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Health maintenance, meaning, and disrupted illness trajectories in people with  
low back pain: a qualitative study

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## Health maintenance, meaning, and disrupted illness trajectories in people with low back pain: a qualitative study

### Abstract

Whilst Bury's (1982) 'biographical disruption' remains important for explaining how people rebuild biography due to the onset of chronic illness, it does not self-evidently explain the problem of managing a fluctuating chronic condition such as non-specific low back pain. Chronic illness rarely leads to long term improvement, where the trajectory is not always linear, and sudden or gradual improvements alongside deterioration are commonly experienced. In the case of low back pain, self-management often involves utilisation of non-pharmaceutical approaches, personal resources for accommodating pain and disability, as well as managing symptoms with clinical treatments to relieve pain. Such a multifaceted approach that is not only concerned with the reduction of symptoms, shifts focus beyond the 'disease' state and a single point of disruption, drawing attention to the use of 'health maintenance actions' to facilitate a proactive response to illness management. We propose this new approach as an alternative way of understanding the experience of patients with fluctuating health conditions such as low back pain.

*Keywords:* Sociology, health maintenance, low back pain, chronic illness, qualitative

## Health maintenance, meaning, and disrupted illness trajectories in people with low back pain: a qualitative study

### Introduction

The concept of 'biographical disruption' (Bury, 1982) has been used to explain the onset, fluctuations, and recovery from chronic illness. It describes initial disruption due to chronic illness as a journey of acceptance, accommodation and adaptation. However, the concept has limitations and in later work Bury argued that illness meanings should be viewed in terms of both consequences and significance for individuals; people may downplay the impact of illness despite the presence of real pain and disability (Bury, 1982; Sanders et al. 2002). To extend the argument, critiques of the concept of biographical disruption have claimed that *continuity* is more evident among those people with chronic illness than Bury (1982) recognised, and which has sometimes been referred to as 'biographical reconstruction' or 'biographical flow'. These studies describe chronic illness as not simply causing 'disruption' to individuals but as representing 'continuity', which emphasise a greater role for human agency. Individuals may still have the freedom to 'act' in the face of chronic illness in ways they did prior to their illness and handle its debilitating and restrictive effects. We follow in this tradition by arguing the importance of agency in people's attempts to manage their pain symptoms. The transition of chronic illness as defined by 'biographical disruption' (with the emphasis on the importance of illness over individual agency) towards 'biographical reconstruction' (with an emphasis on human agency) is an important adjunct to Bury's concept. Our thesis builds on this argument by claiming that the

process of biographical 'reconstruction' involves a broader focus on positive health maintenance and a greater role for individuals to reclaim control over illness.

Further conceptual development also highlights that interpretive approaches demand a 'multidimensional view' of patients' strategies, styles and coping behaviours (Bury, 1991). Bury defines 'coping' as both a psychological concept and as translating into ways that people tolerate symptoms or effects. 'Strategies' refer to actions individuals adopt for 'coping' with illness, and 'styles' refer to ways in which they react to, or define, illness experiences by reference to symbolic meanings and through interaction. Additions to the concept have been suggested. For instance, illness could be 'anticipated' (its perceived future impact) and not only viewed as disruptive in the present, and the trajectory of chronic conditions are not necessarily static or linear (Williams 2000; Ong et al. 2004).

Bridging the expert-lay divide in the clinical setting of the consultation presents an additional challenge to patients with chronic illness and clinicians. First, clinicians may routinely use technical language that is inaccessible to patients. Medical terms harbour specific meanings for patients that may significantly differ from the clinical definition (Prior et al. 2011). Clinical diagnoses can appear confusing or fail to connect with lay understanding. Second, patients' pain experiences may not be addressed adequately in the consultation (Ong et al. 2004). For example, clinicians may conflate 'typical' illness experiences of patients with 'typical' back pain, and in doing so, risk

reducing individual experiences to a number of commonly expected symptoms (Risor, 2009; Griffiths et al. 2010). Third, in the absence of a definitive clinical diagnosis patients may seek health care elsewhere. For example, the delivery of care to patients with low back pain (LBP) could affect patients' responses and recovery (Slade et al. 2009; 2010), and hence congruence between patients and healthcare professionals' expectations about self-management (Cedraschi 1996; Ong et al. 2004). All of these factors will inevitably contribute to the 'biographical disruption' reported by Bury (1982).

