Exploring identity in older adults with chronic pain: an interpretative phenomenological analysis

by

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Essays

Adult Mental Health,
People with Learning Disabilities,
Child and Adolescent,
Older People
Psychotic experiences (e.g. auditory hallucinations and delusions) are not understandable or meaningful. Critically discuss this statement and any implications for treatment.

January 2004 - Year 1
Adult Mental Health Essay
Introduction

The Diagnostic and Statistical Manual of Mental Disorders-Fourth Edition (DSM-IV, 1994) suggests that there is no one way of defining psychosis that is universally accepted. The focus of this essay will be on delusions and hallucinations, which are included in most definitions, with less emphasis on other positive symptoms such as thought disorder. The DSM-IV (1994) describes delusions as "erroneous beliefs that usually involve misinterpretation of perception or experiences" (p275), and hallucinations as "distortions or exaggerations of...perception" (p274). These must occur in the absence of a general medical condition or substance use, and cause disruption in the individuals' life.

This essay will firstly explore the different ways in which professionals explain the occurrence of hallucinations and delusions. In particular the medical model and the models developed by psychodynamic and cognitive branches of psychology will be considered. The Oxford Dictionary (2001) defines 'understandable' in a number of ways. In this essay it will be defined as when one can 'know how someone feels or why they behave in a particular way' or when something is 'to be expected'. The different ways that professionals understand psychotic experiences will obviously have an impact on the way in which they approach treatment. In this first section both psychological and psychiatric approaches to treatment and the theoretical model from which they have arisen will be discussed. There is clearly no one way of understanding that would satisfy every professional group so the effectiveness of the different treatment approaches will be evaluated. For the purposes of this essay I will describe the theoretical standpoints in their extreme forms, although it is often the case that the models and treatment approaches compliment rather than oppose one another.

A clear distinction can be drawn between the different models in terms of whether or not they include the meaning of the experience to the individual having it. The Oxford Dictionary (2001) defines 'meaningless' as 'having no meaning or significance', and has one definition of 'meaning' as 'a sense of purpose'. The medical model, which traditionally separates the mind from the body, does not include meaning, and instead focuses on symptom alleviation. In contrast to this, the psychological models hold the
meaning of the experience as central to the model and in guiding the treatment. There are therefore clearly different opinions about the second half of the title which states that psychotic experiences are ‘meaningless’.

In the second section of the essay the title will be considered with reference to lay-individuals. Different cultures and individuals give spiritual, religious and magical explanations for delusions and hallucinations, and indeed would not use these Westernised diagnostic terms. The impact on an individuals’ well-being of these different ways of understanding these experiences, and of the different senses of meaning that an individual takes from this will be evaluated. The fact that an individuals own understanding of their experience has such a significant impact on their prognosis contests the statement that psychotic experiences in themselves are ‘meaningless’.

Traditionally psychosis was viewed as a different psychological phenomenon to neurosis. Neuroses were seen as illnesses where normal experience occurs, but to a severe degree. Conversely, individuals with psychoses were thought to have symptoms that are qualitatively different from those within a normal range of human experience. Robbins (2002) describes how the relatively recent neuroscientific view of schizophrenia that was prominent about 40 years ago viewed it as an organic illness, with the associated speech and writing seen as a “meaningless breakdown products” (p83). More recently, research has suggested that psychotic symptoms should be viewed as part of a continuum (Van-Os et al. 1999) For example, hallucinations have been found to arise in the context of bereavement (Schreiber, 1995) and paranoid delusional ideas have been found to be present in the general population (Freeman et al. 2003). This has paved the way for professionals to develop models of psychosis that involve disruption of normal processes.

