DOCTOR OF CLINICAL PSYCHOLOGY (DCLINPSY)

Understanding the link between mental defeat and chronic pain

Hazeldine, Charlotte

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Doctorate in Clinical Psychology: Main Research Portfolio

Charlotte Elizabeth Hazeldine

Doctorate in Clinical Psychology

University of Bath
Department of Psychology

July 2015

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# Word Counts

**Critical review of literature:** Non-suicidal self-injurious behaviour in female prisoners: a narrative review.  
7,112

**Service improvement project:** Transition to adult services for those with a life-limiting illness: the parents’ perspective. A qualitative service review.  
4,415

**Main research project:** Understanding the link between feelings of defeat and the experience of chronic pain.  
6,004

**Executive summary** for main research paper.  
1,000

**Connecting narrative**  
3,010
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Main Research Project: Abstract

Background. Recently, ‘mental defeat’ (MD) has been explored amongst the chronic pain population and considered as a sort of ‘self-processing’. Initial research has linked it to anxiety, pain interference and functional disability. Research has recommended that we explore the relationship between MD and other cognitive constructs, such as hopelessness and depression. The present study firstly considers MD as a predictor for pain symptomology and self-efficacy when related cognitive constructs are examined. Secondly, although chronic pain and MD commonly co-occur, causal relationships have yet to be established1.

Method. For the cross-sectional analysis, 59 participants from three pain services completed a questionnaire pack assessing five cognitive constructs; anxiety, depression, hopelessness, pain catastrophizing, and mental defeat. Participants also answered questions about their demographics, pain symptomology and self-efficacy.

Results. Linear regression analyses revealed that anxiety was most strongly associated with pain symptomology, accounting for 26% of the variance. When breaking down pain symptomology, catastrophizing showed the strongest association with sensory pain, and mental defeat the strongest association with affective pain. Finally, mental defeat was the most strongly associated variable with self-efficacy, accounting for 47% of the variance.

Implications. This research has demonstrated the potential importance of assessing mental defeat in chronic pain patients and, where suitable, targeting these feelings during interventions and therapy. This may have an impact on how well people feel able to cope with their pain. Further, the study indicates mental defeat is different to related cognitive constructs involved in pain, such as depression, hopelessness and catastrophizing.

1 The original plan was to clarify the link the between mental defeat and similar cognitive constructs, and then undertake an experiment to clarify the causal role of mental defeat on pain outcomes. What was originally anticipated to be one paper is now two papers. Italicised text is referring to Paper 2, which is presented in full in Appendix D.1.
Service Improvement Project: Abstract

**Background** Today, children with chronic, life-limiting illnesses are often living longer due to improvements in medical diagnoses and therapies and as a result are moving on from child to adult services. We explored the experiences of parents of children transitioning from a community paediatric palliative care service for children with life-limiting illnesses to adult services. The objective was to highlight key areas of strengths and areas for improvement.

**Method** A qualitative methodology was utilised to allow for in-depth, rich and personal accounts of the experiences of parents. Participants were six parents (four mothers and two fathers) from five families in the service who had children either due to transition within the upcoming 12 months or who had transitioned within the last 12 months. Semi-structured interviews took place at the family's home. Interview transcripts were analysed using an inductive thematic analysis approach.

**Results** Five main themes emerged from data; the process of transition, changes to the parental role, loss, uncertainty, and what families valued about the children's service. Within all these themes a range of sub-themes were presented.

**Conclusions** Transition represented a challenging time for parents and this study affirmed the need for undertaking reviews of clinical practice to further understand the ways in which families can be better supported through this period. Key messages included ensuring early and regular communication between parents, the young person and all services involved as well as acknowledging and supporting parents with feelings of loss and uncertainty and changes to their role.
Critical Literature Review: Abstract

Purpose
To review the available literature relating to risk factors and functions of non-suicidal self-injurious behaviour (NS-SIB) amongst female prisoners.

Design/methodology/approach
Databases PubMed, APA PsycNet and Web of Science were searched for English language studies published up to August 2014. Relevant journals and reference lists were also hand searched. Full-text articles were analysed for inclusion. Eighteen studies were narratively reviewed in two ways:

Part One - nine studies that specifically defined self-injury as non-suicidal
Part Two - ten studies where the definition was not clear or analysis was mixed, e.g., NS-SIB and suicide attempts.

Due to the nature of their analyses, one study met criteria for both parts.

Findings
Evidence indicates an association between NS-SIB and childhood sexual and physical abuse and maltreatment; prison environment problems, poor coping, communication and problem solving problems, and notably poor distress tolerance, high emotional intensity and high aversive cognitions. Links to theoretical models are discussed in detail. Comparisons between key associations elicited in Parts One and Two are explored.

Research limitations/implications
Studies were not rated on quality and the analysis was presented in a narrative rather than meta-analytical format. The small sample of papers also limits the impact. The findings may contribute to better identification of at-risk women within prisons, as well as inform psychological interventions.

Originality
No reviews have effectively explored risk factors and functions of NS-SIB amongst female offenders, and research lacks links to theoretical models. This review has addressed both of these problems.

Keywords: Non-suicidal self-injury; Women; Offenders; Risks; Functions.

Article Classification: Literature review
Critical Literature Review

Title: Non-suicidal self-injurious behaviour in female prisoners: a narrative review.

Author Details: Charlotte Hazeldine (University of Bath)
Email: ch291@bath.ac.uk

Academic Supervisor: Dr Catherine Hamilton-Giachritsis (University of Bath)
Email: chg26@bath.ac.uk

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Non-suicidal self-injurious behaviour in female prisoners: a narrative review

Self-injurious behaviours within the prison environment have been reported as a significant threat to inmates, staff and institutional organisations (Smith & Kaminski, 2011) and an ongoing problem (Riaz & Agha, 2011). Over time, empirical research on this topic has included a diverse range of studies, examining risk factors, management, and functions of self-injury. However, findings are frequently contradictory and challenges arise from the use of differing definitions around this behaviour.

Defining self-injurious behaviour

Many have argued that one of the greatest barriers and ongoing challenges for the study of self-injurious behaviour (SIB) is the use of inconsistent and unclear terms and definitions (Dixon-Gordon, Harrison, & Roesch, 2012; Nock, 2010; Power, Brown, & Usher, 2013). Self-harm, non-suicidal self-injury (NSSI), parasuicide, and self-mutilation are just a selection of terms used. More specifically, defining self-injurious behaviour at the ground level within prisons is challenging for staff and, as stated within the Prison Reform Trust's 'Troubled Inside' report (Rickford, 2003), what may be defined as self-injury in one prison may be very different within another. Examples include scratching one's arm, self-administering a tattoo, refusal to eat or attempting suicide through hanging; all of which prison staff within different prisons may record as self-harm.

More recently, researchers and clinicians have started to make more considered distinctions around these behaviours, which is a promising step. The 'classification of self-injurious thoughts and behaviours' theoretical and integrated model by Nock (2010) is a useful guide to explore this topic (see Figure 1.1).
As shown in Figure 1.1, Nock argued that all behaviours which are performed with the intention and knowledge that they will or could cause some degree of physical or psychological injury to oneself, could be conceptualised as 'self-injurious behaviour'. Within this broad classification is a distinction between behaviours in which bodily injury is the intended purpose (for example arm scratching) compared with those in which it is an unintended by-product (for example smoking tobacco and drinking alcohol). This review will solely focus on the intended SIBs. Within the intended self-injurious behaviour category a distinction has been made between those behaviours of 'suicidal nature' where there is intent to die and those that are 'non-suicidal in nature'. Suicidal behaviour and non-suicidal phenomena have both been further categorised into three sub-categories as highlighted in Figure 1.1. For non-suicidal behaviour this can include making suicide threats/gesturers, having suicidal thoughts and finally causing direct and deliberate destruction of body tissue in the absence of an observable intent to die.

Earlier definitions but similar to Nock (2010), come from Favazza (1989, cited in Favazza 1998), Pattison and Kahan (1983), and later Kenny, Lennings, and Munn (2008) who all defined SIB as causing harm to the body tissue in a deliberate manner but without the intent to die, such as cutting, scratching or burning one's
skin (Favazza, 1998; Pattison & Kahan, 1983). Linehan (1986, cited in Brown, 2002) differs to the aforementioned authors and prefers the term parasuicidal behaviour, considered as the deliberate act of self-injury with or without the intent to die. Parasuicidal behaviour can be sub-categorised into 'suicide attempts', 'ambivalent suicide attempts' and 'non-suicidal self-injury' with the latter fitting more closely with those previous definitions presented.

To conclude, the term non-suicidal self-injurious behaviour (NS-SIB) will be used within this review to explore those behaviours where an individual is causing harm to their body without the intent to die. The definition is based on the model previously described by Nock (2010).

Prevalence rates

Prevalence estimates of self-injurious behaviour (SIB) amongst the general prison population are varied, ranging from 2.4% (Smith & Kaminski, 2011) to 48% (Chapman, Specht, & Cellucci, 2005). Prevalence is reported to be even higher amongst prisoners with a mental illness, with up to 61% engaging in SIB (Gray et al., 2003). Largely, research has demonstrated that rates appear to be much higher within the prison population compared with the general population (Meltzer, Jenkins, Singleton, Charlton, & Yar, 2003), where estimates of 4% (Klonsky, Oltmanns, & Turkheimer, 2003) and 7% have been reported (Tait, Brinker, Moller, & French, 2014). In one study, incidents of self-harm over a three year period were 30 times higher in female prisoners compared with the general population of the UK (Hawton, Linsell, Adeniji, Sariaslan, & Fazel, 2014). To note however, these authors used staff records of self-harm incidents to collect data which, is open to variability in reporting and definitions, possibly affecting reliability.

The high prevalence of self-injuring behaviour amongst female prisoners is well established and historically the problem appeared to be increasing. Between 2003 and 2007 there was a reported 48% increase in the incidence rate amongst this population (The Howard League for Penal Reform, 2008). Rates do continue to vary across studies however. Völlm and Dolan (2009) reported a prevalence of 37.8% in 2009 and in 2003, Snow, Greenaway and Paton (2003, cited in Rickford, 2003) reported that 33% of the average daily population within two women's prisons reported engaging in self-injurious behaviour. Caution needs to be applied
for this study however as the sample size was not reported, and data was collected over a relatively short time period of ten months. More up-to-date prevalence rates vary, for example 29% by Riaz and Agha (2011) and 41.1% by Power, Brown, & Usher (2013). This variance in results possibly reflects the differences in terminology and methodology between studies.

There appears to be a consensus within the literature that the prevalence rate for NS-SIB amongst female prisoners is higher than for males (Hawton et al., 2014; Snow et al., 2003 cited in Rickford, 2003). The first study found that between 2003-2009 incidents of NS-SIB were 10 times higher in female prisoners compared with male prisoners. Interestingly, this study demonstrated that, as well as there being more women self-harming in prison than men, the number of incidents of self-injury for women self-harmers was also much higher. In 2009 there were on average 7.4 incidents of self-injury per female self-harmer, compared with only 2.5 for male self-harmers. This would suggest that there are possible factors which make female prisoners more vulnerable to recurring NS-SIB.

The costs of NS-SIB

The costs of NS-SIB within the prison system are wide-reaching, affecting staff, fellow prisoners, services and of course the individual themselves. Research has indicated negative effects on staff morale, confidence and attitudes (DeHart, Smith, & Kaminski, 2009), as well as on institutional resources and behaviour of other inmates (Traver & Rule, 1996). The latter researchers described a contagion effect which takes place, seemingly drawing from the principles of social-learning theory (Bandura, 1977, 2006 cited in Nock, 2010), where previously non-self-harming inmates learned from and imitated the behaviour of self-injuring prisoners.

For the prisoner themselves, the impact of this behaviour can be profound. Research has frequently demonstrated that NS-SIB is one of, or sometimes the most, significant predictor of subsequent suicide (Cooper et al., 2005; Sakinofsky, 2000; Zahl & Hawton, 2004), with one study reporting that female prisoners with a history of NS-SIB were 26 times more likely to report having attempted suicide compared with those without this history (Roe-Sepowitz, 2007). This highlights the importance of gaining a clearer understanding of this phenomenon for better
identification of risks, monitoring and treatment. In 2014, three self-inflicted deaths amongst female prisoners occurred in England and Wales (INQUEST, 2014), significantly lower than in 2003 and 2004 where there were 14 and 13 self-inflicted deaths respectively. These statistics indicate possible signs of improvement in the screening and management of suicidal prisoners. What is important however is to gain more of an understanding of why so many female prisoners engage in SIB without suicidal intent. This leads us into the primary aim of the current review which was is examine the risk factors and functions associated with NS-SIB amongst female prisoners.

Theoretical underpinning
Historically, researchers and clinicians have been interested in why people engage in SIB and several theories have been proposed. The psychodynamic perspective suggests that self-injury is the expression or repression of drives such as life, death and sexual urges (Cross, 1993; Friedman, 1972), to regulate affect and end dissociative episodes (Herpertz, 1995; Miller & Bashkin, 1974 cited in Favazza, 1998), to define the boundary between the self and others, or to protect others from one's own anger or rage (Simpson & Porter, 1981; Suyemoto, 1998). Others have approached this behaviour from an environmental angle, using theories such as the social learning hypothesis (Bandura, 1977, 2006) to argue that this behaviour is learned from observing those around us. Attachment theory has also been posited as an explanation. Simpson and Porter (1981) argue that self-injury is the result of unusual disruptions in the early attachment process, with many of their sample of self-injurers having being abandoned at an early age and experiencing physical and sexual abuse at the hands of family members. They argue that it is a plausible and effective defence that is designed to handle stress by reducing painful emotions. This sample was however small in size, only 20 participants and information was collected via hospital records, therefore we cannot be sure of any possible mediating or moderating mechanisms involved in the correlation between experiencing early trauma and NS-SIB.

Linehan's (1993) theory of borderline personality disorder (BPD) states that the defining feature of BPD is emotion dysregulation, a multi-dimensional construct which includes an inability to tolerate emotional distress. Behaviours commonly
associated with BPD, including deliberate SIB, are thought to function to reduce or eliminate painful emotions that the individual cannot tolerate. Linehan argued that deliberate SIB serves to help the individual avoid or escape from unwanted emotional experiences, and in line with this theory, there is increasing evidence for the role of emotional and experiential avoidance in BPD (Chapman et al., 2005; Lejuez, Daughters, Wolf, Kosson, & Lynch, 2004 cited in Chapman, 2005.) This theory of SIB however is specifically relating to people suffering with BPD, and later work has attempted to create a more generalisable model.

Chapman, Gratz and Brown (2006) developed the 'Experiential Avoidance Model', similarly stating that deliberate self-harm (DSH), characterised by the absence of intent to die, is primarily maintained by negative reinforcement in the form of escape from or avoidance of unwanted emotional experiences resulting in temporary relief. The likelihood of avoidance occurring from an emotional response is affected by poor distress tolerance, emotion regulation skill deficit, high emotion intensity and difficulty regulating when aroused. As can be seen in Figure 1.2, the authors post a variety of possible theories for the experience of the relief, including the opioid hypotheses (DSH elicits endogenous opioids which create analgesia and relieve emotional distress, Coid, Allolio, & Rees, 1983 cited in Coid, 1992; Russ, 1992); distraction hypothesis (physical pain distracts from painful emotional arousal, Gottman & Katz, 1989; Gross, 1998), and finally the self-punishment hypothesis (DSH produces reductions in emotional arousal through a process called self-verification, Swann, Hixon, Steinseroussi, & Gilbert, 1990). Self-verification has been described as covering behaviours including self-criticism, self-deprivation and other perceived deserved negative consequences of perceived transgressions. Chapman et al. (2005) believe that DSH is negatively reinforced by the reduction in the intensity of or escape from unwanted emotional arousal and that this, as well as a habituation to negative effects and rule-governed behaviour, exacerbate the vicious cycle of SIB.
Unlike the theory of DSH by Linehan (1986 cited in Brown, 2002) which is based on a BPD population, Chapman's model applies across the general population and specifically refers to SIB which is non-suicidal in nature. More recently, Nock (2010) developed a theoretical model of SIB integrating several diverse theories and findings around self-injury. As can be seen in Figure 1.3, a range of associated distal risk factors are incorporated in the model including childhood abuse/maltreatment, familial hostility and genetic predisposition for high emotional and cognitive reactivity. Intrapersonal and interpersonal vulnerability risk factors (including poor distress tolerance and poor communication skills respectively) interact with the stress response and NS-SIB-specific vulnerability factors (incorporating for example the opiate, self-punishment and social learning hypotheses) to predict NS-SIB. It is this NS-SIB which serves to regulate the stress response (including over or under arousal and unmanageable social demands).
Figure 1.3. Integrated theoretical model of the development and maintenance of self-injury from Nock (2010)

These models specifically have examined SIB which is non-suicidal in nature, an important distinction and have allowed researchers to gain a useful theoretical base from which to study the risk factors and functions associated with SIB amongst offender populations. There is however a lack of research of this nature and so the was the second aim of the current narrative review is to link key findings regarding risk factors and functions to these theoretical models. Research had previously demonstrated that there were possible differences in reasons why women prisoners engaged either in NS-SIB or in SIB with suicidal intent. Brown, Comtois, and Linehan (2002), for example, reported that women engaging in NS-SIB did so to express anger, punish oneself, generate normal feelings and distract oneself. Those who made a suicide attempt detailed different reasons for the behaviour; to make others better off. This leads us into the final aim of the review which is to determine whether themes arising from studies which have not distinguished between self-injury with or without suicidal intent will reveal any apparent similarities or contradictions when compared with studies explicitly explore NS-SIB only.

Current research into self-injurious behaviour
There remains a lack of quality reviews around this topic. Several years ago Lohner and Konrad (2007) completed a literature review of self-harm for males and females in custody. They argued that findings on potential risk factors for SIB are 'largely contradictory' because of differences in sample selection and
dependent variables, notably deliberate self-harm without suicidal intent versus suicide attempts. Unlike this planned review, in their review Lohner and Konrad (2007) included papers exploring both suicidal attempts and NS-SIB but did not separate out risk factors according to both of these classifications. The review however did allow for an initial synthesising of the risk factors that may play a role in increasing a prisoner’s risks of suicide or self-injury, but not gender specific.

A systematic review was more recently completed by Dixon-Gordon et al. (2012) which aimed to explore risk factors for NS-SIB for male and female offenders, distinguishing NS-SIB from self-injury with intent to die. After examining in detail the studies reviewed within this paper, it is apparent that the study did not meet its aims. Papers such as that by Völlm and Dolan (2009) were included in the review that did not differentiate between NS-SIB and suicide attempts in their analysis. Additionally, only 4.4% of their overall sample reported having engaged in non-suicidal self-injury within the last week and 27% ever. Within their analysis Völlm and Dolan (2009) have two groups; prisoners with a history of self-harm or attempted suicide, and prisoners without this history. When Dixon-Gordon et al. (2012) summarised this paper stating ‘NSSI is associated with depressive symptoms’, it overlooked the fact that the results are based on sample which contains prisoners who have attempted suicide. A similar issue arises in the study by Marzano, Faze, Rivlin and Hawton (2010), included in Dixon-Gordon’s sample. Of their sample of 60 women offenders, only three of these engaged in self-harm without the intent to die. Data analysis did not separate out women with and without suicidal intention. The results from this review are therefore unreliable and do not provide further knowledge regarding factors associated solely with NS-SIB.

In summary, it is well known that prevalence rates are much higher in women prisoners compared with men, and NS-SIB continues to be a problem within the penal system. However, to date, there remains no review of the literature exploring factors and functions associated with this behaviour amongst female prisoners. A vast amount of the literature has included studies with samples consisting both of those engaging in NS-SIB and SIB with suicidal intent, or studies which simply did not provide an explanation of the definition of ‘self-harm’ or ‘self-injury’. It is not known whether the key findings arising out of these studies are yielding interesting
differences or similarities with those studies where the nature of the SIB is explicitly defined as being non-suicidal in nature. Finally, much of the research exploring NS-SIB is correlational in nature and most of the research remains atheoretical. Models of self-harm do exist yet no rationale is provided in the literature as to why these risk factors predict NS-SIB in this population.

**Aims**
1. To build on previous research by undertaking a narrative review of the risk factors and functions associated specifically with NS-SIB amongst adult female prisoners (Part One of the review).
2. To relate the findings to applicable theoretical models of SIB.
3. To compare the results with an overview of themes arising from studies which have not distinguished between self-injury with or without suicidal intent to draw out any apparent similarities and contradictions (Part Two of the review).

**Method**

**Search strategy**
The following databases were searched between June and August 2014: PubMed, APA PsycNet and Web of Science. The search strategy used the following terms: "women offender" OR "women prisoner" OR "female prisoner" OR "female inmate" OR "incarcerated women" OR "federally sentenced women" AND "self harm*" OR "self injur*" OR "self mutilat*". The strategy was checked by a librarian familiar with the databases and MESH terms needed to optimise the search. Additional articles were obtained by citation tracking.