More recently, however, health maintenance rather than the eradication of disease has been placed under the spotlight. Following Antonovsky (1979), Becker et al. (2010) suggest that a 'salutogenic' model of health care (in contrast to 'pathogenic') promises a stronger emphasis on maintaining health, wellness and wellbeing. Acceptance of the pathogenic model of health by most health professionals has dictated that *disease* prevention and management are the optimal routes to better health. However, research consistently has demonstrated that simply decreasing a negative state does not necessarily increase or enhance positive states (Keyes et al. 2002). Health is similar since its presence requires more than just the absence of disease or related risk factors. Halbert Dunn, in his 1961 treatise *High Level Wellness for Man and Society*, described wellness as a positive state of health, a state that goes beyond simple "unsickness". The current paper follows in this tradition by reporting patients' changing experiences of back pain that shift from a focus on incapacity, pain and physical limitation towards

a more positive conception of illness promoting patient empowerment and presents a further iteration to Bury's (1982) 'biographical disruption'.

Around 6-9% of adult UK primary care consultations relate to low back pain (LBP) with the majority being 'non-specific low back pain' (NSLBP), defined as having no identifiable origin from injury or disease. Some are isolated episodes but for a substantial proportion of people the condition becomes chronic as pain becomes recurrent or lasts more than 6 weeks. As a result an estimated 115 million production days are lost as 75% of consulters remain symptomatic after one year and 30% develop persistent disabling LBP (Lamb et al. 2010).

## Methods

### *Study design and context*

The findings reported here are based on multiple qualitative interviews over 3 time points, which explored patients' beliefs about low back pain, illness perceptions and treatment beliefs over 12 months. The interviews were conducted as part of a larger cohort study using self-completion postal questionnaires, also aimed at investigating beliefs and health perceptions. Recruitment of patients for the larger cohort study took place between September 2004 and April 2006, across eight general practice settings within North Staffordshire and Central Cheshire, England. Ethical approval for the study was obtained from the North Staffordshire and Central Cheshire Research Ethics Committees. No further ethics approval was required for the re-analysis of the interviews. The re-analysis helped to refine the original

analyses, and fell within the framework of the original research question. This paper reports findings from cross-sectional qualitative interview data depicting patients' changing experiences of NSLBP. Re-analyses of qualitative data are increasingly used to test new ideas or developments in the research or theoretical literature hitherto unexplored.

#### *Recruitment into the cohort study*

The contact information for all patients aged between 19 and 60 years consulting their general practitioner for low back pain between September 2004 and April 2006 was downloaded each week from databases from eight general practice settings within North Staffordshire and Central Cheshire, England, as part of patient recruitment for the cohort study. A range of codes were considered in assessing appropriate candidates to take part in the cohort study since most patients with low back pain are not given a specific diagnosis when seen in primary care. As such, the codes selected were intended to include all cases of non-specific low back pain (without a clinically identified cause) and at the same time exclude those patients whose codes indicated a 'red flag' back pain diagnosis (i.e. suspected serious underlying spinal pathology such as cauda equina syndrome, significant trauma, ankylosing spondylitis, or cancers for example). The participating practices covered a heterogeneous population, both geographically and socio-economically.

#### *Recruitment into the interview study*



The interview participants included low back pain patients selected from those who had responded to the baseline questionnaire and had consented to further follow-up. The sample selection of potential interviewees was purposive. That is, unlike in random sampling, the sample was specifically selected in line with the needs of the study, which was to gain an understanding of the illness perceptions and treatment beliefs of the different types of individuals consulting their general practitioners for low back pain. To achieve this, the baseline questionnaire responses were used to purposively select male and female participants of different ages who exhibited varying levels of perceived disability according to their scores on the Roland-Morris Disability Questionnaire (RMDQ) (Roland & Fairbank, 2000) and varying illness perceptions regarding their back pain as reflected in their scores on the revised Illness Perceptions Questionnaire (IPQ-R) (Moss-Morris et al. 2002).