Medical model

Psychiatrists work from a medical model of mental illness, understanding psychiatric disorders as coming about due to functional or anatomical abnormality of the brain. Evidence supports the fact that these abnormalities exist. For example, Read, Perry, Moskowitz and Connolly (2001) found that individuals with schizophrenia showed biological abnormalities including cerebral atrophy and hippocampal damage as well as
imbalance in dopamine, serotonin and norepinephrine systems. Medical treatment of schizophrenia therefore has the stabilisation of neurochemicals as its main focus. The form, and particularly the content of delusions and hallucinations are not relevant in this model, and the meaning to the client will not necessarily be formally assessed. Haddock, Tarrier, Spaulding, Yusupoff, Kinney and McCarthy (1998) report that neuroleptic and atypical neuroleptic medication has been found to be effective in the treatment of psychotic symptoms, but that there are substantial number of patients who do not respond or have periodic relapses. The psychiatric profession is aware of this, and the Cartesian dualistic approach which separates the mind from the body is increasingly being rejected and replaced with a more holistic stress-vulnerability model (Kumar & Clark, 2002). For example, neural disconnection is thought to have both genetic and environmental precipitants, and Read et al. (2001) found that brain abnormalities in schizophrenia were similar to those seen in individuals who had experienced trauma. This would suggest that pharmacological treatment alone, while effective in restoring neurochemical balance, is not sufficient if the causes of the biological abnormality are not addressed.

Psychological models

Psychodynamic

Pestalozzi (2003) describes a common view in psychoanalysis that schizophrenic symptoms are due to disturbances in symbolisation. The aetiology of these disturbances is theorised to arise from trauma early in childhood which leads to a disturbance in object relations. Her clinical experience supports this theory, in that the symptoms of schizophrenia seem to be related to an inability to engage in symbolic play as a child. There are two sides to this disturbance: Firstly, an individual is unable to understand and think in a metaphorical way. This concrete thinking is a regression to the sensorimotor phase of childhood, and an attempt to give meaning to a world that is incomprehensible; Secondly, sometimes objects can be seen as "fantastically meaningful" (p739) metaphorically, when in fact they are quite simple.

Pestalozzi (2003) describes a case of a psychotic patient. She suggests that the voice he heard was what we would refer to as the inner voice of our conscience, but that
he heard it in a more concrete way. Although it tortured him it meant that he was never alone. She suggests that schizophrenic people can’t form a symbolic representation of others to keep them ‘present’ in their thoughts and so are unable to cope with being alone. The comfort that can be drawn from a ‘voice’, however negative, can therefore be seen as a powerful factor in maintaining psychosis. She also describes how even a negative voice can be an important component of an individual’s identity.

Understanding psychosis in this way clearly has implications for treatment. Pestalozzi (2003) highlights the importance of considering the meaning of having the experience to the individual, and that moving out of this state will be accompanied by grieving. She also describes how it is important to understand both the metaphorical and the concrete interpretation of what a psychotic individual says. Initially it will be important for the therapeutic relationship to respond to the concrete meaning, staying close to the individual's own imagery, in order to remain where thinking is safe and secure for the patient. She states that in order to accompany someone out of that state, one must first be immersed with the patient in their world. Interpreting statements in a metaphorical way will come later when a patient is able to be more flexible in their thinking.

Another psychoanalytic approach is described by Robbins (2002), who considers that “the language of schizophrenia” (p383) is the key to its understanding. He found that although it is similar to ordinary language in its syntax and word formation, it is qualitatively different in terms of semantics. There is a lack of the distinction that is normally seen between words, things, body states and actions, and this has a determinative and supportive role in delusional and disrupted thinking.

He also found that schizophrenic language had different pragmatics, with none of the self-awareness, thoughtfulness, reflection and communication that is seen in normal language. He theorised that for some people, this involves too much effort and that reflection would involve considering distressing thoughts. His patient confirms this by describing why she would normally speak concretely rather than in an abstract way because “Metaphors take more responsibility” (p393). He suggests that psychotic
patients use language to “undo, reverse and eliminate intolerable reality, both past and present” (p397)

Therapists using this model of understanding psychosis are encouraged to consider the implications of technically not even speaking the same ‘language’ as their client for the therapeutic relationship. They must work to develop a shared language that they both understand, rather than each attempting to infer meaning from the other. It is also important to understand that a psychotic individuals’ delusions and hallucinations represent a tolerable reality, and as such they may be unwilling or unable to engage in therapy that may challenge this.