**Inclusion and exclusion criteria.** Both quantitative and qualitative papers were included if they met the following criteria:

1. the sample was adult female offenders on remand or sentenced (excluding forensic psychiatric patients in a hospital setting)
2. written or translated into English language
3. published any date up to August 2014
4. a definition of non-suicidal SIB explicitly not including suicidality
5. pertaining to: risk factors and functions of NS-SIB
In addition, papers were excluded if they were:
1. case studies
2. theses and dissertations
3. literature reviews

Titles and full abstracts were initially screened to determine if they, a) explored risk factors or functions associated with NS-SIB, and b) sampled female offenders. After this stage the full text paper was scrutinised to determine whether the author's definition of self-harm met the inclusion criteria. Where studies declared to be an exploration of 'self-harm', 'self-injury' and so forth, but whose definition of this behaviour included both non-suicidal and suicidal intent, or where intent was not reported or unknown, these papers were selected for Part two of the review (see Figure 1.4).
Results

Search results

Across the three databases the search terms resulted in eighty-five hits including duplicates. Once duplicates were removed, this resulted in seventy-five papers. Nineteen papers were eligible according to title and abstract. Of these, seven were eligible for the review of NS-SIB studies, and eight were considered eligible for review in part two of this analysis. The study by Borrill et al. (2003) was included within both parts of this review. This was because part of their analysis was undertaken just examining self-harm, included in part one of the review, whereas a further part grouped self-harm and suicide together, included in part two of this review. Cross referencing reference lists yielded four suitable papers making the

Figure 1.4: Process of selecting papers for review

*NB. One paper was eligible for review in both parts of the analysis.
final sample nine papers for NS-SIB only (see Table 1.1) and ten papers for part two of the review (see Table 1.2). In both cases, most papers were quantitative, with only one paper in each part of the review being qualitative.
<table>
<thead>
<tr>
<th>Author</th>
<th>Population sample is taken from</th>
<th>Sample size</th>
<th>Formal DSH/NS-SIB rating scale?</th>
<th>Key associations with NS-SIB</th>
</tr>
</thead>
<tbody>
<tr>
<td>Borrill (2003)</td>
<td>Women inmates from 10 prisons across England, UK.</td>
<td>301</td>
<td>Yes. Section C (suicidality) of the MINI International Neuropsychiatric Interview.</td>
<td>Lifetime NS-SIB associated with history of harmful drinking and with being a victim of violence, including physical assault, sexual assault and violence from family and friends. Drug dependence may be a predictor of NS-SIB in the black female prison population. White women had slightly higher rates of multiple self-harm than black/mixed race women.</td>
</tr>
<tr>
<td>Chapman (2005)</td>
<td>Minimum and maximum security female inmates from a multilevel women’s prison in USA.</td>
<td>105</td>
<td>Yes. Lifetime Parasuicide Count-2 asked about self-harm (no intent to die) and Suicide attempts.</td>
<td>Those with BPD reported greater prevalence of NS-SIB (73%) than non-BPD participant (34%). There was a link between BPD severity and experiential avoidance but not acting as mediator. Thought suppression and mental disengagement approached significance.</td>
</tr>
<tr>
<td>Author</td>
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<tr>
<td>Chapman (2014)</td>
<td>Minimum and maximum security female inmates from a multilevel women’s prison in USA.</td>
<td>104</td>
<td>Yes. The Lifetime Parasuicide Count-2 (LPC-2; Linehan &amp; Comtois, 1996) asked about self-harm (no intent to die) and Suicide attempts.</td>
<td>Active coping negatively associated with presence and frequency of NS-SIB. Avoidant coping and childhood physical/emotional abuse positively associated with NS-SIB. Type of index offence did not differ as a function of NS-SIB status. Length of current prison stay not significantly associated with NS-SIB frequency. Severity of childhood physical/emotional abuse significantly positively correlated with NS-SIB frequency.</td>
</tr>
<tr>
<td>Coid (1992)</td>
<td>Female remand prisoners from UK with history of self-mutilating.</td>
<td>74</td>
<td>No. Battery of questions completed by prisoner containing items on self-mutilation.</td>
<td>Anxiety, anger, depression, irritability &amp; feelings of tension. 69% had a diagnosis of BPD. NS-SIB characterised by a progressive ‘build-up of symptoms’. Mutilation then causes a relief of these symptoms.</td>
</tr>
<tr>
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<tr>
<td>Ireland</td>
<td>Women prisoners at a UK closed prison holding medium to high risk offenders.</td>
<td>190</td>
<td>No. Questions asked concerning SIB. These were scored on a scale of 0 (never) to 3 (often) and combined to produce an overall SIB score.</td>
<td>Decreased social dysfunction</td>
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<td>(2011)</td>
<td></td>
<td></td>
<td></td>
<td>Severe depression</td>
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<td></td>
<td></td>
<td></td>
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<td>Poor emotional coping skills</td>
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<tr>
<td>Mangall</td>
<td>Inmates from a women's prison in USA who had engaged in DSH acts without conscious suicidal intent.</td>
<td>7</td>
<td>No. Semi-structured interviews conducted by researcher exploring the topic of NS-SIB.</td>
<td>Extraversion</td>
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<td>(2010)</td>
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<td>Author</td>
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</table>
| Ireland (2011) | Women prisoners at a UK closed prison holding medium to high risk offenders.                   | 190         | No. Questions asked concerning SIB. These were scored on a scale of 0 (never) to 3 (often) and combined to produce an overall SIB score. | Decreased social dysfunction
|                |                                                                                                                                               |             |                                                                                                 | Severe depression                                                                                           |
| Roe-Sepowitz (2007) | Female inmates from 5 prisons in a southern state of USA.                                                | 256         | Yes. Definition of SM was an affirmative answer to question ‘Have you ever intentionally hurt yourself even though you were not trying to commit suicide?’ from the TSI (Trauma Symptom Inventory, Briere 1995). | Being Caucasian, younger, or serving a higher than average length of sentence associated with a higher rate of reported NS-SIB
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<tr>
<td>Slotboom et al (2011)</td>
<td>Sentenced and on-remand inmates from 4 women's prisons in the Netherlands.</td>
<td>251</td>
<td>Yes. ISWI (International Study on Women's imprisonment) containing questions added regarding self harm.</td>
<td>8 factors found to predict self-harm: repression and lack of respect by staff; problems in prison; lack of contact with family; having young children while in prison, prior treatment for mental health problems, prior detention and native language (non-native speakers had higher likelihood of harming themselves than native speakers).</td>
</tr>
<tr>
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<tr>
<td>Hawton (2014)</td>
<td>Records of self-harm incidents in all prisons in England and Wales between 2004 and 2009 *here just focusing on findings relating to women</td>
<td>26,510 individual female prisoner records</td>
<td>No. Data obtained from notes on self-harm recorded within the prisons</td>
<td>In female inmates, a history of more than five self-harm incidents within a year was associated with subsequent suicide. Younger women, Caucasians and those awaiting sentencing had a higher prevalence of SIB</td>
</tr>
<tr>
<td>Kenning (2010)</td>
<td>Incarcerated women from 1 prison in England</td>
<td>15</td>
<td>No. Qualitative semi-structured interviews with women prisoners</td>
<td>Imported factors - past histories of SA, DV, family neglect, bereavement, having children removed from their care and mental health problems. Situational factors - unpleasant event, being denied something, changes in environment, being moved to another area of the prison, feelings of being bullied, punished and not being listened to</td>
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<tr>
<td>Marzano (2010)</td>
<td>Women prisoners from 10 'closed' female prison establishments in England and Wales, UK</td>
<td>120 (60 SH cases, 60 controls)</td>
<td>Yes. Beck Suicide Intent Scale (Beck, 1974; cited in Marzano 2011), and interview asking whether they had previously self-harmed without suicidal intent or attempted suicide.</td>
<td>Strongest associations with SIB were: current depression, presence of two or more psychiatric diagnoses, history of psychiatric in-patient treatment and previous attempted suicide, especially in prison. Only tested diagnoses not associated with SIB were antisocial PD, substance use and ED's</td>
</tr>
<tr>
<td>Marzano (2011)</td>
<td>Women prisoners from 10 'closed' female prison establishments in England and Wales, UK</td>
<td>120 (60 SH cases, 60 controls)</td>
<td>Yes. Beck Suicide Intent Scale (Beck, 1974; cited in Marzano 2011).</td>
<td>Being on remand, in single cell accommodation and reporting negative experiences of imprisonment strong correlates of SIB. Recent life events, past trauma (inc. different forms of CA), family history of suicide, high depression, aggression, impulsivity &amp; hostility, and low levels of self-esteem and social support also associated</td>
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<tr>
<td>Author</td>
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<tr>
<td>Milligan (2005)</td>
<td>Sentenced women inmates at 1 UK prison</td>
<td>89</td>
<td>Yes. 4 items from the Impulsive Behaviour Scale (IBS: Rossotto, Yager, &amp; Rorty, 1994)</td>
<td>Shame and anger significantly higher for those reporting SIB. Bodily shame and CSA significantly predicted rates of self-harm. Bodily shame strongest independent relationship with SH. Weaker but still significant association with CPA. Caucasian women significantly more likely to SH compared with Afro-Caribbean women. Trend but not statistical sig for women with violent convictions to be more highly represented in SIB group</td>
</tr>
<tr>
<td>Rutherford (2004)</td>
<td>Pre-trial and sentenced women from a UK prison</td>
<td>60</td>
<td>No. Information from retrospective case note reviews from Jan-Dec 1995</td>
<td>Sig higher SIB in PD group. Of SIB group, 77% had history of CSA, 93% had previously used psychiatric services and 81% suffered with a mental illness</td>
</tr>
<tr>
<td>Turner &amp; Tofler (1986)</td>
<td>Female remand &amp; sentenced prisoners from a UK prison</td>
<td>708</td>
<td>No. SIB assessed via clinical interview with a nurse</td>
<td>Those with a history of SIB were significantly younger than those with a history of no SIB ($p&lt;.001$)</td>
</tr>
<tr>
<td>Author</td>
<td>Population sample is taken from</td>
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<tr>
<td>Vollm et al. (2009)</td>
<td>Female remand &amp; sentenced prisoners from 3 UK prisons</td>
<td>638 (281 had history of SIB)</td>
<td>Yes. Questionnaire on suicidal intent and self-harm adapted from Singleton, Meltzer, Gatward, Coid, &amp; Deasy (1998, cited in Vollm et al. 2009)</td>
<td>75% reported engaging in SH to 'relieve unpleasant feelings of anger, tension, anxiety or depression'. No sig association with conviction status or length of sentence and SH. Age approached significance ($p=.08$) with women being slightly younger who engaged in SIB. Significant association with having a history of violent offences, homicide or attempted homicide.</td>
</tr>
<tr>
<td>Zlotnick (1999)</td>
<td>Incarcerated women in a correctional institution in USA</td>
<td>85</td>
<td>Yes. Used the Regulation of Affect and Impulses subscale from SIDES (Structured Interview for Measurement of Disorders of Extreme Stress, Pelcovitz et al 1997)</td>
<td>Women with Antisocial PD reported a significantly higher frequency of SM in last 3 months than those without ASPD but relationship not independent of diagnosis of BPD</td>
</tr>
</tbody>
</table>

Table 1.2 (Continued)
Part One: Clinical characteristics, risk factors and functions of NS-SIB

Nine papers were reviewed for this section. For the eight quantitative studies, sample sizes were generally of an acceptable size, ranging from 74 to 771. Many utilised several different prisons for sampling, and data has come from the USA, UK and the Netherlands. The one qualitative study by Mangnall and Yurkovich (2010) had a small sample size of just seven, and so caution needs to be applied to generalisability here. All were carefully scrutinised for their measurement of NS-SIB, with methods including interviews, checking of medical records, and standardised questionnaires such as the Lifetime Parasuicide Count-2 (Linehan & Comtois, 1996). One challenge arose with the study by Coid, Wilkin, Coid and Everitt (1992) whereby, within the 'Cluster 1' group, one prisoner out of 51 reported self-harm with suicidal motive. Because of the small number after careful consideration this paper was still included within the review.

Demographic Characteristics. The evidence exploring the association between age and likelihood of engaging in NS-SIB is mixed. Three studies revealed that age did not play a significant role (Chapman, Gratz, & Turner, 2014; O'Brien, Mortimer, Singleton, & Meltzer, 2003; Slotboom, Kruttschnitt, Bijleveld, & Menting, 2011), yet contradicting this Roe-Sepowitz (2007) reported a higher prevalence of NS-SIB amongst younger offenders. Chapman et al. (2005) also reported that younger female offenders with BPD had a higher lifetime prevalence of SIB. Caution is applied here however as the sample only consisted of those with a diagnosis of BPD whereas other studies sampled the general female offender population. Some have argued that rates of NS-SIB appear to be higher amongst White Caucasian women (O'Brien et al., 2003; Roe-Sepowitz, 2007) and non-native speakers (Slotboom et al., 2011). Interestingly in the study by Borrill et al. (2003), white women had slightly higher rates of multiple self-harm than black/mixed race women (19% and 12% respectively), but it was black/mixed race women with a drug dependency who had the greatest overall incidence of NS-SIB in the previous month. This would suggest drug dependency may play a role in the association between ethnicity and NS-SIB. Having children under 18 years appeared to be a significant risk factor in one study (Slotboom et al., 2011), but was not examined within the other papers. Similarly serving a greater than average sentence length, in this case 69.9 months (Roe-Sepowitz, 2007), and first
time incarceration (Slotboom et al., 2011) were found to be significantly associated with NS-SIB.

**Psychopathology.** Research exploring psychopathology and NS-SIB amongst women offenders appears to yield some consistent findings. In the study by Coid et al. (1992), 91% of the 51 female 'Cluster 1' self-mutilators reported high levels of anxiety, 80% anger and 86% depression. Ireland and York (2012), however, found that severe depression, but not anxiety, was a predictor of SIB threats and attempts; whilst anxiety, but not depression, was significantly associated with self-injurious cognitions. Finally, in a sample of 109 women, Roe-Sepowitz (2007) revealed significant associations between NS-SIB with anxiety, depression, impaired self-reference, dissociation, intrusive experiences and anger. They further reported associations with bingeing and vomiting, and NS-SIB. To note with this study, participants were those women specifically accessing a trauma and abuse intervention programme, possibly affecting generalisability. Finally, Slotboom et al. (2011) found a significant relationship between prior treatment for mental health problems and NS-SIB.

Having a personality disorder (PD) has been also demonstrated as a risk factor. In the study by Chapman et al. (2005), of 105 women offenders, those with BPD ($n=37$) reported a higher prevalence of NS-SIB (73%), than non-BPD participants (34%), a statistically significant difference ($p<.01$). Further, Coid et al. (1992) found that 84% of female self-mutilators had a diagnosis of BPD and 57% antisocial PD. Finally, O'Brien et al. (2003) reported that prisoners with probable ‘antisocial and other’ and ‘other only’ PDs had higher rates of self-harm than those with ‘antisocial only’ or no personality disorder. Caution clearly needs to be applied here, as the authors described ‘probable’ PD assessed during a clinical interview, and not PD diagnosed from a formal assessment.

Substance abuse has been linked to NS-SIB in several studies (Borrill et al., 2003; O'Brien et al., 2003; Roe-Sepowitz, 2007). Interestingly, Borrill et al. (2003) found that although harmful drinking was significantly associated with lifetime NS-SIB, drug abuse was only a significant predictor for black/mixed race women, suggesting an interaction between ethnicity, dependence and NS-SIB. When compared with a non-self-mutilating group of women prisoners, Roe-Sepowitz (2007) found a significantly greater number of the self-mutilating group engaged in
excessive alcohol use (65.1% v. 46.3%, \( p=0.01 \)) and drug use (81.7% v. 69.4%, \( p=0.05 \)) measured using their Esuba survey. Both Borrill et al. (2003) and O'Brien et al. (2003) used the Alcohol Use Disorders Identification Test (AUDIT; Saunders, Aasland, Babor, de la Fuente, & Grant, 1993), a standardised tool for assessing substance use. Contrasting these findings, Chapman et al. (2005) found that substance abuse did not significantly correlate with NS-SIB frequency.

**History of abuse and maltreatment.** In line with much of the literature, three studies reported an association between the experience of abuse and NS-SIB. Within their qualitative study, Mangnall and Yurkovich (2010) found that all female self-injurers \( (n=7) \) reported experiencing lifetime abuse, yet the type of abuse was not detailed. In the study by Roe-Sepowitz (2007), 89.9% of the self-mutilating women had experienced childhood sexual abuse (CSA), compared with 67.3% in the non-self-mutilating control group, a statistically significant difference \( (p=0.01) \). Similarly, the results for childhood emotional abuse (CEB) in this study were 37.6% and 14.3% respectively, \( (p=0.01) \), and for childhood physical abuse (CPA) 58.7% and 42.9% respectively \( (p=0.05) \). In their study, Chapman et al. (2014) reported that severity of childhood 'physical/emotional abuse' was significantly positively correlated with NS-SIB frequency, but not sexual abuse. One limitation here is that physical and emotional abuse were combined to create an overall category, and so one cannot be certain whether these differing types of abuse would have influenced the outcome if measured separately. Abuse in this study and that by Roe-Sepowitz (2007) was measured using the Child Maltreatment Interview Schedule (CMIS; Briere, 1992 as cited in Roe-Sepowitz, 2007).

**Environmental influences.** Only one paper reported on the relationship between prison environment and NS-SIB. Slotboom et al. (2011) found that having lack of contact with children and family; lack of staff respect; and experiencing problems in the prison environment (examples were not provided), were predictors of NS-SIB amongst offender women. It may be of interest to question whether the problems and environmental influences were affected by other factors such as an inability to tolerate distress and a lack of problem solving and communication skills, which are discussed later as risk factors in their own right. Clearly evidence for the role of environment comes from only one study so caution must be applied to generalisability.
Intra- and interpersonal risk factors. Poor distress tolerance (Coid et al., 1992; Mangnall & Yurkovich, 2010; Roe-Sepowitz, 2007), and the experience of high emotional intensity and high aversive cognitions (Chapman et al., 2005; Coid et al., 1992; Mangnall & Yurkovich, 2010; Roe-Sepowitz, 2007), were found to play a role in NS-SIB for female offenders. Ireland and York (2012) also found an association between NS-SIB and detached coping and lack of emotional coping skills, and similarly, Chapman et al. (2005) reported a significant negative correlation with thought suppression. Chapman et al. (2014) found active coping (measured using the COPE, Carver, Scheier, & Weintraub, 1989) was significantly negatively associated with NS-SIB, but avoidant coping was not significant. Finally, poor communication (Mangnall & Yurkovich, 2010), and problem solving skills (Chapman et al., 2014; Chapman et al., 2005; Ireland & York, 2012) are interpersonal risk factors which have been linked to NS-SIB for this population.

Function and consequences. Researchers have been interested in exploring the function of NS-SIB amongst women offenders and consistent findings indicate that it offers avoidance of and relief from high emotional intensity and aversive cognitions (Chapman et al., 2014; Chapman et al., 2005; Coid et al., 1992; Mangnall & Yurkovich, 2010; Roe-Sepowitz, 2007). What is apparent from much of the literature is that NS-SIB initially leads to feelings of relief but soon the consequences of this behaviour, including reactions from others and own judgements, leads to feelings of guilt or shame, which in turn leads to a need to release these emotions, making further NS-SIB likely (Coid et al., 1992; Mangnall & Yurkovich, 2010).

Part Two: Clinical characteristics and risk factors arising from the literature when NS-SIB and self-injury with suicidal ideation are not separated (‘self-harm’) This section presents the key themes which arose from reviewing ten papers where authors did not distinguish between self-injury with or without suicidal intent within their methodology or analysis. Eight of these papers were quantitative in design, with sample sizes ranging from 60 to 12,821. One paper was qualitative (n=15) and one employed a mixed-method design (n=120). Nine of the studies were conducted within UK prisons and one in the USA (Zlotnick, 1999) with a mixture of remand and sentenced prisoners sampled. One study deemed to be of low quality was that by Rutherford and Taylor (2004) which employed case note
reviews to determine incidence of self-harm, mental illness and so forth. Clearly this retrospective and descriptive methodology is subject to reporting bias and so caution must be applied to the findings.

Demographic Characteristics. Unlike the results identified in Part one of the analysis, where evidence for the link between age and NS-SIB was mixed, there appears to be a more consistent trend here towards younger women being more likely to engage in SIB (Hawton et al., 2014; Turner & Tofler, 1986; Völlm & Dolan, 2009). Only one study in this analysis found a significant association with ethnicity. When comparing a group of self-harmers (n=51) to 'no-self-harmers' (n=58), Milligan and Andrews (2005) reported that 90% of the first group and 68% of the latter were Caucasian, a statistically significant difference (p<.05). Being on remand (Hawton et al., 2014; Marzano, Hawton, Rivlin, & Fazel, 2011) and serving a life sentence (Hawton et al., 2014) have also been associated with greater incidence of self-harm, yet Völlm and Dolan (2009) reported no significant association with conviction length or status. The latter paper contrasts the results reported in Part one of the analysis, by Roe-Sepowitz (2007) and Slotboom et al. (2011), linking sentence length and status to NS-SIB.

Psychopathology. Similar to findings in Part one, there appears to be an association with psychopathology and self-injuring behaviour. Links have been made to anger (Milligan & Andrews, 2005; Völlm & Dolan, 2009), depression (Marzano et al., 2010; Marzano et al., 2011; Völlm & Dolan, 2009), aggression, and a history of mental health treatment (Marzano et al., 2010; Rutherford & Taylor, 2004). Zlotnick (1999) reported that women prisoners with a diagnosis of antisocial personality disorder (APD) reported a significantly greater number of self-mutilation incidents in the previous three months, compared with a 'no APD group' (36% vs. 11%, p=0.02). Further, Rutherford and Taylor (2004) stated that women with a diagnosis of a PD (incorporating borderline PD, psychopathic PD and narcissistic PD) were significantly more likely to have had a history of SIB compared with women in the 'mental illness' category. Caution must be applied when considering the appropriateness of the 'mental illness category', including challenges with dual-diagnosis and conditions not captured such as anxiety disorders. Marzano et al. (2010) found no significant association with PD and SIB. Only one study explored eating disorders and substance use, but found no significant association with SIB (Marzano et al., 2010), contrasting results such as

**History of abuse and maltreatment.** As found in Part one, there appears to be a similar association with the experience of both childhood and lifetime sexual and physical abuse, and self-harm (Borrill et al., 2003; Kenning et al., 2010; Marzano et al., 2011; Milligan & Andrews, 2005; Rutherford & Taylor, 2004). When examining the study by Marzano et al. (2011), there were significantly more women from the self-harming group compared with the no-self-harming group who had experienced childhood sexual abuse (73% vs. 32%), emotional abuse (85% vs. 35%) and physical abuse (72% vs. 27%) as well as physical and emotional neglect. Caution must be applied to the findings from the qualitative study by Kenning et al. (2010), though, as the authors did not provide details on exactly how many women described abuse as a situational factor as a reason for the SIB. Experiencing domestic violence was also linked to SIB in the study by Kenning et al. (2010).

**Environmental influences.** As in Part one, few papers explored the association between environmental factors and SIB. Within this analysis only two papers reported on these factors, and several of the findings were similar to those documented in the study by Slotboom et al. (2011). In their qualitative study, Kenning et al. (2010) cited the following environmental influences on SIB: experiencing an unpleasant event, changes to the environment, bullying, punishment, perceived 'unfairness', and not being listened to. This study also reported an apparent impact of having children placed into care on likelihood of SIB. Finally, Marzano et al. (2011) found those women living in single cell accommodation were 9.5 times more likely to engage in SIB compared with those sharing a cell.

**Intra- and interpersonal risk factors.** Fewer intra- and interpersonal risk factors were identified within this sub-set of papers. Feelings of shame and bodily shame significantly predicted SIB in the study by Milligan and Andrews (2005), with bodily shame partially mediating the effects of childhood sexual abuse on SIB. Furthermore, levels of impulsivity, hostility and low self-esteem were significantly greater in the SIB group compared with a control group in the study by Marzano et al. (2011). Perceived low social support by women prisoners was also a predictive
factor of SIB identified in this study. Poor communication and problem solving skills noted by several studies in Part one were factors not elicited from analysis within this subset of papers.

**Function.** Only two of the nine papers in this subsection reported findings relating to the function of SIB, compared with five papers from the previous analysis. Similar to the results from these, Völlm and Dolan (2009) found SIB served to relieve unpleasant feelings of anger, tension, anxiety and depression amongst women prisoners. Similarly, Kenning et al. (2010) cited functions including a release of anger, avoiding harming others, a means of coping with difficult emotions, a form of self-punishment and a way of relieving pain and frustration.

**Discussion**
The rates of SIB amongst female prisoners have been demonstrated to be 30 times higher that of the general population of the UK (Hawton et al., 2014). Despite this high prevalence and costly effects, research has struggled to make clear gains in understanding the risks and functions associated specifically with NS-SIB amongst this population. What evidence does exist is often plagued by definitional problems, and is largely atheoretical. The present review sought to draw together existing research on NS-SIB amongst female offenders, link these results to theoretical models and compare key findings to those elicited from research in which authors have not distinguished between SIB with and without suicidal intent.

**Conclusions and links to theoretical models**
The review of nine papers in Part one elicited key findings regarding risk factors and functions associated with NS-SIB amongst women offenders, and allowed for exploration of the applicability to theoretical models. The evidence supported certain elements within both the models by Nock (2010) and Chapman et al. (2006). Nock's model appears to take account of a greater range of distal or longitudinal risk factors, whereas Chapman's appears to focus more on the here-and-now influences. The results indicated some evidence for the role of certain 'distal risk factors' forming part of Nock's model. Most significantly were childhood sexual and physical abuse and maltreatment, and although not described as 'familial hostility and criticism' as labelled in the model, there is some evidence that perceived lack of respect and problems in prison makes NS-SIB more likely...
A range of both intrapersonal and interpersonal risk factors arose, suggesting the importance of their place in both models. Only two studies highlighted the role of poor coping, communication and problem solving skills, whereas a greater number of studies cited poor distress tolerance, high emotional intensity and high aversive cognitions as significant risk factors, providing support for both models.