The RMDQ is a back-specific health status measure, specifically designed for use within primary care, reflecting respondents' perceived level of back-related disability and consists of 24 items relating to how the person feels on the day of completing the assessment tool. Scores range from 0 (no disability) to 24 (maximum disability) (Roland & Fairbank, 2000). The average score for the interview sample was approximately 8. The IPQ-R was also used for purposively sampling interview respondents, and it is a measure based on Leventhal's Self-regulation Model of Illness (Leventhal et al. 1984; Leventhal et al. 1987) used to obtain an understanding of a patient's illness perceptions in relation to illness or health threat.

A total of fifty-eight respondents were selected in this way over the course of the study and invited to participate in individual interviews. Of those fifty-eight selected (19 Males, 39 females), thirty-seven (15 males, 22 females) agreed to be interviewed.

#### *Data collection and interview procedure*

All interviews began with an open-ended question asking participants to tell the interviewer in their own words about their experience of having back pain from when they first encountered such pain, up to the current day. This question allowed respondents to talk freely about previous back pain episodes as well as their most recent one. Thereafter the interview primarily focussed on their most recent back pain episode. A topic guide was used to explore key themes such as beliefs about 'cause of pain', 'expected duration of pain', 'perceived curability', and 'management of pain' and 'treatment options'. Participants were encouraged to talk freely on issues relating to their experience of living with such a condition. At the end of each interview interviewees were asked if they could be contacted again for a follow-up interview.

The initial qualitative study investigated the different approaches to the management of the condition by different individuals to depict how patients experience and make sense of NSLBP as a chronic and fluctuating health problem. Specifically, the interviews explored the 12 month period following onset of symptoms that triggered the initial 'major' pain episode and the decision to seek medical advice. Respondents, however, may have had

varying degrees of pain and disability during the initial pain episode, and some will also have had previous pain episodes. Thirty-seven patients with NSLBP were interviewed using a semi-structured approach at three time points: baseline (initial treatment); 6-months; and 12-months. All interviews (total 55) were audio recorded and professionally transcribed verbatim. This approach was taken because repeat interviews were a particularly useful method for examining people's experiences at different time-points. It was not possible to interview all patients at every time point. Therefore, 15 transcripts were 'purposively' selected for detailed re-analysis on the basis that they would provide a diverse selection of participants [age, sex, reported pain and disability] across the different time points, which we felt were a good representation of the key themes across the total interview set. Following analysis of our 15 interviews we compared the key themes with the remainder of interviews to ensure that the emergent themes were compatible across the entire data set. We conducted a 'within case' and 'between case' analysis, the findings from which we feel accurately reflect the main themes presented in this manuscript. The table below illustrates the breakdown of interviews, and those included in the secondary analysis.

**\*\*\*Insert Table about here\*\*\***

N-Vivo 9 qualitative data management software was used to aid the secondary analysis. Members of the research team coded the transcripts independently and compared the coding scheme at regular meetings. Disagreements were resolved through discussion and further re-analysis and

coding. The constant comparative method was used to analyse the data (Strauss & Corbin, 1990; Charmaz, 2006) enabling referencing across individual, group and time dimensions. The analysis was led by a researcher experienced in qualitative methods, and who was not involved in the original phase of the study (TS). This enabled the data to be analysed with no preconceptions about the original findings, and to test a new question (but also keeping an open mind about the emergence of other themes) relating to how people utilise 'health maintenance' strategies rather than, as has been the focus of much previous research, managing illness primarily in order to relieve pain or to foster cure or recovery. The transcripts from the interviews were analysed using a new coding frame that reflected the research team's fresh focus on the data.

First, visual examination and 'coding' provided a broad outline structure to the interview transcripts (Richards, 2009; Saldana, 2009). Second, the data was 'fine coded' to define headings and sub-headings in greater detail. An 'open' coding technique enabled the creation of further codes as new patterns and insights in the data were identified. Third, the team reviewed the coding scheme throughout the analysis, and through merging codes that were duplicates or created new ones. This stage of analysis provided the opportunity to draw out themes of importance within the data set following which it was possible to recognise the key concepts emerging from the data and identify connections between them.

This paper describes the shifting experiences of people with low back pain by describing how people attempted to maintain health in the face of pain and disability.