These psychoanalytic theories of psychosis appear to have been useful in the work with the individual patients that the authors describe. However, it is important to consider whether this ‘understanding’ is based on an accurate reflection of the processes involved in the development and maintenance of psychosis, and whether the use of this approach is supported by outcome evidence. The articles discussed do not quote much research, and instead rely on personal and shared clinical experience. In fact there is limited research in the area. Mueser (1990) carried out a review of the existing research at that time and found that clinical trials failed to show any beneficial effects of psychoanalytic therapy in methodologically sound studies. A trial by Gunderson et al. (1984) found that therapy that focussed on current problems as opposed to the exploration of the past that is carried out in psychoanalysis, had better outcome in terms of rehospitalisation, and vocational and social adjustment. The psychoanalysis did, however, have a more positive effect on patients’ ego-functioning. In more detailed review of their results, Mueser (1990) determined that for some patients, the length of time in the psychoanalytic-type therapy was actually negatively related to outcome, and such a pattern did not appear in the other therapy. She concludes by suggesting that for some schizophrenic patients, psychoanalysis may be too emotionally intense, but states that the evidence is by no means conclusive. However, the evidence for its efficacy is similarly inconclusive, which contrasts with the positive outcome evidence for other therapies such as family therapy and social skills training.
Cognitive

Theory and research within a cognitive understanding of psychosis can be divided into a number of areas:

Cognitive Biases

The understanding of psychotic symptoms along a continuum paved the way for researchers to use models of normal cognitive processes in order to understand how they are disrupted in psychosis. Maher (1988, as cited in Haddock et al., 1998) suggested that delusions are a result of the rational search for explanations for abnormal perceptual experiences. Following on from this Garety and Freeman (1999) found empirical support for the fact that individuals with psychosis show a tendency to draw quick conclusions when gathering information, which may explain why they accept unusual explanations for abnormal events that others may consider further before rejecting. Garety and Freeman (1999) also found support for the theory of Frith (1992, as cited in Haddock et al., 1998) which suggests that delusions arise due to a failure of Theory of Mind, where deficits are seen in a psychotic individuals’ ability to understand social situations and the intentions of others. They may see intention that isn’t there, or not understand someone’s intention so assume they are being deceptive.

Bentall, Kinderman and Kaney (1994) also support a disruption in cognitive processing theory for delusions. They suggest that psychotic individuals have a bias in their attribution of events, and show a tendency to externalise responsibility. This theory is supported by empirical evidence (Garety & Freeman, 1999). Bentall (1990) also applies the attributional bias theory to an explanation of hallucinations, suggesting that sounds and images that an individual produces internally are thought to come from an outside source. This is similar to the work of Frith (1992, as cited in Haddock et al., 1998), who suggests that psychotic individuals fail to monitor their own intentions, and so they will experience their own thoughts and actions as coming from an external source, as hallucinations.

A final cognitive processing deficit was proposed by Hemsley (1993), who suggests a basic disturbance in processes involving the retrieval of information from
memory. This results in problems with understanding and ordering sensory input and intrusion of stored memories into consciousness.

As well as disrupted processes, Garety, Kuipers, Fowler, Freeman and Bebbington (2001) suggest that normal cognitive processes play a part in the maintenance of psychosis. For example, the belief confirmation bias, which may also lead to the development of safety behaviours which prevent the gathering of disconfirming evidence (Freeman & Garety, 2002). Psychotic individuals often have associated depression and anxiety, in which dichotomous thinking are likely to be seen, as well as feelings of hopelessness and fear, which may relate to the content of the delusional thought (Freeman, Garety, Kuipers, Fowler & Bebbington, 2002).