The associations between psychopathology and NS-SIB appeared consistent across the papers, highlighting the risk for women suffering in particular with anxiety, depression, anger and PDs in the prison environment. Clearly this emphasises the need for effective psychological assessment, monitoring and treatment of prisoners within the criminal justice system. Both models highlight the role of the 'stimulus' or 'stressful event' which precedes or triggers the SIB incident. The nine papers reviewed in Part one of the analysis did not yield any data on what types of stimuli or events are common preceding an incident of NS-SIB. Findings relating to the impact of the prison environment from these papers were limited to just one study, and so evidence cannot be reliably generalised. Further research into this area would be valuable. What was clear from the research however, was the significant role that avoidance plays in this behaviour, offering short-term relief from overwhelming aversive cognitions and emotional intensity. This supports the primary component of Chapman's model and the findings from these papers also highlight the maintenance cycles of NS-SIB, i.e., the behaviour offers temporary relief, but negative reinforcement and habituation to the negative effects maintains it in the long-term, a consideration highlighted in both models.

Demographic characteristics do not feature in either Nock or Chapman's model yet from this review some studies indicated a possible role of age and ethnicity. There was however some contradiction in the literature here, and questions could be raised regarding the possible mediating factors in these relationships. Further exploration would be useful in order to determine the importance of incorporating these factors into models. Finally, this review has not sought to evidence the NS-SIB-specific vulnerability theories put forward in Nock's model, such as the Social Learning, Self-Punishment and Pragmatic Hypotheses. Instead the papers in this review have helped to explore the risk factors and functions of NS-SIB.
Studying SIB with and without suicidal intent

The strong rationale underpinning this literature review came from the argument that to date no reviews have successfully explored functions and risk factors associated specifically with NS-SIB amongst female offenders. What this review showed is that after exploring just a small selection of papers, there were some similarities as well as differences in the themes which arose from studies specifically exploring NS-SIB, compared with those where the definitions were not defined or where samples were mixed (those engaging in SIB with, and those without, suicidal intent). Key areas of similarity included the significance of psychopathology (including anxiety, depression, PD and anger), childhood and lifetime abuse (including sexual, emotional and physical), mixed evidence for the influence of age, and limited but some evidence for the role of environmental factors (including problems with prison staff, conflict and lack of contact with children). Key areas of difference across the two parts of the review included the significance of ethnicity and links with other risky behaviours, including substance abuse and eating disorders, where there was greater evidence for associations in Part one. Also, differences arose regarding the importance of emotional and practical coping skills and communication difficulties on SIB with greater evidence for a significant association in Part one of the review.

Despite there being both similar and different themes drawn from the two parts of the review, it could be argued that in order to link research to theoretical models such as that by Nock (2010) which is specifically designed for NS-SIB, it is important to be able to confidently ascertain whether we are exploring SIB with or without suicidal intent.

Limitations

The aim of this literature review was to start drawing clear conclusions regarding the risk factors and functions of NS-SIB amongst women prisoners. Only nine papers were found which met the inclusion criteria thus leaving a small sample to draw conclusions from. A greater quantity of papers would have resulted in greater confidence in the arguments drawn, yet highlights the need for future research in this area. As touched upon earlier, the majority of existing research in this area is correlational and cross-sectional in nature. As a result this limits any interpretation of the relationship and directionality between risk factors and NS-SIB over time, and does not provide information on any causational relationships. A further
limitation within this review arises from the different tools and categorisation systems used by researchers and forensic services for recording and defining SIB. Methods included clinical interviews with a nurse or researcher, as well as via the use of standardised measures such as the Lifetime Parasuicide Count-2 (Linehan et al., 1999). Similarly, the retrospective self-report used in many of the studies may have lead to inaccurate reports of early childhood experiences and antecedents of NS-SIB episodes.

Future research
In order to continue developing our knowledge of the factors and functions associated with NS-SIB amongst female offenders, research needs to continue to distinguish between self-injurious behaviour with and without suicidal intent. This will involve careful consideration of definitions and the choice of assessment tools by both researchers and forensic settings. When exploring correlates of NS-SIB, studies should also use empirically validated diagnostic assessments of psychopathology including PD, anxiety and depression to allow for greater confidence in the findings. Future research also needs to be more theory-driven and link back to models of SIB. This will allow us to deepen our understanding of why factors such as childhood abuse and psychopathology make women offenders more likely to engage in NS-SIB.

Results from certain papers in the review appeared to indicate those women engaging in NS-SIB were also more likely to engage in other harmful behaviours such as substance misuse and eating disorders, and greater exploration is needed to examine the similar and differing functions these behaviours hold for women in prisons. Basing our research and study of these factors on scientifically validated models and theory is crucial. Finally, examining the effectiveness of assessing and monitoring NS-SIB amongst this population as well as undertaking good quality randomised controlled trials to explore the benefits of psychological approaches such as dialectical behaviour therapy (DBT) and cognitive behavioural therapy (CBT) for supporting female offenders at risk of engaging in NS-SIB whilst in prison is recommended. This will be essential for better informing and supporting staff working with female offenders at risk of NS-SIB in order to help them better manage this behaviour in the future.
References


Service Improvement Project

Title: Transition to adult services for those with a life-limiting illness: the parents' perspective. A qualitative service review

Candidate: Charlotte Hazeldine (Clinical Psychologist in Training)
Department of Psychology
University of Bath
BA2 7AY
Email: charlotte.hazeldine@nhs.net

Name and contact details of Academic Supervisor: Dr Maria Loades (Clinical Psychologist)
Department of Psychology
University of Bath
Claverton Down, Bath
BA2 7AY
Email: M.E.Loades@bath.ac.uk

Name and contact details of Regional Supervisor: Dr Catherine Lane (Clinical Psychologist)
Lifetime Service
NHS House
Bath
BA1 3QE
Email: Catherine.Lane@sirona-cic.org.uk

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Transition to adult services for those with a life-limiting illness: the parents’ perspective. A qualitative service review

In 2012 there were more than 40,000 children and young people in England who had long-term health conditions which, for most, would require palliative care and eventually end their lives during childhood (Marie Curie Cancer Care & Together for Short Lives, 2012). Children with chronic life-limiting illnesses are often living longer due to improvements in medical diagnoses and therapies (Blum et al., 1993), leading to more adolescents moving on to adult services. This move is commonly referred to as ‘transition’ and it has been acknowledged that this period needs to be well planned. Feedback however has reported that this is often poor with parents feeling ‘off the radar at 19’ (DH Partnerships for Children, 2008; Marie Curie Cancer Care & Together for Short Lives, 2012) and that there is much scope for improvement (DH Partnerships for Children, 2008; Marie Curie Cancer Care & Together for Short Lives, 2012).

Research continues to explore the young person's experiences of the transition and several key messages have been highlighted. These include the importance of information sharing, early education, staff in adult services being highly knowledgeable about the child’s condition and age-appropriate communication (Shaw et al., 2006; Srivastava, Elkin, & Bilton, 2012). Further, research has also emphasised the importance of also seeking the parental experiences of transition as this can differ from the child's. In their study Anthony et al. (2009) found differences between adolescent heart transplant patients' and their parents' perceptions of transition, with parents demonstrating much higher levels of worry and anxiety. Similarly, from their interviews with parents, Schultz (2013) describe two themes; ‘parents in turmoil’, which included feelings of fear, rejection, and uncertainty; and ‘captive waiting’, waiting for answers before being able to move forward (Schultz, 2013).

Lazarus and Folkman's transactional theory of stress and coping appears to offer some theoretical understanding of the difficulties experienced by parents during this time. The model views psychological stress as a relationship between the person and the environment that is appraised as potentially threatening to one's well-being (Folkman, 1984; Lazarus & Folkman, 1987). Cognitive appraisals of the
situation and coping mediate this person-environment relationship. Cognitive appraisals can take the form of loss, challenge or threat for example and this reflects the findings from studies such as Schultz (2013) and Anthony et al. (2009). Finally, cognitions focus on evaluating perceived control of the situation and resources available and from the literature we can see that transition frequently represents an uncontrollable and uncertain time for parents (Schultz, 2013), possibly leading to feelings of stress.

Although research exploring parental experiences of transition has highlighted several key messages there is little research which has specifically focused on families of children with life-limiting illnesses. Doug et al. (2011) conducted a systematic review of the literature exploring transition for young people with palliative care needs which revealed three key principles underpinning a successful transition. These were; information sharing, communication and planning/coordination. There remains little research however focusing specifically on parental experiences of transitioning with young people who have life-limiting illnesses or palliative care needs. National interest in this topic is expanding and in 2011 Marie Curie launched their 'Young People and Transition Programme' ("Marie Curie Transition Programme," 2012). From their research they identified several key areas concerning parental experiences of transition. This included parents going through their own transition, fewer respite services, and the importance of peer support (Marsh, Cameron, Duggan, & Rodrigues, 2011).

Context

The service at the focus of this project was a community paediatric palliative care service for children with non-malignant, life-threatening or life-limiting illnesses. The 'transition group' within the service commissioned a review to explore the experiences of families going through transition. The objective was to use this data to consider areas for improvement.

Some of the key guidelines the service adhered to included:

1. Introducing the issue of transition early (14 years +) and reviewing regularly.
2. Communication and cooperation between all services and the family.
3. Involving and encouraging the young person to express their views where possible.
4. Balancing the needs of the young person for privacy and increased
responsibility, with the needs of parents to have sufficient information to support the young person.

5. Holding regular meetings with other professionals, particularly those in adult services, to discuss ongoing care needs and handing care over.

**Aim**

To evaluate the current experiences of parents of children transitioning from this child service to adult services by undertaking semi-structured interviews.

**Method**

**Methodological rationale and design**

A qualitative methodology was deemed appropriate to allow for rich and personal accounts of the experiences of parents over the transition period. Similar research in this area has used methods including interviews and focus groups (Tuchman, Slap, & Britto, 2008; van Staa, Jedeloo, van Meeteren, & Latour, 2011). Data collection was considered pragmatically. Interviewing parents at their home was considered the most suitable method for data collection due to the practical limitations of caring for children with a life-limiting illness.

**Participant characteristics and recruitment**

Prior to recruitment this project was approved by the University of Bath Department of Psychology ethics committee. Approval from the service’s Service User Involvement Facilitator was also granted. Finally, the Bath Research and Development research manager reviewed the study protocol and confirmed that the project fell within the specification of ‘service development’ hence not requiring NHS ethical approval.

All participants were over the age of 18 years and of White British ethnicity. Inclusion criteria stated that they were required to be a parent of a child due to transition within the upcoming 12 months or a child who had transitioned to an adult provider within the last 12 months. Originally I had hoped to recruit parents whose child was approaching transition in the upcoming year as well as those who had children who had transitioned in the previous 12 months. This would have allowed me to gain a broad range of experiences across the transition period. Recruitment was sought via opportunistic sampling for this project. Both the lead
clinician (clinical psychologist) as well as nurses in the team were responsible for sourcing suitable families for the study. These staff members firstly had discussions with those families they deemed eligible and who had expressed initial interest in participating. It is not known exactly how many families at this stage were approached. I was then provided with a list of ten families to contact and invitation letters were sent out detailing the project and inviting them to take part in a short interview at their home, of which five families consented to taking part, a 50% response rate. One of these families was also involved in the design of the interview schedule. Four families had a child who was expected to transition within the following 12 months and one family had a child who had transitioned within the last 12 months. A total of six parents were interviewed across the families (four mothers and two fathers). Details are presented in Table 2.1.

Table 2.1. Participant details

<table>
<thead>
<tr>
<th>Family</th>
<th>Pseudonyms</th>
<th>Brief details about child’s condition</th>
<th>Age of child</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Mandy (mother)</td>
<td>Epilepsy, congenital hemiplegia</td>
<td>17 years (pre transition)</td>
</tr>
<tr>
<td></td>
<td>Andrew (YP)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>14</td>
<td>Kathy (mother)</td>
<td>Severe brain damage from birth.</td>
<td>19 years (post transition)</td>
</tr>
<tr>
<td></td>
<td>Daniel (YP)</td>
<td>Deaf, blind, no physical movements, requires feeding tube and catheter.</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>Tracey (mother)</td>
<td>Pitt-Hopkins syndrome - significant breathing difficulties, ventilated overnight, problems with bowels and spine.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Phil (father)</td>
<td></td>
<td>17 years (pre transition)</td>
</tr>
<tr>
<td></td>
<td>Kate (YP)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>Robert (father)</td>
<td>Quadraplegic cerebral palsy, epilepsy, developmental growth delay, visual impairment.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>James (YP)</td>
<td></td>
<td>17 years (pre transition)</td>
</tr>
<tr>
<td>3</td>
<td>Polly (mother)</td>
<td>Cystic fibrosis</td>
<td>17 years (pre transition)</td>
</tr>
<tr>
<td></td>
<td>Ben (YP)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*YP = young person who will be transitioning or has transitioned*
Data collection

Five semi-structured interviews were conducted at the participant's homes by the first author, lasting between thirty minutes and one hour and audio-recorded with the participant's permission. The interview schedule (see Appendix B.1) comprised of both open-ended questions and some closed questions guided by previous literature on transition (e.g. Marsh et al., 2011; Srivastava et al., 2012) as well as the research questions compiled for the study. Interview questions included ‘Describe how and when transition was first introduced to you’ and ‘In what ways, if any, do you feel transition will impact your child and your family?’.

Analysis

Transcripts were analysed using an inductive thematic analysis (Braun & Clarke, 2006). This analytic approach was selected as its flexibility and potential for yielding rich data would be particularly suitable for exploring the reality of families’ experiences during transition. Furthermore, this approach has also been used to analyse interviews in similar studies such as van Staa et al. (2011). Interviews were transcribed and each transcript assigned a colour for ease of recognition. Additionally all participants were given pseudonyms. Following this, transcripts were read and re-read whilst initial ideas and potential coding schemes were noted. Next, initial codes across the data were produced manually and data with the same codes were collated together within each code.

Following this stage, all of the codes were then sorted and combined to form overarching themes and this process was subject to much revision. This stage also involved discussion with two further researchers (qualified clinical psychologists experienced in working with children and families) to examine agreement on thoughts around initial themes arising from the data. Ideas about the relationship between the themes as well as different levels of themes (sub-themes) were subsequently considered which involved reviewing and refining the themes. A ‘thematic map’ as suggested by Braun and Clarke (2006) was drawn up allowing for a visual representation of themes, see Figure 2.1 for the final version of this map. Finally, the analysis and themes were verified by the second author to check the credibility of the analysis.
Quality checking
There is no definitive set of guidelines for determining reliability and validity of qualitative research, however a range of guidance does exist in the literature. Mays and Pope (2000) provide a useful set of questions which allow researchers to question the validity and quality of their qualitative work and these were used in the current study. Questions covered the relevance of the research, clarity of the research question, appropriateness of the design, description of the context, sampling methods, data collection and analysis, as well as reflexivity of the account. As previously mentioned three researchers were involved in the process of ensuring inter-rater reliability during the coding process, an important quality check in qualitative research. A 'paper trail' as suggested by Yardley (2008) of transcripts with codes, descriptions and notes was also created.

Results
Five main themes emerged from the analysis: the process of transition; uncertainty; changes to the parental role; loss; and values families appreciated about the service. Within all of these themes were sub-themes (see Figure 2.1). No themes were excluded on account of not being suitable for the project aims.

<table>
<thead>
<tr>
<th>The process of transition</th>
<th>Changes to the parental role</th>
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<tbody>
<tr>
<td>Discussions with family &amp; young person</td>
<td>Less involvement and influence</td>
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<tr>
<td>Communication between services</td>
<td>Access to information</td>
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<tr>
<td>Visits and introductions</td>
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<th>Loss</th>
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<tr>
<td>Knowledge of the young person</td>
</tr>
<tr>
<td>Close relationships</td>
</tr>
<tr>
<td>A holistic approach to care</td>
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<tr>
<td>Child friendly services</td>
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<table>
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<tr>
<th>Uncertainty</th>
<th>What families valued about the service</th>
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<tbody>
<tr>
<td>Services</td>
<td>Staff liaising on behalf of the family</td>
</tr>
<tr>
<td>Staff in adult services</td>
<td>Accessibility</td>
</tr>
<tr>
<td>Readiness of young person</td>
<td>Reliability</td>
</tr>
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</table>

*Figure 2.1. Themes and sub-themes arising from the data.*

The process of transition
The primary aim of this project was to evaluate the transition process for families and so of particular interest was the theme 'process of transition'. Within this theme, three subthemes arose.
Discussions with the family and young person. All five families reported that initial discussions about transition occurred early enough with the young person ranging from 13 to 15 years when this first occurred. Families reported that discussions took place gradually and regularly enough. One parent reported that the young person had been directly involved in these discussions: “they are preparing [my child]...to make sure he knows what he needs to know” (Polly).

Communication between services. Four families reported that they felt the service’s staff were successfully communicating and liaising with adult services in preparation for the transition and two families discussed the important role of the transition social worker in this communication. “...they’ve been quite good with sharing the details of [child's] condition and everything she needs and uses” (Tracey).

Visits and introductions. Three families explained that they were provided with contact details of staff in adult services who would be taking on the young person’s care. These same families also visited their adult consultant in advance. "Chloe (Named Nurse at the service) showed him around adult services" (Polly). The importance of review meetings leading up to transition was raised by two families.

Uncertainty
Some of the difficulties that families reported during the transition period concerned uncertainty around several key areas.

Services. Four families identified uncertainty around what services the young person could access after transitioning. For some, this included uncertainty about continuing access to the service’s psychological support and sibling groups. "..parents are left in limbo as to what services they’re going to get when they're (young person) 18" (Mandy).

Staff in adult services. A theme which arose for all parents was uncertainty around staff in adult services. This included families wondering; a. what staff would be like and whether they would be knowledgeable about the young person’s condition: "he (adult consultant) may not have any experience of
children with complex needs ...” (Mandy) and; b. whether staff would adapt to the uniqueness of the child: “they won't understand his noises or claps” (Mandy).

**Readiness of the young person.** Four families talked about their uncertainty around the young person suddenly being considered ‘ready’ for adult services and in some cases responsible for managing their condition. "Yes he’s 18 and legally an adult...but it's a bit early to suddenly put everything on him and say 'look after yourself'” (Polly).

**Changes to the parental role**
All parents reflected on the change in their role due to transitioning. This included parents feeling that they had less involvement and influence: "my clout as a parent doesn't feel as strong...people can make decisions that overrule us" (Kathy). Parents also identified changes to the information they were allowed to access regarding their child: "lots of important information wasn't getting back to me directly" (Kathy).

**Loss**
Loss was a key theme which arose for all families and covered a variety of different areas.

**Knowledge of the young person.** For all parents, there was a sense of transition representing the loss of a service and individuals who had known the young person, in some cases their whole life. "We have to say goodbye after all those years when they’ve got all that history and experience and knowledge about her” (Kathy).

**Close relationships.** In addition to this loss of knowledge about the young person, there was also a strong sense of loss of close relationships. This included relationships with consultants, named nurses, psychologists and friendships with other families in the service: "...losing everyone we have become really close to" (Tracey).

**A holistic approach to care.** Several parents identified being struck by a move away from a very 'holistic' approach to care within pediatric services, to a
more 'separate' approach to care in adult services. One parent explained that paediatrics: "manages the whole person covering all the different body parts" which was contrasted to how adult services worked: "it's very much split into your bowel, your respiratory..." (Tracey). Some parents also talked about how the service offered training to schools and day centres on how to use the young person's medical equipment and the loss of this support.

**Child friendly services.** Having their child approach 18 identified for parents the loss of services that were suitable for young people with complex needs. Families raised the issues of adult hospital wards not accommodating parents overnight and not being age appropriate: "in inpatients he'd be surrounded by old men which isn't very nice" (Polly).

**Values that families appreciated about the service**
For all parents, transition highlighted a range of values that they most appreciated about the service.

**The service staff liaising on behalf of the families.** All five families reported that they appreciated the liaising role that the staff in the service took and how this eased the burden on their everyday lives: "... someone who will chase things up and act as a go-between for us with the consultant" (Polly).

**Accessibility.** Four of the families also valued the accessibility of staff within the service, being able to obtain support when needed: "If I need anything I know I can just pick up the phone" (Mandy).

**Reliability.** Finally, these four families also highlighted how reliable and trustworthy staff were: "We know they [service] are always there in the background" (Mandy).

These results were fed back to the service (see Appendix C.1 for further details) and an accessible summary was sent to participants (see Appendix C.2) and put on the service's webpage.
Discussion

Little research to date has explored the experience of transitioning from child to adult services for those with life-limiting illnesses, and the current study has provided an insightful snapshot of parental experiences of this transition. Key findings are considered firstly in terms of areas of strength; where the service appeared to be following local and national transition guidelines. Secondly, key findings in relation to areas for improvement are discussed and recommendations provided.

Areas of strength

There were several areas highlighted where the service were successfully working in line with their local guidelines and those suggested in key policy documents (Department of Health, 2006; DH Partnerships for Children, 2008; Marie Curie Cancer Care & Together for Short Lives, 2012; Royal College of Nursing, 2013). Staff introduced the issue of transition early and discussions continued to occur regularly, and where feasible the young person was listened to and involved in discussions. Parents appreciated these early and gradual discussions, enabling them to feel more prepared. Research has also highlighted the positive impact these continued discussions have on feelings of readiness and preparation for transition (van Staa et al., 2011; Viner, 2008). Furthermore, families felt that the service communicated and liaised with adult services well in advance, a key principle which has been found to underpin a successful transition (Doug et al., 2011; Golberg, Lennox, Burr, Barrow, & Dennard, 2004; Viner, 2008).

Key areas for improvement and recommendations

Local and national guidelines stress the importance of families meeting with and visiting adult services before transition (Department of Health, 2006; DH Partnerships for Children, 2008; Marie Curie Cancer Care & Together for Short Lives, 2012). Research has shown that this is something that families and the young person feel aids a successful transition (e.g. Brumfield & Lansbury, 2004) yet for some families in the study this was not the case. It was recommended to the service that all families are provided with this opportunity prior to transition which should involve liaison with and co-operation from adult services. A further recommendation was the use of leaflets providing written information about the
adult service and staff, a tool which was received favourably by young people in 
cystic fibrosis services in Australia (Brumfield & Lansbury, 2004).

In line with findings from interviews with parents in the Marie Curie Report (Marsh 
et al., 2011), several families in this study expressed concerns regarding the 
young person's readiness for autonomy and responsibility at age 18. Research 
such as that by Betz (2004) and Landau (1995) as well as Best Practice Guidance 
(DH Partnerships for Children, 2008), recommend the use of 'autonomy checklists' 
or 'self-assessments' for helping determine readiness of the adolescent for 
independently managing their condition (e.g. medication use) which can also serve 
to support parental anxiety around this issue. Linked to this, families were also 
concerned that once their child turned 18, as a parent they would be left out of 
decisions and not given information. Following guidance from a good practice 
review of transition by the Royal College of Nursing, (2013) it was recommended 
that parents/carers and young people are supported with discussions about 
information sharing, communication and confidentiality. The importance of working 
towards a gradual and stepped-down approach of care was also recommended as 
a way of slowly building up the parent's and young person's confidence, self-
efficacy, skills and knowledge base. A full list of the recommendations provided to 
the service can be seen in Table 2.2 on the next page.
Table 2.2: List of recommendations provided to the service

**Recommendations**

- Families talked about how they would value a 'transitions' group for parents to attend to share thoughts and ideas about transition.
- An information leaflet signposting services and information about funding/benefits available to the young people and families after transition.
- Earlier discussions with families about whether they can continue to access services such as sibling groups and psychological support offered by [service name].
- Staff to have discussions with young person, parent and if possible adult services to determine how much and what type of information parents will be able to access after transition.
- Checklists to determine readiness of adolescent for independence and responsibility of care.
- Ensure all families have the opportunity to meet with their care staff in adult services and visit the care setting.
- Providing families with some initial information about the adult service and consultant - such as a photograph and name of their new consultant and nursing team.
- Joint clinical appointments between paediatrician and adult physician with family and young person on lead up to transition.
- Working towards a gradual and stepped-down approach of care from child to adult services.
- Ensuring families have a clear and ongoing 'transitional plan' in writing
- 'Passports' or 'About Me' books which can be developed with young person and family on the lead up to transition to help adult services get to know personal details about the young person such as their likes, dislikes and unique communication style.
- Acknowledging and supporting parents with the emotional loss of support, friendships and knowledge of young person. Promote self-care through this difficult period.