## Results

Our analysis takes as its point of departure, Bury's (1982) early concept of 'biographical disruption' and adopts a dynamic perspective to studying chronic illness. Back pain often leads to long term pain and incapacity, with frequent recurrence of symptoms, and can therefore be defined as a chronic illness. We argue that the experience of living with the pain and functional limitation associated with NSLBP is cyclical and largely defined by 'continuity' and 'discontinuity' along the illness trajectory (Williams, 2000; Sugarman, 1998).

Interviews at different time points can capture patients' changing experiences, a method that is underutilised in qualitative research. With this analysis we aim to open up the 'black box' of living with chronic NSLBP and examine patients' daily struggles with pain. We show that people do not always seek a cure for their pain or incapacity, but search for advice and support as a means of maintaining a positive sense of self. Consequently, we propose that future research adopts a greater focus on the way that people attempt to create and enhance physical, mental and social well-being (Antonovsky, 1979; Kellaher & Peace, 2004). Research to date has favoured investigating the 'negative' consequences, rather than the 'positive' dimensions, of chronic pain and disability. Thus, past studies only provide a partial explanation for patients' overall experiences of living with chronic illness. Our findings are divided into

five themes: a) Shifting pain experiences: dealing with illness disruption; b) Shifting pain experiences: from disruption to normality; c) Trade-offs and positive illness management: valued activities; d) Trade-offs and positive illness management: risk acceptance; and, e) Health maintenance: an overview, followed by a summative discussion of our study and its broader implications.

*Shifting pain experiences: dealing with illness disruption*

Concerns that the early symptoms of back pain could indicate ‘serious’ underlying health problems routinely translated into a readiness to reduce or abandon physical activity. For example, the common belief that exercise may aggravate back pain or cause long term damage sometimes led to reduced activity levels or adjustments to lifestyle, particularly in sport, leisure pursuits or in the workplace. During baseline interviews manifestations of ‘loss’ and discontinuity were present as participants abandoned or made radical adjustments to ‘normal’ activities.

It can affect everything... from when you first try and get out of bed in the mornings to get dressed ... I find it really hard to believe, you know, that it's so painful just to... to lift your foot a few inches off the ground...  
(B133 baseline)

Participants perceived certain activities as presenting a greater risk of triggering pain, and ‘high risk’ activities were often abandoned even if they were valued.

... my eldest son lives in [another country] ... [the two week visit] was all arranged. I didn't want to cancel. I wanted to see my son. We were back in six days because I couldn't stand the pain. It was horrible, so we came back. (B133, baseline, original emphasis)

While baseline data shows multiple examples of early 'loss', the 6-month interviews articulate few specific examples of 'lost activities' yet, they reappear in the 12-month interviews and are coupled with thoughts about the future.

I want to do things. I used to work. I can't do that. I want to walk with the children to school in the morning and I can't do that. It's completely controlling my life, this back-pain, now. .... [I worry about...] 'what's going to happen to me when I get older'? (BB1258, 12 months)

This quotation illustrates that perception of 'loss' changes over time with the impact of back pain acquiring increasing prominence. At baseline, the impact of pain on function is acute resulting in an abrupt loss of activities. At 6-months, pain is often perceived to have reduced and some 'lost activities' regained completely or revised with few 'new' losses. At 6 months respondents' views represented a transition phase between the disruption caused by their back pain and the 12 month stage where they began to accept their symptoms and emphasised the importance of learning to live with their pain problem (health maintenance approach). By 12-months many

participants recognised and accepted the permanent loss of certain activities due to the chronic nature of the condition, and attention turned to the recognition that valued activities would have to be abandoned as pain and disability take hold.

*Shifting pain experiences: from disruption to normality*

A central dilemma for participants with NSLBP was uncertainty about the causes of their pain, and reassurance that it was 'real' seemed to have a profound impact on their self-evaluation. Perceptions of pain and functional limitation were reported to be most acute at baseline, when participants often expressed concern that diagnostic testing was incomplete. They also claimed that clinical explanations seemed inadequate as back pain was presented as a common and 'normal' problem affecting most people at some stage in their lives, with no clear options for addressing the problem. However, participants believed that the absence of a formal diagnosis (confirmed on x-ray or MRI) could mask a more 'serious' underlying pathology. For this reason they often sought reassurance from clinical professionals.