One form of treatment that follows on from theories involving cognitive biases focuses on belief modification. Jones and Watson (1997) found that delusions have much in common with perceptually based beliefs, and as such directly challenging them is like suggesting to someone that grass is not green. However, verbal challenge along with reality testing and evidence assessment approaches has been found to be effective (Chadwick & Lowe, 1994).

**Negative schema**

As well as a genetic predisposition that is included in the medical model, many researchers propose that individuals become predisposed to developing psychosis as a result of an impoverished or abusive upbringing that results in the formation of negative schema about the self, the world, and others (Garety et al., 2001). Evidence confirms that individuals with psychosis have low self-esteem (Freeman et al., 1998) and that there is a high lifetime prevalence of traumatic life events among this group (Mueser et al., 1998). For psychologists using this approach, schema therapy addressing the childhood experiences that led to these beliefs can be used to indirectly treat the psychotic symptoms.
Sub-vocalisation

Gould (1950, as cited in Haddock et al., 1998) suggested that auditory hallucinations occur when an individual misattributes the source of the sub-vocalisation that is seen when inner speech is processed. Treatment that follows on from this theory involves the use of tasks that interfere with the sub-vocalisation mechanisms. This is supported in part by research into the effectiveness of distraction techniques and using the muscles involved in sub-vocalisation in other tasks (Haddock et al. 1998)

Meta-appraisal

Chadwick and Birchwood (1994) suggest that the distress related to auditory hallucinations is associated with the beliefs about the voices as well as the content. An individual’s beliefs about how powerful the voice is, who the speaker is and their purpose are all thought to relate to the outcome of the experience. They propose that it is important to consider the individuals’ relationship with the voice in therapy. Persaud and Marks (1995) indeed found that increasing an individuals' sense of control over their hallucinations through an exposure and anxiety reduction technique made them subjectively less distressing.

Clearly, there are a number of different ways in which cognitive psychologists understand the positive symptoms of psychosis. Recently, Garety et al. (2001) have proposed a cognitive model which draws together much of the previous work into a multifactorial model. They suggest that psychosis may occur in an individual with a vulnerable predisposition, of biopsychosocial origin. Factors associated with onset may be adverse life events or environment, illicit drug use and isolation, where anomalous beliefs cannot be ‘checked out’ with others. Psychosis involves emotional change and disruption in areas of cognitive functioning. In this state an individual may have anomalous conscious experiences, either physical or mental, which they appraise as being due to external forces, and lead to the positive symptoms of psychosis. These symptoms are maintained by cognitive and emotional processes, as well as dysfunctional schemas which may have formed part of the initial vulnerability. Isolation and environmental

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factors also maintain the psychosis. Finally, the individuals “secondary appraisal” (p192) of the psychosis, that is ‘what does it mean that I am experiencing this?’ will have an impact on the maintenance or not of the psychosis. This final factor will be considered further in the second part of this essay.

A multifactorial way of understanding psychotic experiences clearly leads to a requirement for a multifactorial method of treatment. As Freeman and Garety (2002) state, delusional beliefs are “unlikely to share a common cause” (p175) so it is necessary to develop an individual formulation, rather than apply a general framework for understanding to every case. Garety, Kuipers, Fowler, Chamberlain and Dunn (1994) used an approach that involved detailed assessment and formulation of the individuals' experiences, followed by a tailored intervention which included provision of coping strategies (e.g. distraction), belief and assumption modification, and sensitive psychoeducation. They found this was effective in reducing the impact of positive symptoms on daily life, and reducing distress and depression. This study is one of a growing body of literature which supports the use of CBT in the treatment of schizophrenia (e.g. Kuipers et al., 1998). This consistent finding has led to the development of NICE guidelines that suggest that CBT be used as the psychological treatment of choice for schizophrenia (Core interventions in the treatment and management of schizophrenia in primary and secondary care, 2002, Section 1.3.3.4).