**Clinical implications**

A range of clinical implications arose as a result of this study, and certain changes were put in place following the feed-back with the hope that these will directly improve the transition experiences for families. Similar to the theme of ‘captive waiting’ elicited from Schultz’s (2012. p359) study, several families referred to the difficulty of being "*in limbo*“ regarding uncertainty about what services both within the service and in the wider community were available to them after transition. If we are to refer back to the model of coping and stress by Lazarus and Folkman
(Folkman, 1984; Lazarus & Folkman, 1987) one could hypothesise that cognitions such as feeling uncertain and ‘in limbo’ will contribute to overall levels of stress and perceived coping. As a result of this feedback, the service decided that a training event would be put in place to refresh staff on how best to discuss with families endings of provision of services. It is hoped that this will then have a positive impact on lowering feelings of uncertainty and possibly then lowering stress levels and psychological wellbeing for parents.

In agreement with the findings by Schultz (2012), loss was a common feeling experienced by parents and covered several areas including a loss of ‘holistic' care and knowledge of the young person. One parent suggested a ‘transition support group' would be a helpful way of parents coming together to acknowledge this loss and promote self-care through this difficult period. As a result of this feedback, the service planned to develop a ‘transition support group' to encourage this self-care. This type of group will hopefully provide parents with a safe and validating environment to talk about difficult feelings regarding transition. In summary it is hoped that the results from this project will directly serve to improve the lives of parents who are supporting children through transition. Both changes at the local level from within the service, as well as contributing towards research via publication of these results may achieve this hope.

Limitations and areas for further study
Within the sample of parents, only one family had completed transition and it was originally hoped that both families approaching, and those who had finished transition, would be recruited. For future work, liaison with adult services would enable recruitment of greater numbers of parents who had recently transitioned from the child service to gain a more representative sample. Furthermore, this study may have benefited from the collection of more extensive demographic information regarding parents' age and educational level. This would have enabled the researcher to explore whether there were any qualitative differences in how the transition period was experienced across these groups. Finally it is important to be aware of the possibility that those parents who decided to take part in the study may have been different to those who did not with regards to their motivation for discussing their experiences. It was the staff members in the service who provided me with the list of possible families to contact to take part in the study.
and so questions could be raised concerning how certain families were chosen over others, and whether there was a selection bias here thus impacting on the representativeness of the sample and generalisability of the results. In future, a more reliable and systematic method such as obtaining a list from the services of all families who met criteria and then randomly selecting a suitable number to be contacted could be employed to address this limitation.

The limitations of using thematic analysis have been considered. It has been argued that researchers using this approach, unlike narrative or biographical approaches, are unable to maintain a sense of continuity and contradiction through any one individual account which reduces how much can be drawn from the data. Further, as an approach it does not allow the researcher to make claims regarding language use or functionality of talk (Braun & Clarke, 2006). The guidelines regarding thematic analysis presented by Braun and Clarke (2006) were closely followed to ensure data analysis was conducted in a reliable and rigorous manner.

An area for further study would be to explore the experiences of the young people themselves. This could be achieved through the use of a focus group or interviews, used in similar research by Srivastava et al. (2012) and also van Staa et al. (2011). Consideration however would need to be given to those young children who would not be able to communicate their views. Due to the nature of the service, many of the young people have profound and multiple disabilities which limits their communication. One parent reflected during interviews that as a mother it is down to her to 'be the voice' of her daughter and so further work would likely require involvement from parents to enable the young person's voice to be heard.

**Self-reflection**

The author of this study had both a personal and professional interest in the area of palliative care; she had worked within a hospice for adults and had a family member receive palliative care in a hospice. It was possible that her focus on the experience of the parents was to some degree influenced by her own experience of being a family member to somebody with a life-limiting illness, an important reflection to be considered. She held strong beliefs that families should be well
supported by professionals and was interested in ways in which this could be improved over the transition of moving from child to adult palliative care services. The involvement of service users in the development of the interview schedule and other researchers in all stages of the data analysis allowed for any potential biases in interpretation to be limited.

Implications for provision of care and research

The findings from this project along with the recommendations were fed back and taken on board by the service which was keen to begin reflecting on the ways in which changes can be made to improve certain areas of the transition process. Some keys changes to arise have been noted including the designing of a new information leaflet about transition, further staff training, summary documents to be sent to specialist physicians in adult services taking on the young person's care detailing transition issues, and ‘personal transition action plans' providing a summary of the young person; their likes, dislikes and so forth. The service also plans to regularly review the process of transition through the use of questionnaires and interviews to inform ongoing service development. These will have clear implications on the delivery of the transition support offered by staff to service users with the aim of improving this period. These will have clear implications on the delivery of the transition support offered by staff to service users with the aim of improving this period. This project has also added to the currently small body of research exploring the experiences of transition from child to adult palliative care services. Further prospective studies examining and evaluating transition protocols should be undertaken to continue addressing the gap in knowledge of this area.

Key Messages

- Early, regular and continued communication involving parents, the young person and child and adult services plays a vital role in preparedness.
- Transition elicits feelings of uncertainty for many parents which can be reduced via better information sharing, offering visits and introductions to new services and improved channels of communication.
- For many parents, transition represents a change in their role and can result in anxiety about child's readiness for autonomy.
- Service reviews allow for a snapshot into current practice and identify key strengths and areas for improvements.
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Main Research Project

Title: Understanding the link between feelings of defeat and the experience of chronic pain.

Candidate: Charlotte Hazeldine
Department of Psychology, University of Bath, BA2 7AY
Email: charlotte.hazeldine@nhs.net

Academic Supervisor: Professor Paul Salkovskis
Department of Psychology, University of Bath, Claverton Down, Bath, BA2 7AY
Email: P.M.Salkovskis@bath.ac.uk

Regional Supervisor: Dr Jeremy Gauntlett-Gilbert
Bath Centre for Pain Services
Royal National Hospital for Rheumatic Diseases, Bath, BA1 1RL
Email: jeremy.gauntlett-gilbert@nhs.net

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Understanding the link between feelings of defeat and the experience of chronic pain

In common usage, the term “defeat” refers to being overthrown in a fight or struggle and by definition, being “defeated” represents the destruction of vigor or vitality, or a sense of wasting or withering (Oxford English Dictionary, 2002). In the psychological literature, mental defeat has been identified as a cognitive construct, potentially involved in the development and maintenance of both post-traumatic stress disorder (Ehlers et al., 1998), and depression (Gilbert & Allan, 1998). Ehlers et al. (1998) defined mental defeat as a perceived loss of all autonomy, a state of ‘giving up in one's own mind’ any effort to remain one's identity as a human being (p.45). A key impact of such state of mind would be an impaired sense of self-efficacy, or belief in one’s ability to succeed in a specific situation; a construct influenced via a person's sense of mastery. If one is mentally defeated to the point where one believes it is impossible to even function as a human being, it is likely this would have a detrimental effect on perceived ability to complete tasks and reach goals. Dunmore, Clark, & Ehlers, (2001) stated that the experience of defeat ‘seriously challenges a person's sense of competence’ (p.1065) and Abramson, Seligman & Teasdale (1978) and Maercker, Beauducel & Schutzwhol (2000) stated that mental defeat amongst prisoners influences perceived ability to cope, as well as leading to more passive, and distractive coping styles. If one is particularly defeated because of experiencing chronic pain for example, it is likely therefore that one's perceived ability to achieve goals despite this pain would be diminished. The behavioural consequences of the impaired sense of self-efficacy, is most likely avoidance and withdrawal (Bandura 1977).

The concept of mental defeat has most widely been studied in relation to uncontrollable traumatic events such as torture, rape or environmental disasters, and in particular has been shown to predict both the development and severity of post-traumatic stress disorder (PTSD) symptoms, and response to treatment (Dunmore, Clark, & Ehlers, 1999, 2001; Ehlers et al., 1998; Ehlers, Maercker, & Boos, 2000). Mental defeat has been considered as a sort of 'self-processing' where a given traumatic situation, such as torture or assault, results in a linked set of negative beliefs about the self in relation to the experience (Tang, Salkovskis, & Hanna, 2007). These authors suggested a link between the impact of chronic pain
and mental defeat. There is considerable evidence of a link between chronic pain and depression (Wilson, Mikail, D’Eon, & Minns, 2001), and Asmundson, Norton, Allerdings, Norton, and Larsen (1998) found that in their sample of 139 chronic pain clinic patients, 34.7% were experiencing PTSD symptoms. Investigating this possibility, Tang et al. (2009) interviewed treatment-seeking chronic pain patients with high levels of health anxiety and identified several themes linked to mental defeat. When describing emotional responses associated with their pain, those experiencing high levels of health anxiety commonly used the word ‘defeated’ to express feelings of a loss of control, autonomy and identity as a ‘functional human being’ (Tang et al., 2009). It was noted in their 2007 paper, that many patients referred to a sense of “defeat of the mind”, the pain “belittling them as a person” and feelings like “not being a human being” (Tang, Salkovskis, & Hanna, 2007, p.1). Based on these findings, Tang, Salkovskis, and Hanna (2007) developed the Pain Self Perception Scale (PSPS), a questionnaire designed to measure mental defeat as a reaction to pain, drawing on both the work of Ehlers et al. (1998), and Gilbert and Allan (1998).

Cognitive theories of chronic pain have highlighted the role of catastrophizing (McCracken, Zayfert, & Gross, 1992; Sullivan, Bishop, & Pivik, 1995; Vlaeyen & Linton, 2000), i.e. the way in which individuals will interpret the pain, (e.g. ‘the pain means that there is something seriously wrong with my body’). Links have been made between catastrophizing and pain severity (Burton, Tillotson, Main, & Hollis, 1995; Simons & Kaczynski, 2012), treatment seeking (Reitsma & Meijler, 1997) and distress and disability (Cook, Brawer, & Vowles, 2006; Vowles, McCracken, & Eccleston, 2008). This type of catastrophizing has also been identified as a factor involved in the maintenance of health anxiety amongst chronic pain patients (Rode, Salkovskis, Dowd, & Hanna, 2006; Tang, Salkovskis, & Hanna, 2007). Tang et al propose that mental defeat may represent a type of catastrophizing around future consequences of the pain, primarily concerning the individual’s sense of identity, agency and self (Tang, Goodchild, Hester, & Salkovskis, 2010).

Mental defeat in relation to chronic pain focuses not on the experience and meaning of pain itself, but instead, is a type of self-catastrophizing focused on the effects of pain as an attack on the person’s life and sense of identity (Tang, Salkovskis, & Hanna, 2007).
Similar to other cognitive behavioural theories of emotional disorders, such as anxiety and depression, the activation of negative self-beliefs in relation to pain impacts on information processing bias, shifting attention towards negative aspects of the pain experience and interferes with coping and self-efficacy, including through the deployment of ‘Safety Seeking Behaviours’ (Sharp, 2001; Tang, Salkovskis, Poplavskaya, et al., 2007). These negative self-beliefs have also been hypothesised to increase the accessibility of negative pain-related memories. These responses can further reinforce catastrophizing thoughts and more general negative beliefs about the person’s ability to cope with their pain and their sense of self (Tang, Salkovskis, & Hanna, 2007). Given the PTSD literature showing the impact that mental defeat has on longer term symptom severity and treatment efficacy, initial research has sought to examine whether treatment seeking chronic pain patients who experience high levels of mental defeat report more pain distress and disability. Tang et al. (2010) reported a significant correlation between mental defeat and pain interference, sleep disturbance, anxiety, depression, functional disability and psychosocial disability and in a later paper found mental defeat was a significant predictor of functioning and distress (Tang et al, 2013). In these two papers, the authors however did not examine whether there was a direct association between feelings of defeat and pain severity, but rather in the 2010 paper showed that the relationship between mental defeat and the above listed outcomes remained significant even when pain intensity was partialled out. Given the known links between mental defeat and symptom severity in PTSD, as well as findings linking depression with pain severity (e.g. Buhrman et al. 2015, & Outcalt et al. 2015) this may be interesting to examine. Only one study has taken steps here so far. García-Campayo (2010) found a significant association between levels of mental defeat in a Spanish sample, assessed using the Pain Self Perception Scale, with pain intensity in patients with fibromyalgia. Further exploration of the relationship between mental defeat and pain intensity would be relevant given the findings from this study and related research in depression, broadening the study all types of chronic pain and not just fibromyalgia as in García-Campayo’s study.

An important implication of impairment of the sense of agency noted in mental defeat would be its effect on person’s perceived ability to produce an effect or change which has been described as playing a central part in mental defeat. Self-
efficacy, a construct used to explain "how much effort people will expend and how long they will persist in the face of obstacles and aversive experiences" (Bandura, 1977, p.194) is a good match with this concept as mentioned earlier. Within the study of chronic pain, self-efficacy has been linked to actual pain tolerance (Keefe et al. 1997, & Council et al. 1988) as well as quality of life, general health, activity level and pain severity (Börsbo, Gerdle, & Peolsson, 2010; Meredith, Strong, & Feeney, 2006; Woby, Urmston, & Watson, 2007). Few studies have directly explored the influence of psychopathology on self-efficacy in chronic pain but Sánchez al.(2011) found that depression was a significant predictor of self-efficacy in fibromyalgia patients. Further exploration around the impact of feeling defeated by pain on a person's sense of self-efficacy would be useful.

When we look at key cognitive-behavioural theories related to distress and psychopathology within chronic pain, including the fear avoidance model, (Lethem, Slade, Troup, & Bentley, 1983; Vlaeyen & Linton, 2000) and health anxiety model (Rode et al., 2006), it is apparent that it is the meaning or interpretation of the pain which plays the central role. From a similar perspective, mental defeat relates to this, with its focus on the meaning of the pain, with regards specifically to a person’s identity, agency and sense of self. This parallels similar theories such as the pain self-enmeshment theory (Pincus & Morley, 2001), which built upon the self-discrepancy theory (Higgins, 1987). Pain self-enmeshment has been construed as a measure of a person’s identity; their sense of who they are and what they might become—their possible selves (Morley, Davies, & Barton, 2005; Pincus & Morley, 2001). Pain self-enmeshment theorises that the experience of chronic pain relates to the degree to which the three schemas of pain, self and illness might overlap and enmesh, affecting information-processing, mood, acceptance of pain and emotional adjustment (Morley et al., 2005; Sutherland & Morley, 2008). Fundamentally it is the degree to which chronic pain disrupts and ‘traps’ negative aspects of the self that determines the focus and degree of enmeshment. What is important to note is that there are many different interpretations of ‘schema’ which, according to Pincus and Morley (2001) contains “a stored body of knowledge that interacts with task demands for attending to and disambiguating stimuli and for encoding and structuring retrieval of information” (p.607). In this sense, it is possible that mental defeat represents the person's self-schema or identity which then interacts with their pain and illness schemas,
influencing their attention and information processing, mood, coping and adjustment.

Although promising, the findings regarding mental defeat and its cognitive and behavioural consequences are limited in scope. Only a small number of studies have been undertaken in this area including one of a qualitative nature (Tang et al., 2009), two assessing the prevalence of mental defeat across community and treatment-seeking samples (Tang et al., 2007, Tang et al., 2013), one examining the effects of mental defeat on pain interference, disability and distress in patients with chronic pain (Tang et al., 2010) and one exploring mental defeat in a Spanish sample (García-Campayo et al., 2010). Research is yet to determine links with other related cognitive variables including depression, catastrophizing, hopelessness and anxiety, and has not yet inferred directional causality on pain outcomes.

Mental defeat, when studied in the field of trauma, has previously been shown to be related to constructs including perceived uncontrollability, humiliation, and hopelessness (Ehlers et al., 2000). Recommendations from research have implied that an important question to be addressed concerns the relationship between mental defeat and other cognitive constructs used in the study of psychopathology and chronic pain, such as catastrophizing, depression, anxiety and hopelessness (Tang, Salkovskis, & Hanna, 2007).

**Aims**

The present research study aims to undertake a cross-sectional analysis of factors which may be associated with mental defeat, specifically self-efficacy, a construct previously linked to a range of outcomes including quality of life, general health, activity level and pain severity in those with chronic pain (Börsbo, Gerdle, & Peolsson, 2010; Meredith, Strong, & Feeney, 2006; Woby, Urmston, & Watson, 2007). In particular, the study aims to examine the role of mental defeat compared with apparently related factors such as hopelessness, mood and catastrophizing. This will allow researchers to begin examining whether mental defeat is associated with self-efficacy separate from other related cognitive factors and thus whether it is appropriate for target in psychological treatment.
Although theory indicates that mental defeat is likely to have an association with a range of cognitive and behavioural outcomes for chronic pain patients, its association with physical pain symptomology has not been widely examined. The closest findings to date are that it appears to be associated with functional disability (Tang et al., 2010), and pain intensity in fibromyalgia (García-Campayo, 2010). The second aim of this study therefore is to explore whether there is an association between mental defeat and pain symptomology, providing data in this area.

Whilst it has been successfully demonstrated that chronic pain is associated with the experience of a pain-related mental defeat, the viability of establishing a causal link has not been examined. This study aims to test whether it is possible to systematically activate or induce mental defeat in treatment seeking chronic pain patients, and to examine whether any shift in levels of mental defeat impacts on self-efficacy and pain symptomology, thus revealing whether there may be a possible causal link. The results from this component of the study are from here on, presented in a separate paper (see Appendix D.1).

**Hypotheses**

This project has four hypotheses:

1. there will be a significant negative association between mental defeat and self-efficacy,
2. mental defeat will account for some of the variance in self-efficacy even when anxiety, depression, catastrophizing and hopelessness are entered into the analysis.
3. there will be a significant positive association between mental defeat and pain symptomology,
4. mental defeat will account for some of the variance in pain symptomology even when anxiety, depression, catastrophizing and hopelessness are the above listed cognitive constructs are entered into the analysis.

**Method**

**Participants**

Participants were treatment seeking chronic pain patients accessing an outpatient pain clinic based in a hospital in Bath (RUH) and Gloucester (GRH), or attending a
residential pain centre in a Bath hospital (RNHRD). Recruitment was facilitated by three regional clinical psychologists within these services. Patients were included in the study if they were (1) aged 18+ (2) English-speaking and could read (3) had a complaint of chronic pain for six months or longer (4) had no co-morbid malignant/terminal disease (e.g. HIV/AIDS, cancer) (5) had no severe psychopathological co-morbidity including substance misuse, schizophrenia, bipolar disorder, major depression with suicidal intention. A priori testing revealed that a sample size of 58 would allow for an effect size of 0.25, (power 0.8, alpha 0.05). The final sample however comprised of 59 patients.

Design and Procedure

Cross-Sectional Analysis. The first part of the study was a cross-sectional analysis of factors involved in self-efficacy and pain symptomology. Participants were given an information sheet explaining that the study was exploring feelings of defeat, pain and how well people feel they can cope with pain. Eligible patients were provided with a questionnaire pack assessing: anxiety, depression, hopelessness, pain catastrophizing, mental defeat, pain symptomology and self-efficacy. They were asked to sign a consent form and post this and their completed questionnaire pack back to the researcher in a pre-paid envelope.

Measures

The following standardised measures were used within the study based on their validity with this sample group and use in existing literature.

The Generalized Anxiety Disorder- 7 (Spitzer, Kroenke, Williams, & Lowe, 2006). The GAD-7 is a seven-item self-administered measure of anxiety with a cut-off score of 7 widely used to indicate clinical levels of anxiety symptoms. Participants rate on a Likert Scale from 0 (Not at all) to 3 (Nearly every day) how much they have been bothered by a range of problems over the last 2 weeks. Total scores can range from 0-21. A higher score indicates higher levels of anxiety. It has been demonstrated to have good reliability internal consistency and factorial validity (Löwe et al., 2008).
The Patient Health Questionnaire-9 (Kroenke, Spitzer, & Williams, 2001). The PHQ-9 is a nine-item self-administered measure of depressive symptoms with a cut-off score of 9 widely used to indicate clinical levels of depression. Participants rate on a Likert Scale from 0 (Not at all) to 3 (Nearly every day) how much they have been bothered by a range of problems over the last 2 weeks. Total scores can range from 0-27. A higher score indicates higher levels of depression. It has been demonstrated to have good reliability and validity (Kroenke et al., 2001).

The Pain Self-Perception Scale (Tang, Salkovskis, & Hanna, 2007). To assess mental defeat, the PSPS was completed by participants who were asked to read 24 statements and rate to what extent these applied to their experiences of pain. These could be rated on a 5-point scale (0="Not at all/Never", 1="Very little", 2="Moderately", 3="Strongly", 4="Very strongly"), generating a total score ranging from 0 to 96. A higher score indicates a greater level of mental defeat. The scale has demonstrated good psychometric properties, including high levels of internal consistency and test-retest reliability (Tang et al., 2007).

Pain Catastrophizing Scale (Sullivan et al., 1995). The PCS was used to measure the participant's catastrophizing thinking associated with pain. It consists of 13 items and the participant is asked to rate how frequently they experience each of these thoughts or feelings when they are in pain. Ratings are made on a five-point scale from 0 (“Not at all”) to 4 (“All the time”), giving a total score ranging from 0 to 52. A higher score indicates more pain catastrophizing cognitions. The PCS has demonstrated high internal consistency and test-retest reliability over a 6–10 week period (Tang et al. 2010).

Pain Self-Efficacy Questionnaire (Nicholas, 2007). The PSEQ consists of 10 items assessing self-efficacy regarding pain. Participants rate their answers on 7-point scale ranging from 0 (Not at all confident) to 6 (Completely confident) with total scores ranging from 0-60. Higher scores indicate stronger self-efficacy beliefs. It has been shown to have good test-retest reliability, internal consistency and construct validity (Nicholas, 2007; van der Maas, de Vet, Köke, Bosscher, & Peters, 2012).
Beck Hopelessness Scale (Beck, Weissman, Lester, & Trexler, 1974). To measure levels of hopelessness, participants completed the BHS. This is a 20-item questionnaire measuring three major aspects of hopelessness; feelings about the future, loss of motivation, and expectations. It consists of twenty questions requiring the participant to respond either true or false and total scores can range from 0-20. A higher score indicates greater levels of hopelessness. Beck et al. (1974) reported good internal consistency (.93) and others have demonstrated adequate reliability and validity (Steed, 2001).

Short-Form McGill Pain Questionnaire, (Melzack, 1987). To assess pain levels, participants completed the SF-MPQ with reference to their pain experience over the past week. The SF-MPQ consists of 15 representative words from the sensory (11 items) and affective (4 items) categories of the standard MPQ (Melzack, 1975). Each pain descriptor is ranked on a 4-point intensity scale (0=“None”, 1=“Mild”, 2=“Moderate”, 3=“Severe”). The sum of these rank values generates a Sensory Pain Rating Index (S-PRI) score (range=0–33) and an Affective Pain Rating Index (A-PRI) score (range= 0–12). The Total Pain Rated Index (T-PRI) score is the sum of the A-PRI and S-PRI (range= 0-45). The measure also includes a 10-cm horizontal visual analogue scale (VAS) as an assessment of the overall pain intensity (ranging from 1-10) and a measure of ‘Evaluative overall intensity of total pain experience’ ranging from 0 (no pain) to 5 (excruciating pain). The SF-MPQ has been demonstrated to have good validity and reliability (Melzack, & Katz, 2001., cited in Tang, Salkovskis, Poplavskaya, et al., 2007).