I'm still not overly convinced that my back pain is caused by a musculoskeletal injury. I am still not over that. Is there something more sinister going on down there? (B080, Baseline, original emphasis)

While the clinical focus in early consultations was to arrive at a diagnosis, patients often sought a resolution to their pain through treatments or



medications. Our follow-up interviews suggest that patients' views were not static, but evolved alongside their ongoing interactions with healthcare services, so that the expectation of complete eradication of pain was gradually dispelled. This resulted in a more nuanced appreciation of the likely course of their back pain symptoms. At the 6-month interview patients' expectations shifted from gaining a conclusive diagnosis and resolution of pain to a greater preoccupation with the *impact* of pain on self and others. Thus, a focus on the 'external' impact of pain rather than its internal causes seemed to mark a change in perspective.

...it's frustrating when you have to wait to make an appointment and then wait for an x-ray, wait all the time and in that time the pain is getting worse. You feel worse. Your family feels dreadful for you. It isn't just you that has the pain. (BB1258, 6-months)

The above quotation illustrates that patients recognised the presence of pathology since the pain was still 'there' after a significant period of time. They became concerned with the ability of health systems to provide appropriate responses to their health needs, suggesting that the negative impact on the individual and their social network related to problems of accessing health care. Furthermore, the impact of living with back pain at six months resulted in an acceptance of a transition to a life with chronic, intermittent pain. The following participant depicts pain as 'a normal day to day' experience.

It was starting to ache, you know, just a normal day to day, when I was sitting. When standing I went straight back into my 'old' stretching routines what I've got, which seem to work for my back... (B080, 6 months)

In the 12-month interviews, understanding about the course of the condition seemed to significantly change, and patients were better able to accommodate the symptoms and disabling effects into their daily routines. The aim was no longer to solely treat or manage the pain, but to adjust to it. Expectations about the likely course of illness became more aligned with the clinical picture of the back pain trajectory which focused on movement and exercise to ease discomfort. Participants remained apprehensive about future pain episodes, yet were pragmatic about accepting their pain and disability.

...it is a concern, yeah absolutely, but now I think sort of I am a bit wiser (and) sort of know how my body works a little bit better, especially as I'm getting older. (B080, 12 months)

In summary, pain perceptions shifted from an initial desire to understand the causes and 'cure' the back pain problem to its gradual acceptance. The early desire for a diagnostic label and understanding causality was replaced by the realisation that they had an ongoing problem, which needed to be managed through a combination of self-care, adjustments to lifestyle, and realistic expectations about the pain trajectory. These shifts were shaped by participants' own pain experiences and through interactions with health

services. Participants recognised that access to healthcare would not bring about a full recovery, and healthcare professionals would not resolve their pain completely, leading to a realignment of expectations. While individuals accommodated their pain differently a prominent feature in this process seemed to be the management of loss, which we discuss below.

*Trade-offs and positive illness management: valued activities*

In contrast to the 'discontinuities' produced by 'lost' activities, participants simultaneously highlighted 'continuities' through 'maintaining valued activities' (Grime et.al. 2010). Our data show how physical and social pursuits became central to self-management. Consequently these activities served a dual purpose; they were often perceived as providing participants with both health and non-health (leisure) benefits.

Maintenance of valued activities is demonstrated most clearly in the baseline and 12 month interviews. At baseline, reference to their importance is often expressed as fear of the impact of pain and is particularly noticeable in relation to key family roles. In the following extract specific impact of pain at home and at work is mentioned, but also how individuals balance competing demands in the context of pain.

Hoovering gets done once a week... because I think ... no, I'm not going to put myself through pain ...I do the things I need to do. I go to work, but by the end of the day I'm really, really struggling... I'm really

really frightened that what if it starts getting worse again and I can't do my job.... I'm the 'bread-winner.' I have to work. (B133, baseline)

The impact on private and public roles is evident in that the participant prioritises work commitments due to their 'bread winner' role. The impact of back pain extends beyond the individual, where work commitments outweigh responsibilities to the private domain and the accomplishment of domestic duties. It is clear that over time the fears expressed at baseline are translated into practical strategies to manage competing demands.