Clearly psychological models differ significantly from medical models in their consideration of the meaning of the psychotic experience to the individual having it. The fact that pharmacological treatment has not been shown to be 100% effective and that some forms of psychological therapy have a positive effect on outcome suggests that considering the experience to be ‘meaningless’ is not helpful in treatment. Indeed, Pestalozzi (2001) suggests that the loss of self-esteem that is seen in psychosis will only be compounded by this type of approach.

Meaning to the individual

It seems that the inclusion of the ‘secondary appraisal’ factor in the model of Garety et al. (2001) is very important. The meaning of the experience, or the inability to
find a meaning for it, is central to the impact of delusions and hallucinations on the individual. Koivisto, Janhonen and Väisänen (2002) carried out a phenomenological study with patients recovering from psychosis. Themes that arose were feelings of a change to self and a loss of control. These were associated with anxiety, anger and shame, as well as a fear of becoming mad. Patients wanted to understand what was happening to them and why.

As discussed earlier, Bentall et al. (1994) suggest that a delusional belief arises from an attempt by an individual to understand their experience, but that an attributional bias exists. They propose that this is a protective mechanism that serves to maintain fragile self-esteem. For example, believing that you are a victim of persecution by an outside source which results in your inability to work is easier to accept than a reality that it is due to your own illness. Garety and Freeman (1999) did not find empirical evidence to support this defensive aspect of the theory. However, Roberts (1991) found no differences in rating of meaning in life scales between chronically deluded participants and Anglican Ordinands. He interpreted this as evidence that having a coherent belief system, whatever the content, is beneficial. In fact individuals who had previously suffered from delusions but were in remission had lower meaning in life ratings and more suicide inclination than both the deluded and religious groups. Qualitative responses seem to provide an explanation for this, with one individual stating that "if it is not true I would be a nobody" (p27), suggesting that facing reality may negatively impact on one’s self esteem. For some people believing that ones experiences mean they have a mental illness holds extremely negative connotations in terms of prognosis. Lee (2000) describes how when he entered a mental health service he felt that he was “on a downhill ride for ever, there was no way out of it” (see website)

The above findings suggest that treatment that involves challenging beliefs either directly or through evidence gathering must pay careful attention to the meaning of an individual holding a particular explanation for an abnormal experience, and the possible negative implications of having a different understanding. Indeed, Roberts (1991) suggest that clinicians must use client ratings of distress and meaning in life before making a decision to treat, rather than judging someone’s quality of life on how it appears to them.
Freeman and Garety (2002) even suggests that for some individuals, aiming to help them cope with their existing beliefs is more appropriate than trying to change them. However, it still remains that discussion about the possible origins and meaning of people’s voices has been found to reduce anxiety and distress (Garety et al. 1994). Similarly, Abma (1998) helped patients gain a different understanding of their experiences using a narrative approach. They provided an alternative to the standard stories that therapists in a general mental hospital held, which suggested that psychiatric patients were dependent on the expertise and care of therapists and led the patients to take up a passive role. Situations in which people had mental illness but were able to lead lives as functional members of society were created.

Lastly, as well as an experience having a meaning while it is happening, individuals may also attribute meaning retrospectively. Psychotic individuals that Murphy (2000) interviewed reported that the experience of suffering from delusions and hallucinations had made them stronger, more accepting of others and empathetic. Similarly, Virginia Woolf (1976) wrote that “madness is terrific, and in it’s lava I still find most of the things I write about”. Murphy (2000) highlights the importance of creating a meaning for psychotic experience through therapy that is positive and acceptable.