Ethical considerations
The study protocol was approved by the Research Ethics Committee, Wales NHS (REC reference: 14/WA/0130), as well as by Research and Development for Gloucestershire Royal Hospital Foundation Trust (reference: 12/035/GHT), Royal United Hospital NHS Foundation Trust (reference: 01853), and Royal National Hospital for Rheumatic Diseases NHS Foundation Trust (reference: RBB 432). Approval was also granted by the Department of Psychology, University of Bath (application number 14-153). Participants were told in the information sheet that the nature of the study may evoke some anxiety and distress and were frequently
reminded that they could withdraw at any time. They were also signposted to appropriate sources of support.

**Analytic strategy**

**Missing data.** Due to photocopying error, one completed questionnaire pack was discarded from the study due to a large amount of missing data. Apart from this case, missing data was limited apart from two participants who failed to complete all items on the Beck Hopelessness Scale, and three participants who failed to fully complete the McGill Pain Questionnaire. Appropriate steps were taken to compute missing values which included using ratio imputation for the BHS and assigning a score of 0 to missing items on the SF-MPQ. The latter decision was made due to feedback from several participants who had assumed they should only tick an answer for the descriptors of pain they actually experienced, and to leave blank those they did not.

**Cross-Sectional Analysis.** Initially, a planned stepwise linear regression analysis was performed to test hypotheses 1a and 1b by examining the associations between the independent variables (IVs) of age, anxiety, depression, mental defeat, hopelessness, and pain catastrophizing with the dependent variable self-efficacy. A second planned stepwise linear regression analysis was performed to test hypotheses 2a and 2b with the same IVs as previously but with pain symptomology as the dependent variable (DV). Following this two further exploratory regression analyses were performed to separately examine the associations between the mentioned IV’s with firstly sensory pain and secondly affective pain. The assumptions for undertaking a regression analysis detailed by Field (2009) were verified and met for all models. This included ensuring all predictor variables were quantitative or categorical, no perfect multicollinearity, verifying homoscedasticity and independent errors, as well as ensuring normally distributed errors.

**Results**

**Participant characteristics**
As an overall group, this sample had a mean age of 47.8 years (SD=11.4) and was largely composed of female participants (76.3%). A majority (67.8%) were
married or living as married, and at the time of testing, 44% were either unemployed, retired or on sick leave. With regards to location of pain within the body, 35.6% of participants experienced back/spinal pain, 32.7% reported either fibromyalgia or pain all over the body, and 27.1% experienced pain in the foot/leg/hip. Other sources of pain included shoulder/neck/head (20.3%), arm/hand (11.9%) and 'other' including testicles and stomach (5.1%). Using the 0-10 visual analogue scale, the mean pain intensity score was 5.0 (SD=1.5), the mean ‘Sensory Pain Rating Index’ score was 19.5 out of a possible 33 (SD=6.1), and the mean ‘Affective Pain Rating Index’ score was 6.8 out of a possible 12 (SD=3.3). The sample scored a mean of 21.3 (SD=11.3) for self-efficacy, with a lower score indicating a lower perceived self-efficacy (possible range of 0-60). On the psychopathology measures, participants obtained a mean score of 11 (SD=5.9) for hopelessness, 11.1 (SD=6.2) for anxiety, 15.8 for depression (SD=6.8), 44.4 (SD=28.2) for mental defeat, and finally 26.9 (SD=10.5) for catastrophizing.

As can be seen in Table 3.1 the participant characteristics were also explored across each site and some differences can be observed. Those patients accessing the national residential pain service (RNHRD) were generally experiencing greater severity on the psychopathology measures, but were similar to patients from the RUH on pain symptomology. Fairly consistently, on average those patients recruited from Gloucestershire Royal Hospital's pain clinic scored lower on the psychopathology and pain measures. As the groups were not compared against each other in the analyses, tests to determine whether these differences met statistical significance were not conducted.
Table 3.1: Participant characteristics

<table>
<thead>
<tr>
<th>Site</th>
<th>GRH (n=25)</th>
<th>RNHRD (n=15)</th>
<th>RUH (n=19)</th>
<th>Overall sample (n=59)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>51.3 (13.3)</td>
<td>40.9 (7.9)</td>
<td>48.6 (8.9)</td>
<td>47.8 (11.4)</td>
</tr>
<tr>
<td>Sex (% female)</td>
<td>68</td>
<td>80</td>
<td>84.2</td>
<td>76.3</td>
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<tr>
<td>Marital status (% married or living as married)</td>
<td>84</td>
<td>60</td>
<td>52.6</td>
<td>67.8</td>
</tr>
<tr>
<td>Employment status (% retired, unemployed or sick leave)</td>
<td>44</td>
<td>40</td>
<td>47.4</td>
<td>44</td>
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<tr>
<td>Sources of pain (%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Back/spine</td>
<td>44</td>
<td>26.7</td>
<td>31.6</td>
<td>35.6</td>
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<tr>
<td>Shoulder/head/neck</td>
<td>28</td>
<td>20</td>
<td>10.5</td>
<td>20.3</td>
</tr>
<tr>
<td>Arm/hand</td>
<td>8</td>
<td>20</td>
<td>10.5</td>
<td>11.9</td>
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<td>Fibromyalgia/all body</td>
<td>24</td>
<td>33.3</td>
<td>42.1</td>
<td>32.2</td>
</tr>
<tr>
<td>Foot/leg/hip</td>
<td>28</td>
<td>20</td>
<td>31.6</td>
<td>27.1</td>
</tr>
<tr>
<td>Other</td>
<td>8</td>
<td>0</td>
<td>5.3</td>
<td>5.1</td>
</tr>
<tr>
<td>BHS</td>
<td>8.3 (5.8)</td>
<td>14.3 (3.7)</td>
<td>12.1 (6.1)</td>
<td>11.1 (5.9)</td>
</tr>
<tr>
<td>PHQ-9</td>
<td>11.9 (5.9)</td>
<td>21.2 (4.3)</td>
<td>16.6 (6.5)</td>
<td>15.8 (6.8)</td>
</tr>
<tr>
<td>GAD-7</td>
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<td>15.6 (4.3)</td>
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<td>11.1 (6.2)</td>
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<td>PCS</td>
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<td>33.4 (10.3)</td>
<td>28.1 (9.5)</td>
<td>26.5 (10.9)</td>
</tr>
<tr>
<td>PSEQ</td>
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<td>13.2 (6.5)</td>
<td>21 (8.9)</td>
<td>21.3 (11.3)</td>
</tr>
<tr>
<td>PSPS/Mental Defeat</td>
<td>25.8 (20.7)</td>
<td>73.5 (16.4)</td>
<td>45.1 (24.6)</td>
<td>44.2 (28.2)</td>
</tr>
<tr>
<td>SF-MPQ (VAS)</td>
<td>4.7 (1.7)</td>
<td>5.4 (1.6)</td>
<td>5.1 (1.3)</td>
<td>5.0 (1.5)</td>
</tr>
<tr>
<td>SF-MPQ (Sensory)</td>
<td>18.0 (6.2)</td>
<td>19.9 (5.7)</td>
<td>21.05 (6.3)</td>
<td>19.5 (6.1)</td>
</tr>
<tr>
<td>SF-MPQ (Affective)</td>
<td>5.7 (3.2)</td>
<td>7.8 (3.0)</td>
<td>7.3 (3.3)</td>
<td>6.8 (3.3)</td>
</tr>
<tr>
<td>SF-MPQ (Total pain rating)</td>
<td>23.7 (8.5)</td>
<td>27.7 (7.6)</td>
<td>28.3 (8.8)</td>
<td>26.2 (8.5)</td>
</tr>
</tbody>
</table>

Self-efficacy

A stepwise hierarchical linear regression was run to test hypothesis 1a that there would be a significant negative association between mental defeat and self-
efficacy, and hypothesis 1b that mental defeat would account for some of the variance in self-efficacy when anxiety, depression, catastrophizing and hopelessness were entered into the analysis. As can been seen in Table 3.2 below, of all the independent variables, mental defeat showed the strongest significant association with self-efficacy, $\beta = -.69$, $t (59) = -7.23$, $p=.001$, and as a variable, explained a significant proportion of the variance in self-efficacy, $R^2 = .47$, $F(1,59) = 52.26$, $p=.001$ supporting hypotheses 1a and 1b. Overall higher levels of mental defeat were associated with lower ratings of self-efficacy.

Table 3.2: Regression analysis coefficients (self-efficacy)

<table>
<thead>
<tr>
<th>Step 1</th>
<th>B</th>
<th>SE B</th>
<th>$\beta$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Constant</td>
<td>33.53</td>
<td>2.00</td>
<td></td>
</tr>
<tr>
<td>Mental defeat</td>
<td>-.28</td>
<td>.38</td>
<td>-.69*</td>
</tr>
</tbody>
</table>

Note: $R^2 = .47$. *$p<.001$

None of the other tested variables accounted for any of the variance in self-efficacy scores and were excluded from the model.

**Total pain rating index score**

A stepwise hierarchical linear regression was then run to test hypothesis 2a that there would be a significant positive association between mental defeat and total pain symptomology, and hypothesis 2b that mental defeat would account for some of the variance in pain symptomology even when anxiety, depression, catastrophizing and hopelessness were entered into the analysis. Results showed a significant positive correlation between mental defeat and total pain score supporting hypothesis 2a, $r=0.51$, $n=59$, $p<.001$. As can be seen in Table 3.3 anxiety had the strongest association with total pain rating, $\beta = .51$, $t(59) = 4.52$, $p= .001$, explaining a significant proportion of the variance, $R^2 = .26$, $F(1,59) = 20.41$, $p=.001$. 
Table 3.3: Regression analysis coefficients (total pain)

<table>
<thead>
<tr>
<th>Step 1</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>B</td>
<td>SE B</td>
<td>B</td>
</tr>
<tr>
<td>Constant</td>
<td>18.34</td>
<td>1.99</td>
<td></td>
</tr>
<tr>
<td>GAD-7</td>
<td>0.71</td>
<td>0.16</td>
<td>.51*</td>
</tr>
</tbody>
</table>

Note: $R^2 = .26$. *$p < .001$

No other tested variable including mental defeat explained any further variance in total pain symptomology and were excluded from the model, refuting hypothesis 2b.

**Sensory and affective pain ratings.** Following the previous planned primary analysis, secondary analyses were subsequently undertaken to explore any associations between the above detailed predictors with different types of pain; sensory and affective pain. Two further hierarchical regression analyses were run. Firstly, as shown in Table 3.4 pain catastrophizing showed the strongest association with sensory pain rating, $\beta = .40$, $t(59) = 3.38$, $p < .01$, explaining a significant proportion of variance $R^2 = .16$, $F(1,59) = 10.73$, $p < .01$. None of the other tested cognitive variables accounted for any further variance in sensory pain and were excluded from the model.

Table 3.4: Regression analysis coefficients (sensory pain)

<table>
<thead>
<tr>
<th>Step 1</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>B</td>
<td>SE B</td>
<td>B</td>
</tr>
<tr>
<td>Constant</td>
<td>13.55</td>
<td>2.00</td>
<td></td>
</tr>
<tr>
<td>Pain catastrophizing</td>
<td>.22</td>
<td>.07</td>
<td>.40*</td>
</tr>
</tbody>
</table>

Note: $R^2 = .16$. *$p < .01$

Secondly, as shown in Table 3.5, mental defeat had the strongest association with affective pain rating, $\beta = .62$, $t(59) = 6.01$, $p < .001$, and explained a significant proportion of variance, $R^2 = .39$, $F(1,59) = 36.06$, $p = .001$. None of the other tested cognitive variables accounted for any further variance in affective pain and were excluded from the model.
Table 3.5: Regression analysis coefficients (affective pain)

<table>
<thead>
<tr>
<th></th>
<th>B</th>
<th>SE B</th>
<th>β</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step 1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Constant</td>
<td>3.56</td>
<td>.63</td>
<td></td>
</tr>
<tr>
<td>Mental defeat</td>
<td>.072</td>
<td>0.1</td>
<td>-.62*</td>
</tr>
</tbody>
</table>

Note: $R^2 = .39$. *$p<.001$

In summary, higher levels of catastrophizing were mostly strongly associated with higher ratings of sensory pain, and higher levels of mental defeat were most strongly associated with higher affective pain scores.

**Discussion**

This study primarily sought to contribute towards an understanding of the impact of mental defeat on the experience and behaviour of people suffering from chronic pain. The study of mental defeat in other areas of research, such as in trauma, had previously drawn comparisons with other cognitive constructs such as depression, hopelessness and catastrophizing. This study aimed to examine the association between feelings of mental defeat and self-efficacy, when also accounting for other related cognitive constructs. Furthermore, although mental defeat had previously been linked to functional disability in chronic pain patients (Tang et al., 2010), research had not begun testing whether there was any association with the experience of participants' pain symptomology as had been previously found with pain catastrophizing (Burton et al., 1995; Simons & Kaczynski, 2012). This study sought to add evidence here by examining the links between the cognitive constructs of anxiety, depression, mental defeat, hopelessness and catastrophizing with overall pain ratings, and then separately sensory and affective pain qualities.

Consistent with hypotheses 1a and 1b mental defeat was negatively associated with self-efficacy and showed the strongest association with self-efficacy when examined with anxiety, depression, catastrophizing and hopelessness. These psychological variables and age did not separately account for any further variance in the outcome. With regards to overall pain rating, consistent with
hypothesis 2a mental defeat was positively associated with pain severity. Results however did not support hypothesis 2b as mental defeat did not explain any of the variance in pain severity once anxiety had taken 26% of the variance. Secondary analyses were run to gain further information about associations with sensory and affective pain ratings. Of all of the tested variables, mental defeat demonstrated the greatest association with affective pain (incorporating qualities such as punishing and frightening pain), and catastrophizing showed the strongest association with sensory pain (incorporating qualities such as throbbing and stabbing pain). Each of these associations will be considered in turn.

**Mental defeat, self-efficacy and affective pain**
The link between mental defeat and low - self-efficacy is understandable when considering theory and other research in the area. In an early qualitative exploration of mental defeat in chronic pain, patients interviewed by Tang et al. (2009) described feelings of a loss of control, autonomy and ability to maintain their identity as a human being. In short, many felt like they had 'given up'. Research has demonstrated that the activation of negative beliefs about the self in relation to pain can increase accessibility of negative pain-related memories, biases information processing and shifts attention towards negative aspects of the pain. All of these can negatively influence the person’s ability to cope (Sharp, 2001; Tang, Salkovskis, Poplavskaya, et al., 2007). When cognitions associated with defeat, such as 'I feel defeated by life' and 'I don't feel able to deal with things that life throws at me', are activated, related research in areas such as depression and catastrophizing indicates that the individual will likely experience a negative information bias about their current coping ability, focus in on the tasks they cannot achieve and reflect on memories of when they have struggled to cope with the pain. These mechanisms will all serve to reinforce the belief that one cannot cope with the pain, thus feeding back into feelings of defeat.

Equally, in line with the cognitive activation theory, the results would suggest, not surprisingly, that when defeat cognitions are activated, individuals with chronic pain are more attuned and focused in on the emotional qualities of their pain, so will rate it as more 'punishing', and 'cruel' for example. This would suggest that defeat cognitions may bias people’s labelling or perception of the affective experience of pain.
Catastrophizing and pain

The association found between pain catastrophizing and sensory pain is in line with several findings from similar research. Burton et al. (1995), Hermann, Hohmeister, Zohsel, Ebinger, & Flor (2007) and Simons & Kaczynski (2012) all found that chronic pain patients higher in catastrophizing reported higher pain severity. The fear avoidance model (Lethem et al., 1983; Vlaeyen & Linton, 2000) and health anxiety model (Rode et al., 2006) have guided understanding of these findings. The fear avoidance model states that pain initiates a set of cognitive, emotional and behavioural responses which can at times, exacerbate pain and disability. If the pain is interpreted as threatening or catastrophic (e.g. ‘the pain is causing my body damage’), this typically leads to an excessive fear of pain and injury which gradually incorporates a fear of physical movement. People thus limit their physical activity, and this avoidance then limits the individual’s opportunity to disconfirm these beliefs. Although in the short-term the pain may decrease due to resting, in the long-term inactivity leads to more pain, disability and poorer quality of life (Crombez, Eccleston, Van Damme, Vlaeyen, & Karoly, 2012). This pain is then feeding back into initial beliefs about illness and makes avoidance more likely to continue, a vicious cycle.

Anxiety and pain

The association between anxiety and overall pain rating (incorporating sensory and affective pain) found in this study is interesting. Similar research has found an association, but specifically when examining pain-associated anxiety (e.g. McCracken et al., 1992). It has been suggested that pain anxiety directs attention towards pain symptomology (Arntz, Dreessen, & Merckelbach, 1991), which appears to overlap with the pain catastrophizing literature, based on the health anxiety and fear avoidance theories. It is possible however that there could be mediating links to explain an association between anxiety and pain. Asmundson and Norton (1995) found that chronic back pain patients with high anxiety sensitivity reported more fear of pain and tended to have greater avoidance of activities than those with lower anxiety sensitivity, despite equal levels of pain. Later the authors showed that high anxiety directly exacerbates fear of pain, affecting escape and avoidance behaviours (Asmundson & Taylor, 1996). From what we know of the health anxiety and fear avoidance literature, this may then
result in greater pain symptomology. It is important to consider the directionality of these types of associations; one cannot determine whether higher anxiety causes more pain or whether higher levels of pain leads to heightened anxiety.

Limitations
This study is not without limitations. Recruitment from a national residential pain service resulted in a sub-group of participants who were arguably more severely psychologically distressed than the ‘average’ outpatient attending a local chronic pain clinic. The results however revealed that as a sub-group these individuals scored similarly to patients from local pain clinics on pain symptomology, and so would suggest the results are not biased towards those with greater pain severity. The sample size of 59 was adequate but a higher numbers of patients sourced from a range of clinics would improve the study. The sample also comprised of 76.3% females and so future work would benefit from gaining greater data from males. Unfortunately the study did not record duration of pain symptomology and this may have been interesting data. Finally, the nature of the cross-sectional analysis means that we are not able to determine causational relationships. Undoubtedly there are reciprocal relations among feelings of defeat, pain symptomology and self-efficacy.

Research implications
Further research is needed to experimentally examine the extent to which the associations noted in this study are causal or not. The impact of an experimental induction of mental defeat on self-efficacy and symptomology was the focus of the pilot study reported in Appendix D.1, which found that the manipulation of state mental defeat is possible following an adapted Velten Mood induction procedure. Whilst this initial work is promising, the study was not able to answer the question regarding impact on self-efficacy and pain symptomology. Previous research has suggested that there may be a relationship between the activation of negative self-beliefs and engagement in safety seeking behaviours (SSBs) in chronic pain (Sharp, 2001; Tang, Salkovskis, Poplavskaya, et al., 2007). Future research examining whether those higher in mental defeat are engaging in more SSBs (such as avoidance of activity and reliance on medication) and if so, whether this affects self-efficacy and pain symptomology would be interesting. Finally, longitudinal studies examining mental defeat would also be useful to track
changes over time and research could consider the use of mental defeat prospectively as a predictor for how well patients do in chronic pain rehabilitation programmes for example.

**Clinical implications**
The results from this study indicate that mental defeat may be an important factor in how well individuals perceive their ability to cope with chronic pain as well as the extent to which they perceive their pain in an emotional or affective manner. Tang et al. (2010) offer hope by arguing that as opposed to general mood states such as depression, the specific psychological processes involved in mental defeat are amenable to more direct interventions and that interventions should specifically target these types of cognitions in therapeutic treatments. The aim may be to help patients challenge and reframe their experience of chronic pain in order to help them improve their sense of identity, self and agency and work towards values-based goals. If causality between mental defeat and self-efficacy pain symptomology can be established then it would be a target for assessments and psychological interventions for those struggling with chronic pain. Interestingly at this point the PTSD and chronic pain literature has not identified specific interventions which have been shown to be effective in reducing mental defeat. We therefore can only suggest speculative approaches which would need to be evaluated in the context of addressing the cognitions and self-schemas around the pain, such as cognitive behavioural therapy (CBT) and acceptance-based therapy (ACT). Furthermore, more cognitively framed strategies similar to those used in self-esteem (e.g. Fennell, 2009) may also be helpful; for example keeping a positive data log focused on achievement where defeat is usually experienced. Finally, if interventions are able to improve feelings of self-efficacy this could have beneficial effects on mood, quality of life, general health, activity level and pain severity in those with chronic pain (Börsbo et al., 2010; Meredith et al., 2006; Woby et al., 2007).
References


adolescents: current methods and further development. The Journal of Pain, 8(10), 802-813.


Tang, N. K., Goodchild, C. E., Hester, J., & Salkovskis, P. M. (2010). Mental defeat is linked to interference, distress and disability in chronic pain. Pain,


Paper 2 for Main Research Project

Experimental activation of mental defeat using a mood induction task

Please refer to appendix D.1 for the write-up of this component of the research project.
Executive Summary

Understanding the link between feelings of defeat and the experience of chronic pain.

Background
In research, mental defeat has been identified as a psychological construct, potentially involved in the development and maintenance of post-traumatic stress disorder (Ehlers et al., 1998), and depression (Gilbert & Allan, 1998). Ehlers et al. (1998) defined mental defeat as a perceived loss of all autonomy, a sort of giving up in one's own mind the ability to maintain one's identity as a human being. To date, this construct has most widely been studied in relation to uncontrollable traumatic events such as torture, and has been shown to predict the likelihood of developing PTSD, severity of symptoms and response to treatment (Dunmore, Clark, & Ehlers, 1999, 2001; Ehlers et al., 1998; Ehlers, Maercker, & Boos, 2000). In recent years researchers have looked at feelings of defeat amongst chronic pain patients, and have described this as a sort of 'self-processing', where the pain experienced results in a set of negative beliefs about the self (Tang, Salkovskis, & Hanna, 2007). Both the health anxiety model (Rode et al., 2006) and fear avoidance models, (Lethem, Slade, Troup, & Bentley, 1983; Vlaeyen & Linton, 2000) have stressed the important role of the meaning or interpretation of the pain on outcomes like disability and distress.

Initial research has shown that feeling defeated by pain is associated with health anxiety, pain interference, sleep disturbance, and functional disability (Tang et al., 2010). Researchers recommended that studies should look at the relationship between mental defeat and other cognitive constructs related to psychological distress and chronic pain, such as catastrophizing, depression and hopelessness. The present study was interested in whether feelings of mental defeat was associated with pain symptoms and how well people felt they can cope with pain, known as self-efficacy. Other cognitive constructs (anxiety, depression, catastrophizing and hopelessness) and age were also examined. Secondly, although many people with chronic pain report feeling defeated, we do not know whether these types of feelings actually cause a change in things like self-efficacy and pain levels. The current study attempted to determine whether it was possible...
to increase and decrease feelings of defeat in chronic pain patients using a mood induction task, and whether these feelings would cause changes in pain symptoms and self-efficacy.

**Method**

59 patients from three local pain services completed a questionnaire pack asking about:

- demographic information (age, sex, source of pain, etc)
- anxiety
- depression
- hopelessness
- catastrophizing
- mental defeat
- pain symptomology
- pain self-efficacy.