I [lie on a mattress on the sun lounger in the early evening]... I much prefer to lie down... be in bed, but I am obliged to stay up and... and do things, yeah. [Rather than be without husband's company] ...watching him [husband] iron his own shirts [is frustrating]. I want to do that for him [and] its tiring [having care of grandchildren], yes... yeah and I have pain at the end of the day but it's worth it, isn't it? (BB1258, 12-month)

Individuals identified activities which were important to them and actively sought ways of managing their continuation within the context of living with chronic back pain. The identification of family roles such as 'breadwinner' or 'carer' within the narratives highlight the challenges which can occur and which compel patients to 'weigh up' the pros and cons of continuing with valued activities and suffering pain as a consequence. The first example illustrates reluctance by the respondent to take any unnecessary risks with

aggravating the pain, whilst feeling the need to remain at work and maintain the 'breadwinner' role. The trade-off is that the housework is reduced to manage the competing demands of home and work, with work considered as more important. The second example illustrates the competing demands of housework (ironing) and care giving responsibilities for grandchildren. However, this example differs in that the risk of aggravating the pain symptoms is balanced against the benefits of looking after the grandchildren, with the trade-off involving the relinquishment of certain domestic tasks. Thus, whilst the respondent in the first example (at baseline) expressed uncertainty of the potential consequences of balancing domestic tasks and work commitments, the second example demonstrates a calculated decision to weigh up the risk of engaging in activities that may exacerbate the pain. Although both examples illustrate similar trade-offs between engaging in physical activities and potential negative health consequences, the second example shows that people become more proactive and decisive in evaluating the risks. The enjoyment of interaction with grandchildren confers mental and social benefits, thus maintaining a sense of general well-being.

Respondents adopted a proactive stance in relation to managing their social 'roles' in the context of pain, which becomes evident in the 6 month interviews and even more pronounced in the 12 month interviews. It is evident here that living with back pain involved ongoing decision making about the tasks and activities that could be fulfilled in the context of living with back pain. Health maintenance might be defined here as the increasing tendency to make proactive 'trade-offs' between physical tasks and activities that could lead to

future exacerbations in pain and disability and these decisions are psychologically, socially and physically contextualised.

*Trade-offs and positive illness management: risk acceptance*

Individual trajectories reflect a complex mix of loss, revision and retention resulting in varying combinations of frustration and resignation. However, most participants reach a point where they begin to re-introduce 'lost activities' or to re-prioritise 'valued activities' in order to reduce the impact of pain on everyday life. This is marked by a willingness to accept risk of pain recurrence even though these activities are perceived as potential pain triggers which threaten the equilibrium achieved through medication or treatment. 'Risk acceptance' represents an important turning point in an individual's pain experience but cannot be fixed to any particular time point. Much depends on the activity in question and on individuals' motivation with some 'accepting risk' sooner than others. For example, at baseline, individuals were often confused about the level and type of activity that was considered 'safe'. Identifying activities that were likely to trigger pain was considered necessary, and imposing boundaries was also deemed important, though not always adhered to.

It can affect all different things in your life. .... I mean, I love driving; I'll [normally] go anywhere but now, if I drive for too long... It's very hard to get out of the car... then I've got to start walking or whatever I'm doing.  
(B133, baseline)

In contrast, the 6-month data indicates an increasing confidence in managing pain. Responses reflect individuals' unique context and circumstances, but tend to be highly pragmatic.

I would just ease down or change, go and find a different exercise and an activity 'cos I need to do activity; I need to keep myself fit, that I do. Perhaps I might turn to swimming. (B080, 6 months)

Well... well, it might be that I'm... [more cautious] ... where in the past you might have said, "well there's a DIY job to be done," and I'm not really feeling like doing it ... I'd get somebody else to do it for me... (B1420, 6 months)

In both of the extracts participants found alternative ways of achieving certain tasks, redefining their own capacity to fulfil them, and imposed limits to curtail the potential impact of their back pain. The 12-month interviews are a continuation of this strategy. Perception of pain as largely a manageable problem continues, with participants keen to assert control through exercising choice. Pain risk management becomes a part of routine everyday decision-making. Whilst at baseline participants were risk-averse due to the uncertainty surrounding their back pain, at 12 months they had acquired experiential knowledge with which to balance the risks and better anticipate the effects of their choices.

