don’t deserve any more than those without pain
Six participants’ Q-sorts exemplified this factor. Here, injustice is rejected. Pain is normal to everyday life. No one deserves to suffer chronic pain. Those who do suffer don’t deserve more than others. After all, there are worse fates to suffer. Chronic pain sufferers are fortunate to have the National Health Service. What is most important is the ability to cope and to be independent.

Account four: pain is depressing. No one understands it
One lay participant Q-sort exemplified this factor. Here the body in pain is poorly understood. The current medical system is unsatisfactory. Chronic pain is difficult to relate to and isn’t acknowledged as it should be. Pain also renders a sufferer powerless to live a normal life. No one deserves to suffer this way. The ignorance of pain is limited to society. Personal relationships are unaffected by pain. In reacting to the pain experience, anger is not justified. There are no grounds for anger, because there is no blame. Depression is more likely.

Account five: the chronic pain sufferer is victimised. Something should be salvaged from this injustice.
Two participants’ Q-sorts exemplified this factor. Not everyone will suffer pain. Those who do suffer continue to feel victimised by pain. There is also secondary victimisation by society, for failing to acknowledge pain, and for prejudice. It is difficult to empathise with those in pain. Pain is depressing. However, the injustice of chronic pain should be reappraised and something positive taken from it.

Account six: pain makes life difficult, but hoping for justice won’t help
One spouse Q-sort exemplified this factor. There is nothing worse than pain. Pain control is a human right, and, equally, chronic pain sufferers should be taught to help themselves. However, there is a gap between what should happen here and what is
happening, and individuals in chronic pain suffer needlessly. No one wants to hear someone complain of chronic pain, unless paid to do so. Chronic pain is not given due care and attention. This mentality extends into society in general, where there is a perception that chronic pain sufferers are treated badly. It is difficult to empathise with the chronic pain condition, unless it has been experienced personally. Pain is a unique subjective experience that can only be fully appreciated by a sufferer. How a sufferer should react to their pain experience is not at issue here, although hoping for justice won’t help.

Account seven: pain is part of life. Sufferers deserve more than those not in pain
One health professional lecturer Q-sort exemplified this factor. Pain is not unfair. It is part of life and comes to us all. It is bad luck. That is not to preclude the negativity of pain. One should hope to be free of it. No one deserves to suffer pain. When pain is experienced, more is deserved, because sufferers aren’t accountable for their pain. No one is to blame. More than anything else, help is needed for the psychological effects of pain. Pain is depressing and it isn’t possible to be happy in this suffering.

Account eight: an inadequate medical system is to blame for the suffering of pain
Eleven participants’ Q-sorts exemplified this factor. The chronic pain sufferer has just cause to be angry about their predicament. They suffer needlessly because of limited medical facilities. The medical system in general is at fault for not meeting the need for pain relief. Everyone has a right to pain control and to unconditional treatment. So there is a strong rejection of pain and the suffering it brings. It is important never to stop hoping to be free of pain. This isn’t about rights so much as a need to have control over one’s pain, and thus one’s life. Pain has a life of its own. It is cruel and unforgiving.

4. Overall Conclusion
Analysis and interpretation continues, but two key conclusions can be drawn overall. Firstly, although at times rejected or oblique, justice-related concepts inform an understanding of the implicit norms and rules which inform everyday life. Pain as injustice is most contested when pain is presented as “part of life” and there is acceptance. Secondly, injustice is often perceived when pain is perceived as somehow “wrong” and requires being rectified, in the context of its management, and societal responses to pain. The research presents unique and diverse perspectives of justice issues in chronic pain. Adding lay and health professional samples has brought much richness to the data that will be addressed in research output. Chronic pain and spouse accounts of injustice differ in focus in an actor-observer analogy whereby chronic pain sufferers report most injustice at an external, societal level, while spouses report most injustice at an internal, relationship level. We believe these exploratory results fill a gap in current knowledge about how chronic pain is experienced from multiple perspectives in society within a justice framework. At this point, as expected, the research raises more questions than answers. We make suggestions for future research on this basis (see future research priorities).

Activities and Outputs
Current project outcomes are (i) a novel Q-sample of justice-related items in chronic pain (ii) invited research talks at the University of Kent (iii) poster presentation at The British Pain Society (BPS) annual conference, 2009 (iv) reports of the study findings posted to chronic pain and spouse participants across primary and secondary care, and support group settings, where reports are also available to non-participants. No research articles have yet been submitted for publication, as the extension in recruitment demanded more
time and continued until towards the end of the project. However, two main journal articles are in progress. The first reports the IPA study of focus group participants and the second a combined two study report of the Q-methodology studies. Both will be targeted at mainstream social science applied to health journals such as “Health” and “Social Science and Medicine”. A topical review in this area, to be submitted to the journal PAIN is also under way and will be informed by these research findings. Other planned dissemination activities include: (i) a confirmed workshop at the BPS annual conference, 2010 (ii) an application submitted for a poster presentation at the European Pain Conference (EFIC) in Lisbon, 2009 (iii) an application submitted for a collaborative workshop at the IASP World Pain Congress in Montreal, 2010.

Impacts
There are implications of the research for how key Government stakeholders deliver information to make chronic pain sufferers aware of their possible financial and other entitlements on an equal basis to facilitate fair opportunity for everyone. Collaborative “gatekeepers” could facilitate this support. A gap was also highlighted in how spouses are targeted for support, which could impact upon current carer support provision.

Future Research Priorities
This research will be used to develop a measure of justice beliefs in chronic pain to help inform future work in this field. Discussions are already under way between the study investigators as to the precise direction of this work. Key future research questions are:

1. What are the origins of perceived injustice and how are decisions about this reached at a social and cultural level?

2. How does an individual who suffers from chronic pain react to perceived injustice in this context and what are the key motivations behind this?

3. How are perceptions of injustice influenced by chronic pain as a result of trauma and how does this impact upon the chronic pain experience and a perceived view of one’s position in the world?

4. How are decisions about whether or not to seek compensation or to litigate for chronic pain reached, and is any ‘psychological compensation’ reached at the end of this process?

These are important and challenging questions in this emerging but essential field of research and will be of great theoretical and practical importance. Further applications will be made to ESRC to support this work.
References


Additional materials: Annexes

A. Key recruitment materials
1. Letter to participants template
2. Study expression of interest form
3. Study information sheet template
4. Study consent form template

B. Key research materials
5. Phase 1 Chronic pain sufferer focus group semi-structured interview schedule
6. Phase 1 Spouse/partner focus group semi-structured interview schedule
7. Phase 1 Demographic Questionnaire template.
8. Phase 2 Q-sort task (containing 47 justice and chronic pain items which is also a study output)
   a. Instructions to participants
   b. Q-sorting grid
   c. Q-sample of justice items (also study output)
   d. Comment sheet
   e. Biographical information sheet