Participants could opt in to completing the mood induction task after completing the questionnaires. Eleven participants were randomly assigned to the ‘mental defeat’ condition and nine to the positive condition (lowering feelings of defeat). A research session took place where the participant rated their current anxiety and depression level, and then completed a short questionnaire asking about feelings of defeat at that present moment, specifically designed for this project. The participant then completed the mood induction task, lasting about 15 minutes. This involved reading and dwelling on statements which were either positively or negatively framed. Participants then re-completed the questionnaire asking about feelings of defeat. This allowed researchers to determine whether levels of defeat had increased or decreased because of the reading task. Lastly, participants re-completed questionnaires asking about self-efficacy and pain symptoms. People in the negative group also completed the positive task to ensure the effects of the task were reversed. Finally participants re-rated their anxiety and depression levels to ensure they had not been lastingly affected by the task.
Results

- Mental defeat showed the strongest association with self-efficacy. Feeling more defeated was linked to a lower confidence in being able to cope with pain.
- With regards to overall pain, anxiety showed the strongest association; higher anxiety was linked to higher pain ratings. Further tests were run to gain more information about associations between age, anxiety, depression, catastrophizing, hopelessness and mental defeat with sensory and affective qualities of pain.
- From the list of factors mentioned above, mental defeat showed the strongest association with affective pain (incorporating qualities such as punishing, cruel and frightening pain).
- Pain catastrophizing was the most strongly associated with sensory pain; higher scores were linked to greater severity in sensory pain qualities such as throbbing and sharp pain.
- The newly created 'state mental defeat scale', adapted from the Pain Self-Perception Scale, was tested and showed to be a reliable and valid measure of 'here-and-now' feelings of defeat.
- Checks revealed that the mood induction task was successful for both the positive pain self-perception and mental defeat groups, demonstrating that these 'here-and-now' feelings of defeat are susceptible to change. The induction was unsuccessful for 4 out of 20 participants.
- Due to problems with the method of the study, it was not possible to analyse the data as hoped to examine the effect of changes in mental defeat on self-efficacy and symptomology. Future research here is needed to determine causal relationships.

Implications for research and clinical practice

This study has contributed interesting information to the relatively small amount of current research exploring mental defeat and chronic pain. It has highlighted the relationship between feelings of defeat and how well patients perceive their ability to cope with pain, even when related constructs such as anxiety, depression, hopelessness and catastrophizing are examined. This suggests that mental defeat as a construct is capturing some element of the chronic pain experience that these other constructs are not. Future research is now needed to test for causal
relationships between mental defeat and different outcomes in chronic pain. The development and testing of the state mental defeat measure has contributed towards future research, showing that shifts in acute feelings of defeat can be shifted, therefore allowing for causality testing.

If causality can be established then it would be a target for assessments and psychological interventions for those struggling with chronic pain. The cognitive nature of mental defeat would suggest that therapies such as CBT or ACT have the potential to develop treatment strategies to alleviate distress caused from feelings of defeat.
Connecting Narrative

This connecting narrative provides greater contextual information as well as reflections around the process of selecting, designing and completing my main research project, service improvement project, critical literature review and case studies.

Study selection and development

Service improvement project (SIP). The aim of my SIP was to explore the experiences of parents of children with a life-limiting illness during transition to adult services. The hope was to determine how well the service was meeting its objectives in ensuring a supportive and well-planned transition for families. The local clinician had initially detailed her plans for a related project in the research handbook circulated to trainees, which is how I initially became aware of the project. The topic appealed to me for several reasons. I had a personal interest in palliative care, yet my prior experience was largely focused on adults in hospices. I was interested in developing my knowledge around practice and policies regarding services for young people, and from discussions with my regional supervisor and reading around the topic, I became particularly interested in the challenges that young people and families faced when transitioning. After meeting with my supervisor and undertaking a review of the literature, a qualitative design was thought to be an appropriate methodology for eliciting personal and rich data regarding this process. Due to the severity of many of the children's learning and communication difficulties, it was decided at the planning stage, that only parents would be interviewed for the project. The interview schedule was developed via listening to the needs of the service, reviewing similar literature and by input from service users (discussed further later). Both my regional and university supervisors also approved the schedule and protocol for the project.

Main research project (MRP). During my first year of training I developed a research proposal to undertake a study exploring the impact of health anxiety on patients with mild cognitive impairment (MCI). Health anxiety was a topic I had developed an interest in arising from a piece of clinical work undertaken on my 'working age adult' placement. Having read interesting research into the effects of
health anxiety on patients with multiple sclerosis, I developed with Professor Salkovskis a proposal for a project exploring associations between health anxiety, quality of life and subjective performance on cognitive testing in patients with MCI. I experienced several challenges during the planning stage of this project when liaising with local clinicians and memory clinics. A local Clinical Psychologist was undertaking a similar study, and had already created links with services and clinics to ensure sole recruitment to her project. Although I offered collaborative working with this researcher, this was not reciprocated and it became clear that access to adults with MCI within the region would be challenging. After having spent several months developing this project and having had the protocol fully approved by the course, in agreement with my clinical tutor and research supervisor, I decided to abandon this study and develop a new project. This was a very challenging and stressful period for me, feeling that I had fallen behind my cohort and my own personal deadlines.

Having a background in clinical health psychology and experience working on a qualitative research project in chronic pain prior to training, this was an area I have wanted to gain more experience in. Spending some time reading papers exploring the qualitative impact of chronic pain on individuals, I became interested in a novel paper discussing the concept of 'mental defeat' in this population. Discussions with Professor Salkovskis around possible areas for future research here led to me developing a new project, with the aim of unpicking this relatively new cognitive construct associated with chronic pain. As a result of having to abandon the first project, I believe that the choosing and development of this new project was unavoidably done in a hurry, and unfortunately to some decisions and being rushed. These mostly concerned the details in the methodology, which was disappointing as the main aim had been to examine the association and determine causality between mental defeat and pain outcomes.

**Critical literature review (CLR).** Whilst on placement with an IAPT service I attended a talk by a local self-harm association, PASH. At this point in my training, I had very little knowledge of self-harm theory and limited experience of working clinically with individuals who self-harmed. During this talk the speaker commented on the high prevalence of self-harm amongst individuals in the prison system, and this sparked my desire to read more about this. I became interested
in studies noting particularly high prevalence of self-harm amongst women offenders, and yet could see flaws in reviews around risk factors for this population. I was lucky to have early supervision on this project from Dr Megan Wilkinson-Tough and later Dr Catherine Hamilton-Giachritsis who both have extensive forensic experience and gave me some useful guidance. It was decided this topic would be well suited to a systematic or narrative review. I did encounter some challenges with paper selection for the review due to only a limited number of studies which had clearly defined or measured non-suicidal self-injurious behaviour (NS-SIB). Due to many papers not defining whether the SIB was suicidal or not in nature, I was initially limited to only nine papers for review. Although this was an interesting reflection on the current research, it left me with a limited scope to the review. At this point, my supervisor was in agreement that it would be of interest to review studies clearly examining NS-SIB and also those studies where definitions were not provided or samples were mixed with suicidal and NS-SIB, to explore whether there was an overlap of themes.

**Ethical and R&D approval**

**Service improvement project.** Once the project had been designed I consulted with a local R&D manager as well as checking with the National Institute for Health Research (NIHR) website to determine whether this project fell under the category of research or service development/evaluation. Both confirmed the project was service evaluation so would not require NHS ethical approval. The Service User Facilitator for the organisation was also contacted, and after reading the protocol she provided me with the go-ahead for the project. Finally, ethical approval was also granted by the Department of Psychology, University of Bath.

**Main research project.** For the main research project I was aware of the importance of applying for NHS ethical approval as early as possible as this can take several months to complete. Never having completed an IRAS form before meant that I had to seek support from my supervisors as well as peers on certain elements. The biggest obstacles that arose when attending the research ethics committee (REC) meeting and from further communication, was around their concerns regarding the mood induction aspect of methodology. This resulted in me taking more time to create a ‘risk flowchart’ and discuss with the lead clinicians.
a suitable protocol should any such difficulties arise. Once full ethical approval had been granted, I was able to swiftly obtain ethical approval from the University of Bath's Psychology Department, as well as R&D approval from the three NHS trusts that I planned to recruit from. Prior to commencing my training, I had completed a Good Clinical Practice Training day which guided me in ensuring that all my research projects and case studies adhered to ethical guidelines.

**Case studies.** Full written consent was obtained from service users allowing me to write up the cases. The rationale behind writing up the intervention was explained and they were told that the report would be made anonymous and any identifiable information removed. Throughout training, I also filmed many of my clinical sessions with service users and ensured that full written consent was obtained prior to this, utilising local trust documents where available.

**Recruitment and data collection**

**Service improvement project.** Originally I had hoped to recruit parents whose child was approaching transition in the upcoming year as well as those who had children who had transitioned in the previous 12 months. This would have allowed me to gain a broad range of experiences across the transition period. Both the lead clinician (clinical psychologist) as well as nurses in the team provided me with a list of families who fitted the criteria and who had expressed initial interest in participating in the study. Ten invitation letters were sent out to eligible families detailing the project, of which five families consented to take part, a 50% success rate. Unfortunately only one of these families had completed transition, with the remainder transitioning in the upcoming year. Linking in with adult services to recruitment more families who had recently transitioned may have been a strategy to have improved this difficulty. Despite this, I managed to interview six parents across the five families and gained in-depth and rich information about approaching and passing through the transition period. One of the families was also involved in developing the interview schedule which was invaluable.

**Main research project.** Recruitment for my MRP was challenging and resulted in a smaller sample size than I had hoped for. Initially I had four local pain services who had agreed to facilitate recruitment; Bristol NHS, Royal United
Hospital (RUH) Bath NHS, Gloucestershire Royal Hospital (GRH) NHS and The Royal National Hospital for Rheumatic Diseases (RNHRD) NHS. Unfortunately once I had reached the stage of requiring the clinicians to create an IRAS account to authorise the REC form, the lead clinician based at the Bristol based pain clinic dropped out of the project with no explanation and I was unable to continue with this possible source for recruitment. Furthermore, from the start of the project, the lead for the Gloucestershire site decided that they were not willing to facilitate recruitment to the mood induction component of the project. They were concerned about the psychological impact this would have on patients, despite the project having received full ethical approval. This resulted in three services (RUH, RNHRD and GRH) recruiting participants to complete the cross-sectional analysis part of the study (filling in a questionnaire pack), and two services (RNHRD and RUH) recruiting also for the mood induction task. I actively started recruitment for the project in June 2014, allowing myself just under a year for data collection. Recruitment rates however remained low to start and I believe this occurred due to several reasons.

The RNHRD routinely provided patients with their own questionnaire packs to complete, and I believe that for several months my packs were simply not been given out. To address this, I met with the team to undertake a 30minute presentation giving more information about my project in the hope this would improve motivation. I also experienced challenges in this service accessing consenting patients to complete the mood induction task. I was told by a clinician that I was not to contact any participant who scored highly on their baseline depression measure (PHQ-9) within the questionnaire pack, even if this individual had opted in to complete the mood induction. Further, because of the structure of the patients' week in this residential pain service, I was also limited practically on the days and times I could meet patients to complete the induction task. Patients were in group sessions during the day from 9am-4.30pm and so I was limited to seeing patients only on a Friday afternoon when they were not in a group. Because this was a service receiving national referrals, many patients lived far away so it was not possible to arrange home visits either.

It was only in the last six months of my project when a new Assistant Psychologist started with the team who was able to take a lead on organising packs to be
handed out, arranging rooms for the mood induction and so forth that this situation improved slightly. Completing my first elective placement at the pain clinic in the RUH for six months was also a great help. Being able to get to know patients as well as staff made a significant difference and this was where I obtained a large proportion of my participants from. By April 2015, my final sample size was significantly lower than I had planned for, despite my best efforts. It highlighted to me the challenges of undertaking research in NHS settings when you do not know the teams or patients well and are relying on others for recruitment.

**Case studies.** Data collection formed an important part of my case studies, particularly for those following a single case experimental design. In many of the services I worked such as IAPT and CYP-IAPT CAMHS, outcome measures were routinely used with clients, facilitating regular data collection. Completing a placement within a hospice for adults, as well as on my learning disability placement encouraged me at times to be more creative with my selection and use of outcomes measures. For example within the hospice my supervisor encouraged me to collaboratively design a 'measure' with my patient ensuring we were working towards meaningful goals for her. This included her being able to talk to her family about her death, as well as feeling confident in being able to assertively talk to medical professionals about her wishes for treatment. This was a useful experience and learning point for my future career.

**Contributions to research and clinical practice**
The final section of this connecting narrative considers the contributions that my research projects and case studies have made to research and clinical practice.

**Service improvement project.** The findings from this project along with the recommendations were fed back and taken on board by the service. I also completed a poster presentation based on this work at the BPS’ Child and Young Person Conference in 2014 which gave me an opportunity to disseminate the work with clinicians and researchers. At a clinical level, there are many ways in which the findings have contributed to changes in practice. For example, the service decided to; create an information leaflet for families about transition, offer further staff training, and send summary documents to specialist physicians in adult services taking on the young person's care. The implications here are that families
will hopefully feel more confident in the handing over of knowledge and care of their child's condition, and that adult services are provided with more in-depth and personal information about the young person. Being able to reduce feelings of anxiety, uncertainty and isolation is vital for families in these situations, many of which experience many day-to-day challenges of caring for a child with a life-limiting illness. As a result of the project, the service also explained that they planned to regularly review the process of transition through the use of questionnaires and interviews to inform ongoing service development. This project will hopefully be published in a suitable journal and contribute to the current lack of evidence exploring the impact of transition on parents who have a child with a life-limiting illness, with the aim of improving this in the future.

**Main research project.** The construct ‘mental defeat’ has only recently been studied in relation to the experience of chronic pain and questions have been raised about its relationship with other related cognitive variables such as depression and hopelessness. What this research project has revealed is that mental defeat plays a significant important role in how well people feel they can cope with their pain, as well as their experienced level of ‘affective pain’. These associations were significant even when factors such as anxiety, depression and hopelessness were examined. Clearly this could have clinical implications for patients. I would advise pain clinics to utilise a mental defeat measure during assessments, as this may be a relevant focus for interventions or therapy.

Although difficulties arose with the mood induction component of the project, important findings were still elicited. This is the first study to test and demonstrate experimental manipulation of feelings of defeat using an induction task is possible. The state mental defeat measure which was created for the study demonstrated good validity and reliability, and is potentially an important tool for future research in this area.

**Critical literature review.** Unlike other similar reviews of self-harm in offender populations, my critical literature review explored risk factors and functions for women prisoners engaging specifically in non-suicidal self-injury. Research had indicated a rational for studying self-harm with and without suicidal intent separately, and I believe my review has made important headway in this
area. Self-harm and suicide have been shown to be continuing problems in forensic settings and at times challenging for staff to manage. By having a greater understanding of risk factors which make women offenders more likely to engage in self-injury, for example having a history of childhood sexual and physical abuse, a diagnosis of a personality disorder and poor social and communication skills, we are more able to predict those at risk and consider better ways of assessing prisoners. Furthermore, having greater evidence around the function or role that self-harm plays for this population is vital for planning appropriate methods of support, and therapeutic interventions within a prison environment. This review has also contributed to the literature by carefully considering the applicability of theoretical models of self-harm to women offenders engaging in this behaviour, with the hope that future research and interventions are grounded in theory and evidence.

**Case studies.** At a research level the case studies provide evidence for the applicability and benefits of using single-case experimental design to ensure greater therapeutic care for service users. Across my case studies I have explored the success of working within a cognitive behavioural framework to support service users experiencing conditions such as anxiety and OCD. Furthermore, they demonstrated the ways in which therapists can make adaptations during therapy, for example when working with children or in a physical health setting. The case studies also highlight the importance of sometimes needing to hold an awareness of possible alternative formulations or considerations such as attachment theory, and systemic factors for example. It is hoped that from adding to current research, these types of case studies will have a role in ensuring the care we offer to clients is evidence-based and theoretically driven.
Acknowledgements

I would firstly like to express my appreciation and thanks to my supervisors at the University of Bath; Professor Paul Salkovskis, Dr Maria Loades, Dr Catherine Hamilton-Giachritsis and Josie Millar who all encouraged, inspired and supported me with my research.

I would also like to thank several key people who were involved in the data collection for my research projects; Dr Mike Osborn, Dr Polly Ashworth, Dr Catherine Lane, Dr Jeremy Gauntlett-Gilbert, Sarah Rook and Natalie Wellington. Your efforts were greatly appreciated. Of course, a big thanks also goes to all of the service users, without whose contribution, this work would not have been possible.

A special thank you goes to my family and friends. Words cannot express how much I have valued your support, encouragement and confidence in me over the last three years. In particular, I would like to thank Neil, my husband-to-be. I cannot thank you enough for your unfaltering belief in me during my training; it certainly has been a journey! You forever offered a willing listening ear and remained my calm voice of reason and compassion throughout.
Appendix A.1
Journal Guidelines

Submitting to International Journal of Prisoner Health Manuscript requirements

Please prepare your manuscript before submission, using the following guidelines:

**Format**
All files should be submitted as a Word document.

**Article Length**
Articles should be between 4000 and 7000 words in length. This includes all text including references and appendices. Please allow 350 words for each figure or table.

**Article Title**
A title of not more than eight words should be provided.

**Article Title Page**
An Article Title Page should be submitted alongside each individual article. This should include:

- Article Title
- Author Details (see below)
- Acknowledgements
- Author Biographies
- Structured Abstract (see below)
- Keywords (see below)
- Article Classification (see below)

**Author Details**
Details should be supplied on the Article Title Page including:

- Full name of each author
- Affiliation of each author, at time research was completed
- Where more than one author has contributed to the article, details of who should be contacted for correspondence
- E-mail address of the corresponding author
- Brief professional biography of each author.

**Structured Abstract**
Authors must supply a structured abstract on the Article Title Page on the Article Title Page, set out under 4-7 sub-headings (see our "How to... write an abstract" guide for practical help and guidance):

- Purpose (mandatory)
• Design/methodology/approach (mandatory)
• Findings (mandatory)
• Research limitations/implications (if applicable)
• Practical implications (if applicable)
• Social implications (if applicable)
• Originality/value (mandatory)

Maximum is 250 words in total (including keywords and article classification, see below).

**Keywords**

Please provide up to 10 keywords on the Article Title Page, which encapsulate the principal topics of the paper.

**Article Classification**

Categorize your paper on the Article Title Page, under one of these classifications:

• Research paper
• Viewpoint
• Technical paper
• Conceptual paper
• Case study
• Literature review
• General review.
Appendix A.2

Relevant ‘Instructions to Authors’ for the 'International Journal of Prisoner Health'

To note: The paper would be formatted appropriately prior to submission, for example changing from APA to Harvard Referencing style.

Please prepare your manuscript before submission, using the following guidelines:

Categorize your paper on the Article Title Page, under one of these classifications:

- Research paper
- Viewpoint
- Technical paper
- Conceptual paper
- Case study
- Literature review
- General review.

Articles should be between 4000 and 7000 words in length. This includes all text including references and appendices. Please allow 350 words for each figure or table.

Authors must supply a structured abstract on the Article Title Page on the Article Title Page, set out under 4-7 sub-headings:

- Purpose (mandatory)
- Design/methodology/approach (mandatory)
- Findings (mandatory)
- Research limitations/implications (if applicable)
- Practical implications (if applicable)
- Social implications (if applicable)
- Originality/value (mandatory)

Maximum is 250 words in total (including keywords and article classification).

Please provide up to 10 keywords on the Article Title Page, which encapsulate the principal topics of the paper.
Appendix A.3
Relevant ‘Instructions to Authors’ for the journal 'Pain'

General Information

The Journal of Pain publishes original articles related to all aspects of pain and pain management and welcomes submissions from clinical and basic researchers, medical specialists, psychologists, nurses, physical therapists, social workers, and workers in related fields. The Journal of Pain is interdisciplinary in focus and committed to advancing knowledge about pain mechanisms and pain management. The Journal will publish reports of original clinical research, reports of original basic research, Focus Articles, Critical Reviews, and Letters to the Editor. Studies that contribute to the development and testing of pain theories and that test specific hypotheses based on a theoretical rationale are particularly encouraged.

Formatting requirements

There are no strict formatting requirements but all manuscripts must contain the essential elements needed to convey your manuscript, for example Abstract, Keywords, Introduction, Materials and Methods, Results, Conclusions, Artwork and Tables with Captions.

If your article includes any Videos and/or other Supplementary material, this should be included in your initial submission for peer review purposes. Divide the article into clearly defined sections.

Abstract
An abstract of 200 words or less should describe concisely the purpose of the study, the main findings, and conclusions, all in one paragraph without subheadings. References may not be included in the abstract.

Perspective
This item, limited to 50 words, should appear at the end of the abstract. The perspective presents a synopsis of the work to facilitate understanding of its significance. Authors of basic science reports should highlight the potential clinical relevance of their results for the benefit of clinical readers. Authors of clinical science reports should highlight the underlying mechanisms for the results, for the benefit of clinical scientists and basic scientists. Example: "Perspective: This article presents the psychometric properties of a new measure of spouse responses to patient chronic pain and well behaviour. This measure could potentially help clinicians who seek to assess how spouse responses may contribute to patient pain and disability." References should not be included in the Perspective.

Key words

Five key words should be provided following the Perspective.
Appendix B.1
SIP Transition Project: Interview Schedule

Post transition version

- Tell me about your child .... (age, health, diagnosis)
- Tell me about any services [service name] offered your child and your family
- What services do you access for your child's needs: before and after transition?
- When did you transition to adult services?
- Describe how and when transition was first introduced to you.
- Can you tell me more about what form these discussions took and the types of information were you given?
- What are your thoughts on how early and regularly discussions around transition took place?
- Are there any ways that you feel you could have been better prepared?
- Did you have any contact with the psychology service at [service name]? If so what form?
- Do you have any opinions about how psychology could be better involved in transition?
- In what ways, if any, did you feel transition impacted on your child and your family?
- What were your experiences of information sharing between child and adult services or between you and your child?
- Did transition have any impact on your social networks such as support systems, friendships etc?
- Finally, how would you summarise your overall experience of transition?

Pre- transition version

- Tell me about your child .... (age, health, diagnosis)
- Tell me about any services [service name] are offering your child and your family
- What services do you access for your child's needs?
- When will your child transition to adult services?
- Has transition been discussed with you? If yes:
  - Describe how and when transition was first introduced to you.
  - What type of information were you given?
- What are your thoughts on how early and regularly discussions around transition are taking place?
- If you haven't had a discussion yet about transition would you like this to be discussed with your family? When and with which staff?
- In what ways do you feel staff can best prepare you for transition?
- Did you have any contact with the psychology service at [service name]? If so what form
- Do you have any opinions about how psychology could better support families for transition?
- Do you have any particular concerns about the transition process?
- In what ways do you feel transition might impact on your child and on your family?
- Are there any ways you feel [service name] could help reduce this impact?
Appendix B.2
Induction task statements and instructions read by participants

In a moment I will give you some statements to read. Each of these statements is written on a piece of card. Read the statement and think about **how it applies to you** and times you have **felt like this**. Focus on the **feeling** and try to **feel the mood** suggested by these statements. Do you understand?