*... I don't envisage [getting worse] and if it did, I'd still try and 'crash through it' ... until [I reach] a point where my body just 'gives out' and I say, "enough is enough." ... So, it's not going to stop me. (B080, 12-months)*

Participants increasingly accepted the risk of pain in order to maintain a reasonable quality of life. Activities that increased the risk of triggering a pain episode were carefully considered and when selected enabled participants to benefit from 'valued activities' and achieve a sense of continuity.

#### *Health maintenance: an overview*

Participants evaluated their pain and its triggers, in order to maintain normality. They recognised the functional limitations caused by back pain and deployed ways of actively managing them, so that 'normal life' could go on as before. Consequently, 'continuity' should be understood in relation to those valued activities that participants retained despite difficulty, and which could therefore remain throughout a period of *disruption*. Biographical disruption did not automatically lead to long term incapacity/inactivity, as people recalibrated their physical limitations; emphasising the centrality of human agency in this process. Risk acceptance and risk avoidance moved in and out of focus, helping participants to maintain continuity of their self and identity.

In contrast, discontinuities included those activities which individuals abandoned or lost. Discontinuity in the context of chronic NSLBP can refer not only to an activity which is permanently ended but also to one which has been



interrupted or revised in order to accommodate pain fluctuations and unpredictability. Conceptually, it is important to regard 'continuity' and 'discontinuity' as responsive and dynamic. Achieving continuity in one area of life can, potentially, create discontinuity in another and how participants chose to balance the risks and benefits of competing activities was unique to them.

Over the 12-month period study participants recognised back pain as a fluctuating and recurrent experience. They sought ways of accommodating the 'disruption' caused by back pain and redefined it as a condition characterised by an unpredictable trajectory. This stands in contrast with the more linear model of illness presented by others (Faircloth et al. 2004; Bury, 1982), that involves a single point of disruption, and which is followed by a process of accommodation and adaptation. These authors, however, do recognise the 'identity work' that goes on in the course of living with a chronic or disabling illness, though they perhaps place less emphasis on the strategies individuals adopt to manage or 'muddle through' as a route towards 'stability' (rarely one that is 'pain free'). The discourse of resilience and confronting illness despite the odds is missing in many of these studies with the accounts of participants reflecting a resigned acceptance of chronic illness, either due to a sense of fatalism or the inevitability of ageing (Pound et al. 1998). Our findings illustrate the widespread use of proactive strategies by respondents in order to maintain their valued activities and accept certain 'risks' in order to facilitate a sense of continuity. This indicates the importance of human agency, for our participants, in negotiating difficult trade-offs despite the presence of pain and disability. Narratives of resilience and health

maintenance in the context of chronic illness disruption were common. Kelly and Field (1996), following Bury (1991), conclude that as chronic illness develops, the management of the associated physical problems precede coping with the disruptions to relationships because they are the prime focus of the experience of living with illness. Although we do not disagree with this finding, we would argue that following a period of 'accommodation' our participants' strategies shifted quite firmly towards a focus on health maintenance through 'preserving' their valued activities and trading-off risks and benefits. The emphasis was on trying to maintain overall health (i.e. physical, psychological and social) despite the chronic illness rather than responding directly to managing and accommodating the illness within their biography.

## Discussion

The findings presented describe individuals' changing perceptions in the context of chronic NSLBP. Whilst Bury's (1982) work remains useful in the context of rebuilding biography due to a major change in health it does not necessarily focus on the context of living with a fluctuating chronic condition such as NSLBP (Asbring, 2001; Exley & Letherby, 2001). Many chronic illnesses rarely see long term improvements, and the trajectory is not linear, with sudden or gradual improvements as well as deterioration, which is a common pattern depicted in patient experiences (Ong et al. 2004). For these individuals, 'rebuilding' identities reflects a process of personal resource management rather than cure. As a result, moving beyond a single point of disruption (Bury, 1982) provides valuable insights to patient engagement with

multiple points of change and draws attention to 'continuities' and 'discontinuities' in people's illness experiences (Sugarman, 2001; Williams, 2000). Framing the lived experience of NSLBP as a dynamic and fluid process shifts attention to change management. A 'health maintenance' perspective on explaining adjustments to pain experiences helps to develop a better understanding of how 'continuity and discontinuity' underpin active bodily 'redefinition' and 'recalibration'. A salutogenic model emphasises positive strategies to lead a 'valued' life. This is a dynamic approach illustrating the 'adaptation principle', which explains that humans adapt quickly to improved or worsening life conditions, demonstrated by the fact that life satisfaction tends to return to baseline levels within a year after both positive and negative life events (Haidt 2005). Individuals may return to 'normal' following an illness episode even if they encounter problems. For instance, people may return to paid work even where pain is causing problems with physical function. Consequently, 'hope' and 'despair' become part of their narrative alongside optimism about the future (Corbett et al. 2007).