<table>
<thead>
<tr>
<th>Negative self perception group</th>
<th>Positive self perception group</th>
</tr>
</thead>
<tbody>
<tr>
<td>“I felt that I had lost my standing in the world”</td>
<td>“I felt I had a strong standing in the world”</td>
</tr>
<tr>
<td>“I felt that there was no fight left in me”</td>
<td>“I felt I had lots of fight in me”</td>
</tr>
<tr>
<td>“I felt like I was losing my inner resistance”</td>
<td>“I felt I had lots of inner resistance”</td>
</tr>
<tr>
<td>“I felt humiliated and that I was losing my sense of inner dignity”</td>
<td>“I felt a strong sense of inner dignity”</td>
</tr>
<tr>
<td>“I felt I was losing my will power”</td>
<td>“I felt a strong sense of will power”</td>
</tr>
<tr>
<td>“I felt that I was one of life’s losers”</td>
<td>“I felt I was one of life’s winners”</td>
</tr>
<tr>
<td>“I felt I had lost important battles in life”</td>
<td>“I felt I had won important battles in life”</td>
</tr>
<tr>
<td>“I felt down and out”</td>
<td>“I felt well-to-do”</td>
</tr>
<tr>
<td>“I felt that I had given up”</td>
<td>“I felt that I could keep going”</td>
</tr>
<tr>
<td>“I didn’t feel able to deal with things that life threw at me”</td>
<td>“I felt able to deal with things that life threw at me”</td>
</tr>
<tr>
<td>“I felt completely knocked out of action”</td>
<td>“I felt ready for action”</td>
</tr>
<tr>
<td>“I felt defeated by life”</td>
<td>“I felt uplifted by life”</td>
</tr>
<tr>
<td>“I felt less like a human being”</td>
<td>“I felt valued as a human being”</td>
</tr>
<tr>
<td>“I felt like I wanted to die”</td>
<td>“I felt like I had a lot to live for”</td>
</tr>
<tr>
<td>“I didn’t care what happened to me anymore”</td>
<td>“I really cared about my future”</td>
</tr>
<tr>
<td>“I felt like an object”</td>
<td>“I felt alive, like a real person”</td>
</tr>
<tr>
<td>“I felt completely at the mercy of what was happening to me”</td>
<td>“I felt completely in control of what was happening to me”</td>
</tr>
<tr>
<td>“I felt powerless”</td>
<td>“I felt in control”</td>
</tr>
</tbody>
</table>
Appendix B.3
Anxiety and depression visual analogue scale for mood induction task

On a scale of 0 - 10 how would you rate your **current mood** in terms of feeling:

<table>
<thead>
<tr>
<th>Not at all anxious</th>
<th>Extremely anxious</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Not at all sad</th>
<th>Extremely sad</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
</tbody>
</table>
Appendix B.4
State mental defeat/pain self-perception scale

This questionnaire is about how you feel **RIGHT NOW**.

In the following, you will find a number of statements that describe thoughts and feelings that people sometimes experience at such times.

Please rate the extent to which these statements apply to your experience **AT THE PRESENT MOMENT** by circling the appropriate number. There are no right or wrong answers to these questions.

Please remember that this questionnaire is about how you feel and think **RIGHT NOW**.

<table>
<thead>
<tr>
<th>Thought or feeling applies to me</th>
<th>Not at all/ Never</th>
<th>Very little</th>
<th>Moderately</th>
<th>Strongly</th>
<th>Very strongly</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

Because of my symptoms...

1. I feel that life has treated me like a punchbag..............
   0 1 2 3 4

2. I feel that my confidence has been knocked out of me...
   0 1 2 3 4

3. I feel that I have sunk to the bottom of the ladder..........
   0 1 2 3 4

4. I feel defeated..............................................
   0 1 2 3 4

5. In my mind, I feel I've give up............................
   0 1 2 3 4

6. I feel destroyed as a person..................................
   0 1 2 3 4

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Appendix C.1
Presenting SIP findings to the service

A summary of the findings was presented to the service by initially meeting with the chair of the ‘transition group’ who then discussed the findings with the whole group. An accessible summary document detailing the project was circulated electronically to the team and uploaded to the service’s website to be accessed by staff and service users.

Reactions of the service
A summary of the key reactions from the service are describe below:

- Staff expressed disappointment that not all families reported having access to contact details for staff in adult services
- Staff felt that all families should have visited the adult service by the point when they had been interviewed
- The chair of the transition group felt that families should have been more knowledgeable about whether they could continue to access services such as psychology and sibling groups after transition
- Staff believed it to be a positive sign that families had been introduced to the idea of transition at a suitable age and conversations had occurred regularly in line with their guidelines
- Staff appreciated hearing what families valued most about the service and the positive impact this has on their lives
- The team felt that the findings and recommendations have given them ideas and helpful recommendations for how to improve the transition process.
Appendix C.2
Lay Summary for Staff and Families

Transition to adult services for those with a life-limiting illness: the parents’ perspective. A qualitative service review.

A Service Improvement Project by Charlotte Hazeldine, Clinical Psychologist in training, University of Bath in collaboration with [clinician's name and service].

March 2014.

Introduction

Today, children with chronic life-limiting illnesses are often living longer due to improvements in medical diagnoses and therapies (Blum et al., 1993), leading to more adolescents transitioning from child to adult services. It has recently been acknowledged by all involved that transition needs to be planned well in advance, yet feedback has reported that this is often poor with parents feeling "off the radar at 19" and that there is much scope for improvement (DH Partnerships for Children, 2008; Marie Curie Cancer Care & Together for Short Lives, 2012). Parental concerns have included parents going through their own transition, fewer respite and short break services and the importance of peer support (Marsh et al., 2011).

Aim

• To review the current experiences of parents of children transitioning from [service name] to adult palliative care services by undertaking interviews with the hope of guiding any future improvements to practice.

Method

• This project was approved by the University of Bath Department of Psychology ethics committee and the Service User Involvement Facilitator at [service name].
• Invitation letters were sent out to potential participant families and five families expressed interest in taking part.
• Four families had a child due to transition within the next 12 months and one had a child who had transitioned within the last 12 months.
• Interviews were conducted at the family's homes lasting around one hour with questions like, 'Describe how and when transition was first introduced to you'.

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Interviews were transcribed and analysed using a method known as inductive thematic analysis (Braun & Clarke, 2006). All participants were given false names to ensure their responses not identifiable.

**Results**

Five main themes emerged from the interviews with parents and within these were a range of sub-themes (see diagram).

1. **The process of transition**
   - **Discussions with family & young person**
     - All 5 families reported initial discussions about transition occurred early enough and were gradual and regular.
     - The young person ranged from 13 to 15 years when this first occurred.
     - Where possible the young person had been directly involved in these discussions.

   - **Communication between services**
     - 4 families reported [service name] staff were successfully communicating with adult services in preparation for the transition.
     - 2 families discussed the important role of the transition social worker in this communication.

   - **Visits and introductions**
     - 3 of the 5 families said they were provided with contact details of staff in adult services who would be taking on the young person's care. These same families also visited their adult consultant before the transition.
2. Uncertainty

Services

“Parents are left in limbo as to what services they’re going to get when they’re 18” (Mandy)

- Four families were uncertain about what services the young person could access after 18.
- E.g. uncertainty about continuing access to psychological support and sibling groups.

Staff in adult services

“They won’t understand his noises or claps; that’s how he communicates” (Mandy).

- All parents were uncertain about what staff would be like and whether they would know about the young person’s condition
- They were also concerned about whether staff would adapt to uniqueness of the child.

Readiness of the young person

“Yes he’s 18 and legally an adult...but it’s a bit early to suddenly put everything on him and say ’look after yourself’” (Polly).

- 4 families talked about their uncertainty around the young person suddenly being considered ‘ready’ for adult services and in some cases responsible for managing their condition because they had reached the age of 18.

3. Changes to parental role

“My clout as a parent doesn’t feel as strong. People can make decision that overrule us” (Kathy).

- Parents expressed a feeling that they had less involvement and identified changes to the information they were allowed to access regarding their child.
4. Loss

Knowledge of young person

“We have to say goodbye after all those years when they’ve got all that history and experience and knowledge about her” (Polly).

- Transition represented the loss of a service and individuals who had known the young person, in some cases their whole life, and who had a wealth of knowledge about them and their condition.

Close relationships

- Strong sense of loss of close relationships and attachments with consultants, named nurses, psychologists and other families.

A holistic approach to care

- A move away from a very 'holistic' approach to care within paediatric services, to a more 'separate' or 'body parts' approach to care in adult services.
- Some talked about the loss of [service name]'s role in training schools and day centres on how to use the young person’s medical equipment.

Child friendly services

- Parents identified the loss of services that were suitable for young people with complex needs. For example adult hospital wards not accommodating parents overnight and not being age appropriate for young people.

5. Values that families appreciated about [service name]

Staff liaising on behalf of the family

- All families reported that they appreciated the liaising role that staff in [service name] took and how this eased the burden on their everyday lives.

Accessibility

“If I need anything I know I can just pick up the phone” (Mandy).

- 4 families valued the accessibility of staff, being able to obtain support when needed.

Reliability

- 4 families highlighted how reliable and trustworthy [service name] staff were.
**Recommendations**

- Families talked about how they would value a ‘transitions’ group for parents to attend to share thoughts and ideas about transition.
- An information leaflet signposting services and information about funding/benefits available to the young people and families after transition.
- Earlier discussions with families about whether they can continue to access services such as sibling groups and psychological support offered by [service name].
- Staff to have discussions with young person, parent and if possible adult services to determine how much and what type of information parents will be able to access after transition.
- Checklists to determine readiness of adolescent for independence and responsibility of care.
- Ensure all families have the opportunity to meet with their care staff in adult services and visit the care setting.
- Providing families with some initial information about the adult service and consultant - such as a photograph and name of their new consultant and nursing team.
- Joint clinical appointments between paediatrician and adult physician with family and young person on lead up to transition.
- Working towards a gradual and stepped-down approach of care from child to adult services.
- Ensuring families have a clear and ongoing 'transitional plan' in writing
- 'Passports' or 'About Me' books which can be developed with young person and family on the lead up to transition to help adult services get to know personal details about the young person such as their likes, dislikes and unique communication style.
- Acknowledging and supporting parents with the emotional loss of support, friendships and knowledge of young person. Promote self-care through this difficult period.

**Acknowledgements**

I would like to thank the families who gave up their valuable time to take part in this project. I would also like to thank staff members at [service name] who helped with recruitment.

If you would like more information or for a copy of the complete report please email: charlotte.hazeldine@nhs.net.
Appendix D.1

Experimental activation of mental defeat using a mood induction task

This paper presents the results from the mood induction component of the research project. Due to only recruiting a small sample, as well as problems with the design of the project, this is considered a 'pilot study'. In retrospect the methodology should have planned for participants to complete the McGill Pain Questionnaire and PSEQ immediately before and after the induction task due the temporary effects of the mood induction. This type of methodology has been undertaken by similar studies, for example Tang et al. (2008). Instead, in the current study measures were only completed by participants at baseline (when completing the questionnaire pack at home) and immediately after the induction task. This meant that there was a large delay between completing the two measures, meaning that we are not able to determine with certainty that any changes in the outcome measure would be solely due to the effect of the mood induction task.

Background

Whilst the study by Tang et al. (2010) indicated an association between feelings of defeat in chronic pain patients with outcomes such as pain interference, sleep disturbance, anxiety, depression, functional disability and psychosocial disability, the findings are entirely correlational and the inference of causality has yet to be tested. Similar to the current study, Tang et al. (2008) sought to determine the causal effects of an experimentally induced depressed mood on pain response and tolerance levels in chronic pain patients. The results indicated that induction of depressed mood using a musical induction procedure was possible in 72.4% of cases. The induction of depressed mood resulted in significantly higher pain ratings and lower pain tolerance, whilst induced happy mood resulted in significantly lower pain ratings and greater pain tolerance. The primary aim of this part of the study was to test the viability of establishing a causal link between mental defeat and self-efficacy and symptomology.
The project was largely interested in two main questions:
1. Is it possible to systemically activate feelings of mental defeat and positive pain self-perception using a specifically designed induction task based on the Velten Mood induction procedure?

2. When there is a shift in levels of mental defeat, does this impact on pain symptomology and self-efficacy? In particular, do those in the mental defeat induction group have a significantly lower self-efficacy rating and higher pain symptomology rating post-induction than those in the positive pain self-perception group?

**Hypotheses**
This component of the research project has two primary hypotheses:

1. Participants will show a significantly greater reduction in their rating of self-efficacy (from their baseline measure) following a negative pain self-perception (mental defeat) induction task compared with a comparison group undertaking a positive pain self-perception induction task.

2. Participants will show a greater improvement in their rating of self-efficacy (from their baseline measure) following a positive pain self-perception task compared with a comparison group undertaking a negative pain self-perception induction task.

**Method**

**Participants**
For the mood induction part of the research, recruitment took place from two of the three services involved in the cross-sectional analysis; Royal United Hospital (RUH) Bath, and Royal National Hospital for Rheumatic Diseases, Bath (RNHRD). All participants completing the mood induction were required to have completed the questionnaire pack forming the cross-sectional analysis. Scores from the questionnaire packs were inspected and where necessary discussions were held with the clinical team to ascertain the participant’s suitability for completing the mood induction task. For example the RNHRD did not allow their patients to undertake the induction task if they scored highly on the question measuring suicidal thoughts on the PHQ-9.
After receiving their completed consent form and prior to contacting participants to arrange a research session, individuals were randomised to one of two conditions; 1. Mental defeat (negative pain self-perception) induction, or 2. Positive pain self-perception induction. Simple random sampling without replacement in blocks of 6 was undertaken utilising an online software tool. The final sample for this phase comprised of 20 patients; 9 completing the positive mood induction and 11 completing the negative mood induction.

**Design and Procedure**

This part of the study employed a between-groups randomisation design to compare the effects of 'pain self-perception' induction for two groups of chronic pain patients. This was chosen to allow for the systematic experimental investigation of the effects of mental defeat/pain self-perception on a patient's level of self-efficacy and pain severity. The completed questionnaire pack (from the cross-section component of the study) formed the baseline measures. The participant was invited to attend a research session which took place either in a clinical space in the hospital or at the participant’s home. Firstly, the participant completed a consent form, and rated their current anxiety and depression levels using a visual analogue scale from 0-10 (see Appendix B.3). They then completed a ‘state mental defeat scale’ adapted from the Pain Self-Perception Scale (Tang, Salkovskis, & Hanna, 2007) specifically for this project, consisting of 6 items relating to their current feelings of defeat.

At this point, the participant completed the induction task which followed the methodology of the Velten Mood Induction procedure described by Clark (1983). Participants were asked to read, for ten minutes, eighteen statements taken from the Pain Self-Perception Scale (Tang, Salkovskis, & Hanna, 2007) and think about how it applies to them and times they have felt like this. They were asked to ‘focus on the feeling and try to feel the mood suggested by these statements’. Participants in the positive pain self-perception group completed the same task but the statements were reframed positively (see Appendix B.2).

After the induction task participants recompleted the ‘state mental defeat scale’ to allow the researcher to complete a manipulation check to ascertain whether the task had successfully activated or reduced levels of mental defeat. Participants
then completed the Pain Self Efficacy Questionnaire (Nicholas, 2007) and the Short-Form McGill Pain questionnaire (Melzack, 1987). Those in the negative induction group then completed the positive induction task to reverse the effects of the task. To finish the session, participants re-rated their current anxiety and depression levels on the visual analogue scale, and were then fully debriefed and offered a £5 gift voucher as a reimbursement for their time. Where participants felt that their mood was still affected by the task, appropriate steps were taken (for example completing a mindfulness task or discussion about appropriate sources of support).

**Measures**

Measures used in the questionnaire pack were:

- The Generalized Anxiety Disorder-7 (Spitzer et al., 2006)
- The Patient Health Questionnaire-9 (Kroenke et al., 2001)
- The Pain Self-Perception Scale (Tang, Salkovskis, & Hanna, 2007)
- Pain Catastrophizing Scale (Sullivan et al., 1995)
- Pain Self-Efficacy Questionnaire (Nicholas, 2007)
- Beck Hopelessness Scale (Beck, 1974)
- Short-Form McGill Pain Questionnaire, (Melzack, 1987).

**‘State Mental Defeat/Pain Self-Perception Scale’**. A state mental defeat scale was developed using six items from the Pain Self-Perception Scale (Tang et al, 2007). These items were chosen as they had the highest item total correlations, a score indicating how well different items are measuring the same construct (see Table 4.2 in results section). The original PSPS instructs participants that the questions concern how people feel 'at present' in relation to their symptoms. On the state scale we wanted to place even more emphasis on the questions focusing only on the acute, here-and-now nature so asked them to rate how they feel 'because of their symptoms, right now, at this present moment'. As with the full PSPS, using a visual analogue scale participants rated to what extent they felt these 6 statements applied to them right at that moment (see Appendix B.4).
Ethical considerations

The study protocol was approved by the Research Ethics Committee, Wales NHS (reference: 14/WA/0130), as well as by Research and Development for Gloucestershire Royal Hospital Foundation Trust (reference: 12/035/GHT), Royal United Hospital NHS Foundation Trust (reference: 01853), and Royal National Hospital for Rheumatic Diseases NHS Foundation Trust (reference: RBB 432). Approval was also granted by the Department of Psychology, University of Bath (application number 14-153). Participants were told in the information sheet that the nature of the study may evoke some anxiety and distress and were frequently reminded that they could withdraw at any time. They were also signposted to appropriate sources of support. Participants were fully briefed and debriefed in person about the study.

Analytic Strategy

Due to the problems with the design of the study previously discussed, many of the statistical analyses were not run in the way that they were originally intended. The results section below provides information about the analytic strategy utilised for this part of the study and where it was not possible to report findings, an outline of the analytic strategy is reported.

Results

Participant characteristics

The sample of participants who completed the mood induction task had a mean age of 47.3 years (SD=9.3) and was mostly composed of female participants (80%). 55% were married or living as married, and at the time of testing, 35% were either unemployed, retired or on sick leave. With regards to location of pain within the body, 30% reported back/spinal pain, 40% reported either fibromyalgia or pain all over the body, and 25% experienced pain in the foot/leg/hip. Other sources of pain included shoulder/neck/head (20.3%); arm/hand (5%) and 'other' including stomach (5%). On the 0-10 visual analogue scale, the mean pain intensity score was 6.8 (SD=1.5), the mean Sensory Pain Rating Index score was 21.1 out of a possible 33 (SD=6.5), and the mean Affective Pain Rating Index score was 6.9 (SD=3.1) out of a possible 12. The sample scored a mean of 21.3 (SD=11.3) for self-efficacy, with a lower score indicating a lower perceived self-efficacy (possible range of 0-60). On the psychopathology measures, the sample obtained a mean
score of 11.9 (SD=5.6) for hopelessness, 12.4 (SD=5.1) for anxiety, 17.1 for depression (SD=6.6), 45.5 (SD=23.9) for mental defeat, and finally 29.5 (SD=10.2) for catastrophizing.

Table 4.1 on the next page details the participant characteristics across both sites and some differences can be observed. Patients from the national residential pain service (RNHRD) were generally suffering with greater severity on the psychopathology measures, in particular on the mental defeat scale. This group also scored lower on the pain-self efficacy measure. Scores on the pain symptomology measures were fairly similar across the two groups. On average those patients recruited from Gloucestershire Royal Hospital's pain clinic scored lower on the psychopathology and pain measures.
Table 4.1: Mood induction participant characteristics

<table>
<thead>
<tr>
<th></th>
<th>RNHRD (n=3)</th>
<th>RUH (n=17)</th>
<th>Overall sample (n= 20)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Positive induction</td>
<td>1</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>Negative induction</td>
<td>2</td>
<td>9</td>
<td>11</td>
</tr>
<tr>
<td>Age</td>
<td>41.7 (11.8)</td>
<td>48.3 (9.21)</td>
<td>47.3 (9.6)</td>
</tr>
<tr>
<td>Sex (% female)</td>
<td>66.7</td>
<td>82.4</td>
<td>80</td>
</tr>
<tr>
<td>Marital status (% married / living as married)</td>
<td>60</td>
<td>52.9</td>
<td>55</td>
</tr>
<tr>
<td>Employment status (% retired/unemployed/sick leave)</td>
<td>40</td>
<td>41.2</td>
<td>35</td>
</tr>
<tr>
<td>Sources of pain (%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Back/spine</td>
<td>26.7</td>
<td>23.5</td>
<td>30</td>
</tr>
<tr>
<td>Shoulder/head/neck</td>
<td>20</td>
<td>5.8</td>
<td>5</td>
</tr>
<tr>
<td>Arm/hand</td>
<td>20</td>
<td>5.8</td>
<td>5</td>
</tr>
<tr>
<td>Fibromyalgia/all body</td>
<td>33.3</td>
<td>47.1</td>
<td>40</td>
</tr>
<tr>
<td>Foot/leg/hip</td>
<td>20</td>
<td>17.6</td>
<td>25</td>
</tr>
<tr>
<td>Other</td>
<td>0</td>
<td>5.8</td>
<td>5</td>
</tr>
<tr>
<td>BHS</td>
<td>14.3 (3.7)</td>
<td>11.8 (6.3)</td>
<td>11.9 (5.6)</td>
</tr>
<tr>
<td>PHQ-9</td>
<td>21.2 (4.3)</td>
<td>16.2 (6.7)</td>
<td>17.1 (6.6)</td>
</tr>
<tr>
<td>GAD-7</td>
<td>15.6 (4.3)</td>
<td>12.0 (5.3)</td>
<td>12.4 (5.1)</td>
</tr>
<tr>
<td>PCS</td>
<td>33.4 (10.3)</td>
<td>27.7 (9.7)</td>
<td>29.5 (10.2)</td>
</tr>
<tr>
<td>PSEQ</td>
<td>13.2 (6.5)</td>
<td>28.1 (9.0)</td>
<td>20.4 (8.6)</td>
</tr>
<tr>
<td>PSPS/Mental Defeat</td>
<td>62.7 (15.3)</td>
<td>42.5 (24.2)</td>
<td>45.5 (23.9)</td>
</tr>
<tr>
<td>SF-MPQ (VAS)</td>
<td>5.4 (1.6)</td>
<td>6.6 (1.5)</td>
<td>6.8 (1.5)</td>
</tr>
<tr>
<td>SF-MPQ (Sensory)</td>
<td>19.9 (5.7)</td>
<td>21.06 (6.7)</td>
<td>21.1 (6.5)</td>
</tr>
<tr>
<td>SF-MPQ (Affective)</td>
<td>7.8 (3.0)</td>
<td>6.9 (3.3)</td>
<td>6.9 (3.1)</td>
</tr>
<tr>
<td>SF-MPQ (Total pain rating)</td>
<td>27.7 (7.6)</td>
<td>28.0 (9.3)</td>
<td>27.9 (9.0)</td>
</tr>
</tbody>
</table>

Examining the characteristics of the mental defeat state scale

In order to examine the internal consistency of the 6-item scale (pre-induction) a Cronbach's Alpha score was obtained. This demonstrated good internal consistency (α = 0.91). Corrected item total correlations were examined which revealed the lowest scoring item from the scale was item 1, 'I feel that life has treated me like a punchbag', (r=0.49). Had this item been removed, a higher overall Cronbach's Alpha score would have been obtained (α = 0.94). See Table 4.2 for results on all the items.
Table 4.2 Item characteristics for state mental defeat scale

<table>
<thead>
<tr>
<th>Item</th>
<th>Corrected Item-Total Correlation</th>
<th>Cronbach's Alpha if item deleted</th>
</tr>
</thead>
<tbody>
<tr>
<td>Item 1 (punchbag)</td>
<td>0.49</td>
<td>0.94</td>
</tr>
<tr>
<td>Item 2 (confidence)</td>
<td>0.88</td>
<td>0.88</td>
</tr>
<tr>
<td>Item 3 (ladder)</td>
<td>0.80</td>
<td>0.90</td>
</tr>
<tr>
<td>Item 4 (defeated)</td>
<td>0.87</td>
<td>0.86</td>
</tr>
<tr>
<td>Item 5 (given up)</td>
<td>0.80</td>
<td>0.89</td>
</tr>
<tr>
<td>Item 6 (destroyed)</td>
<td>0.79</td>
<td>0.90</td>
</tr>
</tbody>
</table>

**State component of mental defeat.** An analysis was run to examine the correlation between pre-induction total 'state mental defeat' and baseline mental defeat scores to provide information about the consistency in mental defeat levels. Overall, the results indicated a significant correlation ($r=.70, p<0.01$), suggesting good construct validity for the 'state' mental defeat scale. When correlating overall change in state mental defeat score (pre to post induction task) with baseline mental defeat score, there was a non-significant correlation ($r=.26, p>.05$). This indicates that change in mental defeat does not simply reflect how severe the feelings were when completing the full questionnaire at baseline.

**Manipulation checks**

This analysis was originally intended to be a manipulation check for the mental defeat induction, but given the problems with subsequent analyses, it has been considered more from the perspective of effectiveness of the defeat induction.