In this study we acknowledge that illness experience in chronic NSLBP is dynamic, where a patient's journey is subject to both 'continuities' from before back pain began and 'discontinuities' which result from forced or negotiated changes. This builds on Bury's original concept of 'biographical disruption' (Bury, 1982). Our findings also show that the changes to self and identity that Bury identified did not occur at only one point of disruption, but at several stages in the back pain trajectory, each leading to adjustments. It is at these critical junctures that the greatest need for clinical support may be required,

the aim of which is not only to help relieve symptoms but empower patients to optimise their health and wellbeing (Becker et al. 2010). One strategy is to help patients to maintain 'valued activities' (Morden et al. 2011; Janke, 2012). In our data, 'valued activities' relate to physical, social and leisure pursuits which our participants frequently struggled to maintain. Clinicians may support the identification of 'valued activities' which provide individuals with the resources to effectively self-manage their health conditions.

Although we support a 'salutogenetic' approach (Becker et al. 2010; Antonovsky 1998) with its strong emphasis on optimising health not disease, we do not ignore the debilitating physical consequences of back pain, and in this regard our findings point to a middle way between the need to help patients control their pain and disability (pathogenesis) and optimising health and wellbeing (salutogenesis). Salutogenesis refers to a focus on factors that enhance health and wellbeing rather than on factors that cause disease. People with low back pain rarely lead a pain free life, and in this context a health enhancing, rather than disease eradication, strategy may be appropriate if it enables patients to manage their condition more effectively in the long-term.

Our findings also show that patients' changing perceptions of back pain are managed in the context of two competing positions: patients' search for pain relief, and medicine's failure to provide a long term resolution. This conflict was often resolved in favour of accommodating the chronic pain and 'doing the best' with what was often a debilitating illness. Although patients'

expectations of a medical 'fix' for their back pain were gradually revised, it was evident that a general absence of early clinical guidance led patients to struggle with managing their condition. Consequently, patients learnt about the impact of pain on daily activities through 'experimentation' and 'testing out' the activities to be pursued or avoided. This finding has implications for the management of patients with back pain, because it highlights considerable unmet patient need. Back pain often involves significant fluctuations in responses where sufferers seem to initially experience uncertainty and fear about pain triggers and recurrence, followed by a greater focus on practical pain management strategies. Advice and support from primary care clinicians therefore needs to be responsive to the different stages of the low back pain illness experience.

## Conclusion

The findings highlight an evolving patient perspective on the diagnosis, treatment and everyday impact of NSLBP. The data confirm Cedraschi's (1996) view that professionals who actively engage with the needs of individual patients are likely to achieve greater congruence and favourable patient outcomes; that is, adaptation to, and greater stability in, managing pain. There may be a tendency to overlook the importance of changes to pain severity and disability in back pain and clinical care may be too concerned with providing support in relation to the diagnostic label rather than to individual patient experiences; 'pain as pathology' rather than 'pain in the patient'. Future training initiatives for healthcare professionals need to consider positive and responsive management of low back pain by identifying

practical strategies that enhance wellbeing, and not only those that aim to resolve the underlying pain problem, which often will not disappear despite clinical intervention. Our findings reveal that respondents managed their back pain relatively effectively, and indications are that with greater input of the type we recommend could result in further improvements in patients' self-management of their back pain symptoms.

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## Table

**Table: Composition of serial interview 'sets' for analysis**

Recruited at:	Full set of 3 interviews	Baseline and 12 month pair	6 month and 12 month pair	Single interview	Total sets remaining
Baseline	25	1	0	0	26
6-month	12	0	6	0	18
12-month	3	1	2	5	11
Total number of original transcripts	40	2	8	5	55
Selected for re-analysis	9 (3 x 3)	2 (1 x 2)	4 (2 x 2)	N/A	15