In order to examine whether there was a significant change in the shift of mental defeat scores across both groups, an independent samples t-test was run. The results revealed a mean increase on mental defeat of 2.25 for the negative group, and a mean decrease of 2.56 for the positive group. The difference between these two mean changes was found to be statistically significant ($p=.001$).

The data were then split by induction group category and two paired samples t-tests were run to determine whether there was a significant change in pre- and post-induction levels of mental defeat. For the negative group results revealed a lower pre-induction score (mean=10.55) compared with post-induction
(mean=13.09), a statistically significant difference, $p=.0001$. For the positive group, participants scored on average 15.56 on pre-induction mental defeat, and 13.00 on post-induction mental defeat, a statistically significant difference ($p=.0001$).

Table 4.3 on the next page details the pre- and post-induction mental defeat scores for each participant within the two groups. Within the positive induction group, 1 participant shifted in the opposite direction (moving 1 point higher on mental defeat) and 1 participant’s score remained constant. The remaining 7 scored lower on the post-measure, with change in scores ranging from 1 - 7. Within the negative induction group, 1 participant shifted 1 point towards lower mental defeat, and two remained the same at pre- and post-induction. The remaining 9 scored higher on the post-measure, with the changes ranging from 1-11.
Table 4.3. Pre- and post-induction scores on state mental defeat scale

<table>
<thead>
<tr>
<th></th>
<th>State mental defeat</th>
<th>State mental defeat</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>pre-induction</td>
<td>post-induction</td>
</tr>
<tr>
<td>Positive induction</td>
<td></td>
<td></td>
</tr>
<tr>
<td>group</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Participant 1</td>
<td>19</td>
<td>12</td>
</tr>
<tr>
<td>Participant 2</td>
<td>20</td>
<td>16</td>
</tr>
<tr>
<td>Participant 3</td>
<td>15</td>
<td>12</td>
</tr>
<tr>
<td>Participant 4</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Participant 5</td>
<td>12</td>
<td>8</td>
</tr>
<tr>
<td>Participant 6</td>
<td>17</td>
<td>17</td>
</tr>
<tr>
<td>Participant 7</td>
<td>16</td>
<td>12</td>
</tr>
<tr>
<td>Participant 8</td>
<td>18</td>
<td>17</td>
</tr>
<tr>
<td>Participant 9</td>
<td>22</td>
<td>23</td>
</tr>
<tr>
<td>Negative induction</td>
<td></td>
<td></td>
</tr>
<tr>
<td>group</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Participant 10</td>
<td>8</td>
<td>7</td>
</tr>
<tr>
<td>Participant 11</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Participant 12</td>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td>Participant 13</td>
<td>20</td>
<td>22</td>
</tr>
<tr>
<td>Participant 14</td>
<td>13</td>
<td>24</td>
</tr>
<tr>
<td>Participant 15</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Participant 16</td>
<td>10</td>
<td>14</td>
</tr>
<tr>
<td>Participant 17</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>Participant 18</td>
<td>15</td>
<td>17</td>
</tr>
<tr>
<td>Participant 19</td>
<td>12</td>
<td>17</td>
</tr>
<tr>
<td>Participant 20</td>
<td>21</td>
<td>23</td>
</tr>
</tbody>
</table>

An independent samples t-test was also run to compare changes on each mental defeat state item across the two groups. As can be seen in Table 4.4, there was a significant difference on all measures, apart from one; item 6 (feeling destroyed as a person).
Table 4.4: Differences in change in state mental defeat items across groups

<table>
<thead>
<tr>
<th>Change in Item</th>
<th>Induction condition</th>
<th>N</th>
<th>Mean</th>
<th>St. dev</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 (punchbag)</td>
<td>Negative</td>
<td>11</td>
<td>-0.36</td>
<td>0.67</td>
<td>0.04*</td>
</tr>
<tr>
<td></td>
<td>Positive</td>
<td>9</td>
<td>0.22</td>
<td>0.44</td>
<td></td>
</tr>
<tr>
<td>2 (confidence)</td>
<td>Negative</td>
<td>11</td>
<td>-0.36</td>
<td>0.51</td>
<td>0.01*</td>
</tr>
<tr>
<td></td>
<td>Positive</td>
<td>9</td>
<td>0.33</td>
<td>0.50</td>
<td></td>
</tr>
<tr>
<td>3 (ladder)</td>
<td>Negative</td>
<td>11</td>
<td>-0.36</td>
<td>0.81</td>
<td>0.02*</td>
</tr>
<tr>
<td></td>
<td>Positive</td>
<td>9</td>
<td>0.56</td>
<td>0.72</td>
<td></td>
</tr>
<tr>
<td>4 (defeated)</td>
<td>Negative</td>
<td>11</td>
<td>-0.45</td>
<td>1.04</td>
<td>0.01*</td>
</tr>
<tr>
<td></td>
<td>Positive</td>
<td>9</td>
<td>0.89</td>
<td>0.78</td>
<td></td>
</tr>
<tr>
<td>5 (given up)</td>
<td>Negative</td>
<td>11</td>
<td>-0.45</td>
<td>0.69</td>
<td>0.04*</td>
</tr>
<tr>
<td></td>
<td>Positive</td>
<td>9</td>
<td>0.33</td>
<td>0.87</td>
<td></td>
</tr>
<tr>
<td>6 (destroyed)</td>
<td>Negative</td>
<td>11</td>
<td>-0.55</td>
<td>1.04</td>
<td>0.09</td>
</tr>
<tr>
<td></td>
<td>Positive</td>
<td>9</td>
<td>0.22</td>
<td>0.83</td>
<td></td>
</tr>
</tbody>
</table>

*p<.05

Analyses were also run to explore differences in pre-induction mental defeat scores across the groups. As can be seen in Figure 3.1 on the next page, the two groups differed in the levels of mental defeat pre-induction, with those in the negative group on average scoring lower (mean=10.55) than those in the positive group (mean=15.56). An independent samples t-test was run to determine whether this difference was statistically significant. Results revealed this was a non-significant difference however (p=.594).
Given that we were aware of the pre-existing difference in state mental defeat scores between the two groups, a univariate Analysis of Co-variance (ANCOVA) was then performed with pre-induction state mental defeat level as the covariate and the post-induction state mental defeat as the DV. What this revealed was that if the two groups had presented with the same mean score for pre-induction state mental defeat, the mean post-induction score for the negative group would have been 15.5 and 10.1 for the positive group, a statistically significant difference \( (p<.01) \).

**Impact of mood induction on self-efficacy and pain symptomology**

To gain experience, I decided to run the analyses that would have been performed on the data had the study been successful. The analyses are meaningless and therefore results are not reported here, yet it demonstrates what the data strategy would have looked like. For self-efficacy and total pain rating, a repeated measures multiple analysis of variance (MANOVA) was completed, with the
induction condition as the between-subjects variable, and manipulation (baseline and after mood induction) as the within-subject variable. Bivariate correlation analyses were also run separately for the two groups to examine the correlation between state mental defeat change with pain symptomology, self-efficacy and post-induction state mental defeat.

Discussion
This component of the study primarily sought to determine the causal effects of an experimentally induced shift in feelings of defeat on self-efficacy and symptomology in chronic pain patients. Firstly, the study sought to determine the viability of systematically activating feelings of defeat and positive pain self-perception using a specifically designed induction task based on the Velten Mood induction procedure. Secondly the aim was to determine whether there was a difference in self-efficacy and symptomology following an induction task between those in the positive and negative groups.

The 'state mental defeat scale' was developed specifically for this project, adapted from the full PSPS. The aim was to create a more 'acute', 'here-and-now' scale for measuring immediate feelings of defeat before and after the mood induction task. Results demonstrated good internal consistency for the scale, but future revision may consider removal of item 1 ‘life has treated me like a punchbag’ which had the lowest corrected item-total correlation. The results however demonstrate a promising tool to be used in future research when exploring 'state mental defeat'.

Manipulation checks were performed on the state mental defeat scores pre- and post-induction task to determine whether a shift in the expected direction had occurred. Overall the results indicated that the mood induction had been successful for both groups. Those in the mental defeat group had on average significantly higher scores post-induction and those in the positive group had lower scores. What this demonstrates is that mental defeat is susceptible to change following a brief 15minute task requiring rumination about pain. For some participants however, the induction task was not successful and change did not occur. Within the negative induction group, two participants scored the same at pre- and post-induction and one participant became less mentally defeated by 1 point. Within the positive group, one participant's score remained constant and one
participant shifted 1 point towards higher mental defeat. This type of result has also been demonstrated in other studies using mood induction methodology, indicating that some individuals are not susceptible to mood change using experimental techniques. For example in their study Tang (2008), reported that 21.6% of the sample did not meet criteria on the manipulation checks for a musical mood induction task. On a qualitative note, in the current study, the two participants in the positive group reported to the researcher after the task that reading the positive framed statements acted as a reminder of how they used to feel, and how unreachable they believed the statements were for them at that time. This reflects the idea from the self-discrepancy theory (Higgins, 1987), whereby the incongruence between the perceived current self and ideal self can cause low mood and poor adjustment. Furthermore, although participants were not told which experimental group they were in, it is not possible to say with certainty that demand characteristics did not affect the change in mental defeat scores. The inclusion of a neutral group had originally been planned in the development of the project, but due to feasibility difficulties, it was decided to focus on recruitment just for a positive and negative group. Developing this study in the future would incorporate three groups into the methodology.

Unfortunately it was not possible in the current study to examine whether the activation or reduction in feelings of defeat caused a shift in self-efficacy and symptomology in a sample of treatment seeking chronic pain patients. Further research is now needed here in order to have a greater understanding of the causal role that feelings of defeat may have on outcomes in chronic pain. It is recommended that any future mental defeat induction studies employ measures assessing constructs such as catastrophizing, rumination and attentional processes to explore for any mediating links with pain outcomes. Results from these types of studies would inform psychological assessments and treatment strategies for chronic pain patients, as well as add to the small evidence base around the role of mental defeat in chronic pain.
References


Appendix E.1

Information relevant to ethical review and conduct for Service Improvement Project

From: Jeffrey Gavin [J.Gavin@bath.ac.uk]
Sent: 03 July 2013 14:53
To: Hazeldine Charlotte (SOMERSET PARTNERSHIP NHS FOUNDATION TRUST); Caroline Ransford
Subject: ethics - rcf-13-120

Dear Charlotte Hazeldine

Reference Number 13-120

The ethics committee have considered your application for the study entitled 'Exploring the child and family experience of transition from pediatric to adult palliative care services', and have given it conditional ethical approval.

The committee have raised the following points which they would like you to attend to before giving the study full ethical approval:

Please explain further what steps will be taken if somebody experiences distress.

Please send the revised document to Caroline Ransford - you can do this by email.

Remember that you may not collect any data until you have ethical approval.

Yours sincerely

Dr Jeff Gavin
Acting Chair of Psychology Ethics Committee

--

--------
Dr Jeff Gavin
Department of Psychology
University of Bath,
Bath BA2 7AY, England
Re: ethics - ref-13-120
Jeaffrey Gavin [J.Gavin@bath.ac.uk]

Sent: 08 July 2013 12:08
To: Hazéline Charlotte (SOMERSET PARTNERSHIP NHS FOUNDATION TRUST); Caroline Ransford [C.A.Ransford@bath.ac.uk]

Dear Charlotte

Reference Number 13-120

Thank you for satisfactorily attending to those amendments. I can now confirm that you have full ethical approval for your study.

Best wishes with your research.

Dr Jeff Gavin
Chair Psychology Ethics Committee

Dr Jeff Gavin
Department of Psychology
University of Bath,
Bath BA2 7AY, England

ph: +44 1225 386591
Fax: +44 1225 386752
http://staff.bath.ac.uk/pssig/index.html
RE: Service evaluation
Martha Cox [Martha.Cox@sirona-cic.org.uk]

You forwarded this message on 02/05/2013 16:05.

Sent: 01 May 2013 09:09
To: Hazeldean Charlotte (SOMERSET PARTNERSHIP NHS FOUNDATION TRUST)

Yes do go ahead – it looks great – I will be interested in hearing about your results when you get them

Best wishes

Martha

Martha Cox
Service User Involvement Facilitator
Sirona Care and Health
St Martin’s Hospital
Clara Cross Lane
Eath
BA2 5RP

☎ 01225 831328
Research and Development - Confirmation of service development not research

Re: FW: SIP in Sirona
Lisa Austin [L.Austin@bath.ac.uk]

You replied on 08/05/2013 08:38.

Sent: 07 May 2013 16:04
To: Hazelde Charlotte (SOMERSET PARTNERSHIP NHS FOUNDATION TRUST)
Cc: L.Austin@bath.ac.uk

Good to hear from you. Hope life good with you.
Yes we both think this is service development not research.

Wishes
Lisa

On 02/03/2013 15:54, Hazelde Charlotte (SOMERSET PARTNERSHIP NHS FOUNDATION TRUST) wrote:

Hi Lisa

Sorry it’s taken so long to get back to you, it’s been slow finalising plans for this. I have sent you my proposal for the project as well as the participant information sheets and consent forms (all version 1).

The query we have is whether this constitutes a service evaluation rather than research. My supervisor questioned the fact that if we interview parents of children who have now left the service to move to adults services does this go further than the realms of a service evaluation and venture into research territory.

Your thoughts on this would be greatly appreciated!

Many Thanks
Charlotte
Appendix E.2

Information relevant to ethical review and conduct for Main Research Project

University of Bath Ethical Approval

<table>
<thead>
<tr>
<th>Psychology Ethics Committee</th>
</tr>
</thead>
<tbody>
<tr>
<td>Telephone +44 01225 383061</td>
</tr>
<tr>
<td>Facsimile +44 01225 386752</td>
</tr>
<tr>
<td>E-mail: <a href="mailto:h.lucey@bath.ac.uk">h.lucey@bath.ac.uk</a></td>
</tr>
</tbody>
</table>

Thursday, 19 June 2014

Dear Charlotte

**Ethics application:** 14-153

**Title of project:** Understanding the link between the feelings of defeat and the experience of chronic pain

The Psychology Ethics Committee have considered your ethics proposal for the above study and have given it full ethical approval.

Best wishes with your research.

[Signature]

Dr James Gregory

Psychology Ethics Committee
NHS Ethical Approval

Wales Research Ethics Committee 1
Sixth Floor, Churchill House
17 Churchill Way
Cardiff CF10 2TW

Telephone: 029 2037 0623
E-mail: jagit.sidhu@wales.nhs.uk
Website: www.hra.nhs.uk

04 June 2014

Miss Charlotte Hazeldine
Clinical Psychologist in Training
University of Bath
Cleaverton Down
Bath
BA2 7AY

Dear Miss Hazeldine,

Study title: Understanding the link between feelings of defeat and the experience of chronic pain
REC reference: 14/WA/0130
IRAS project ID: 128920

Thank you for your letters of 19 May 2014 and 1st June 2014, responding to the Committee’s request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair, Dr K Craig.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Manager, Mrs Jagit Sidhu, jagit.sidhu@wales.nhs.uk.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation [as revised], subject to the conditions specified below.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study:
You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at [http://www.rdforum.nhs.uk](http://www.rdforum.nhs.uk).

Where a NHS organisation’s role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).
Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<table>
<thead>
<tr>
<th>Document</th>
<th>Version</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Covering letter on headed paper</td>
<td></td>
<td>31 March 2014</td>
</tr>
<tr>
<td>Evidence of Sponsor insurance or indemnity (non NHS Sponsors only)</td>
<td></td>
<td>15 July 2014</td>
</tr>
<tr>
<td>Interview schedules or topic guides for participants [RUH/Frenchay/Glou/RNHDRD]</td>
<td></td>
<td>28 March 2014</td>
</tr>
<tr>
<td>Letter from sponsor</td>
<td></td>
<td>17 March 2014</td>
</tr>
<tr>
<td>Non-validated questionnaire [PSEQ]</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other [Lay Summary]</td>
<td>1</td>
<td>28 March 2014</td>
</tr>
<tr>
<td>Other [Letter send with questionnaire pack]</td>
<td>1</td>
<td>28 March 2014</td>
</tr>
<tr>
<td>Other [Flowchart]</td>
<td>1</td>
<td>28 March 2014</td>
</tr>
<tr>
<td>Other [Mental Defeat State Scale]</td>
<td></td>
<td>28 March 2014</td>
</tr>
<tr>
<td>Other [Validated Questionnaire PCS]</td>
<td></td>
<td></td>
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<tr>
<td>Other [Validated Questionnaire - Beck Hopelessness Scale]</td>
<td></td>
<td></td>
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<tr>
<td>Other [Effects of mood on pain responses and pain tolerance]</td>
<td></td>
<td></td>
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<tr>
<td>Other [CV]</td>
<td>J Gauntlett-Gilbert</td>
<td>12 February 2014</td>
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<tr>
<td>Other [Validated Questionnaire McGill Pain ]</td>
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<tr>
<td>Other [Debrief Letter Phase 1]</td>
<td></td>
<td>28 March 2014</td>
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<tr>
<td>Other [Risk Flow Chart]</td>
<td>1</td>
<td>28 May 2014</td>
</tr>
<tr>
<td>Other [Validated Questionnaire Mental Defeat Scale Salkovskis &amp; Tang]</td>
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</tr>
<tr>
<td>Participant consent form [Phase 2]</td>
<td></td>
<td>28 March 2014</td>
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<tr>
<td>Participant consent form [Phase 1]</td>
<td></td>
<td>28 March 2014</td>
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<tr>
<td>Participant information sheet (PIS)</td>
<td>2</td>
<td>19 May 2014</td>
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<tr>
<td>REC Application Form</td>
<td>3.5</td>
<td>27 March 2014</td>
</tr>
<tr>
<td>Research protocol or project proposal</td>
<td>1</td>
<td>28 March 2014</td>
</tr>
<tr>
<td>Response to Request for Further Information</td>
<td></td>
<td>01 June 2014</td>
</tr>
<tr>
<td>Response to Request for Further Information</td>
<td></td>
<td>19 May 2014</td>
</tr>
<tr>
<td>Summary CV for Chief Investigator (CI)</td>
<td>C Hazeldine</td>
<td>20 March 2014</td>
</tr>
<tr>
<td>Summary CV for supervisor (student research) [P Salkovskis]</td>
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<td>03 May 2014</td>
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<tr>
<td>Summary CV for supervisor (student research) [J Millar]</td>
<td>2</td>
<td>02 April 2014</td>
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<td>Validated questionnaire [GAD-7]</td>
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<tr>
<td>Validated questionnaire [PHQ-9]</td>
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</table>

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.
After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

Notifying substantial amendments
Adding new sites and investigators
Notification of serious breaches of the protocol
Progress and safety reports
Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

| 14/WA/0130 | Please quote this number on all correspondence |

With the Committee's best wishes for the success of this project.

Yours sincerely

Dr K J Craig
Chair
Email: jagit.sidhu@wales.nhs.uk

Enclosures: "After ethical review – guidance for researchers" [SL-AR2]

Copy to: Jane Miller - j.i.millar@bath.ac.uk
Mrs J McCaulder-Ojeda - Ojeda@mhrd.nhs.uk
Dear Dr Mike Osborn

Re:  REC 14/WA/0130
RD 01853

Project: Understanding the link between feelings of defeat and the experience of chronic pain

Thank you for your application for approval of the above project, I am pleased to inform you that the project has been approved. University of Bath will act as sponsor.

The R&D department, as part of the R&D review, consider the issues relevant to Site Specific Assessment, as appropriate. However if your project requires ethical review, you must demonstrate to the R&D department that you have also obtained written full approval from the Research Ethics Committee (REC) before the research begins. Our approval is subject to full ethical approval, where ethical approval is applicable.

It is the Principal Investigator responsibility that this project is carried out according to Good Clinical Practice and within the guidelines of the NHS Research Governance Framework for Health and Social Care. Full information about the Research Governance Framework can be obtained via the internet on http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4108962

Unless you have been given an Investigator research site file by the sponsor or Chief Investigator, you must use the RUH template Investigator research site file, to enable easy research audit. This file can be obtained from the Research and Development Office in the Wolfson Centre RUH.

You have responsibility for ensuring that all participants sign informed consent and that the protocol agreed by the REC is adhered to by yourself and any other co-workers. Please ensure that the version of the protocol and supporting documents held by the Research and Development Office are the same as the ones approved by the REC and provide up-to-date versions if necessary. Project documentation approved by R&D:

- Protocol version 1, 28/03/2014
- Participant consent form (Phase 2), 28/03/2014
- Participant consent form (Phase 1), 28/03/2014
- Participant Information Sheet version 2, 19/05/2014

May I also remind you that as Principal Investigator or Chief Investigator you will be required to provide us with information concerning, safety, monitoring and outcome information for this study, including a lay summary upon completion of the research. Investigators who fail to provide timely information on projects may compromise their ability to obtain Trust approval for future work.

RUH R&D approval for this study is valid until 29/05/2015. Requests to extend the period of approval must be made, in writing, to the Research and Development Office.
6th June 2014

Dr Jeremy Gauntlett-Gilbert
BCPS
RNHRD, Bath

Dear Jeremy

RBB 432 – Feelings of defeat and the experience of chronic pain

Thank you for your application for approval of the above project, I am pleased to inform you that the R&D Committee approved the project. The University of Bath will act as Sponsor.

Details of this project will be entered onto the RNHRD database. The reference number for your project is RBB 432 and this should be used in all correspondence. A short progress report will be required annually or at the end of the project, whichever occurs first.

All research approved by the R&D Committee should follow good clinical practice and adhere to the systems in place for Research Governance. All Principal Investigators must undertake Good Clinical Practice training and are responsible for ensuring that their research staff have received appropriate training.

You are responsible for ensuring that, all participants sign informed consent (whenever applicable) and that the protocol agreed by the local research ethics committee is adhered to by yourself and any co-workers.

You are required to provide us with information about any amendments to the protocol, changes in funding, personnel or end date and any research-related adverse events. Any staff working on this study at this site must be issued with a contract with RNHRD (honorary or substantive) or Letter of Access before they commence work on the study at this site. Please make sure that the RNHRD is acknowledged on all academic papers which may be written as a result of this research.

In addition, other information may be requested from time to time and a lay summary of the results will be requested from you at the end of the study. This study may be subject to audit by the R&D Office.

We wish you well with this research.

Yours sincerely

Jane Carter
R&D Manager

Cc: Charlotte Hazeldine
Our R&D ref: 14/035/GHT

26th June 2014

Dr Polly Ashworth
Clinical Psychologist
Gloucestershire Hospitals NHS Foundation Trust
Gloucestershire and Herefordshire Pain Self-Management Service
Gloucestershire Royal Hospital
Great Western Road
Gloucester
GL1 3NN

Dear Dr Ashworth,

Study title: Feelings of defeat and the experience of chronic pain.
REC reference: 14/WA/0130

Thank you for forwarding information on the above study. I can confirm the approval of Gloucestershire Hospitals NHS Foundation Trust for the above study to proceed.

Your project will now be added to the Gloucestershire Health Community Research Register which will identify the following:

- Chief Investigator(s): Miss Charlotte Hazeldine
- Principal Investigator(s): Dr Polly Ashworth
- Sponsoring Organisation: University of Bath
- Host Organisation: Gloucestershire Hospitals NHS Foundation Trust
- Type of Study: Educational project

It is important that all research conducted with NHS patients and/or staff complies with the Research Governance Framework. We would advise you to notify us at the above address, quoting our reference number for your study with regards to the following information.

- Protocol Changes/Amendments to the study
- Change of Principal Investigator/local Research Team at site
- Untimely closure of study
- Final study closure date
- Final recruitment figure of study

Chair: Professor Clair Chilvers DSc
Chief Executive: Dr Frank Harsent PhD, MBA

www.gloshospitals.nhs.uk