**Cultural and religious explanations**

When working in a multi-cultural country such as Britain it is important to consider that people from different cultural and religious backgrounds may not find the traditional Western biopsychosocial model of psychosis acceptable. It is important to note that the DSM-IV (1994) does take into account the fact that some cultures may hold beliefs that others would classify as ‘bizarre’ and that for some, perceptual experiences are normal parts of, for example, religious experiences.

Castillo (2003) studied the trance experiences of Indian yogis. The goal of their meditative trance is a divided consciousness, which in a Westernised diagnostic system would be described as dissociation. In this state, one achieves distance from the suffering of life, and it is noted that as in many psychotic individuals, many of the yogis had
experienced trauma in childhood. In a trance state yogis were found to experience auditory and visual hallucinations, and they also held strong beliefs about their spiritual power. Castillo (2003) suggests that the psychological processes involved in entering into this trance state are not dissimilar to those involved in becoming psychotic, and that both serve as a form of escape. However, a key difference is that, unlike psychotic individuals in Western culture yogis are not perceived to be mentally ill, and they are highly respected by the local population. This very different understanding of hallucinations and delusions is not uncommon - Bourguignon (1972, as cited in Castillo, 2003) found that from 437 societies, self-induced auditory and visual hallucinations were seen in 89%.

In non-Western cultures, transient psychoses with complete recovery are 10 times more common than in Western cultures (Susser & Wanderling, 1994). Castillo (2003) explains this by suggesting that the “biogenetic brain disease” (p9) explanation for psychosis that is given in Western society implies incurability and personal failure. This leads to acceptance of one’s situation, depression and anxiety, which contribute to the maintenance of symptoms. There is also a backdrop of fear and criticism of mental illness within Western culture (Phelan, Link, Stueve & Pescosolido, 2000) which is likely to result in social isolation and distress. By contrast, traditional beliefs about a spiritual or magical cause for psychosis are traditionally treated by healing rituals, as well as heightened social support and sympathy, and a prescribed period of rest (Castillo, 2003).

Pote and Orrell (2002) considered the perceptions of mental illness in different ethnic populations living in Britain. They found that compared to white British individuals, Bangladeshi participants were less likely to see suspiciousness or hallucinations as indicative of mental illness; and Afro-Caribbean individuals were less likely to view unusual thought content as a symptom. The DSM-IV (1994) reports that clinicians have a tendency to overdiagnose Schizophrenia. These two findings considered together suggest that within Western models, holding different beliefs about psychotic experiences may be being ‘diagnosed’ as lack of insight, which is associated with severity. Thus although the DSM-IV (1994) calls for cultural sensitivity, it seems that this is not always seen.

Adult Mental Health Essay
Peters, Day, McKenna and Orbach (1999) found that different religious groups give psychotic experiences different meanings. They found that members of ‘New Religious Movements’ (groups which have beliefs that differ from mainstream ideology) endorsed more items on a delusional ideation scale and a conviction scale than non-religious and Christian participants did, showing equal levels to deluded participants. However, their level of distress was comparable to the Christian and non-religious groups, and significantly less than the deluded participants. They concluded that psychotic experiences are on a continuum, and that for some the experiences do not interfere with functioning. They suggest in the diagnosis of psychosis, interference with functioning should be more important than ‘bizarreness’ of belief.

The fact that different cultures have such different understanding and meanings associated with psychotic experience indeed seems to suggest that Western diagnostic systems do not meet the needs of the whole population. However, there is evidence that some clinicians do take this factor into account. For example, Eles, Lowe and Wellman (2003) found that practise nurses assessed psychotic experiences by considering their nature (e.g. spiritual, persecutory), the outcome, both positive and negative, and the personal and cultural context in which it arose.

Clearly respect must be held for an individual’s beliefs about their own experiences. Lund and Schwartz (1998) found that Xhosa speakers they interviewed believed witchcraft was involved in their ‘amafufunyana’ (which fits Western classification for schizophrenia), and this served to remove stigma from the condition and place blame elsewhere. However, they used both traditional and Western treatment, favouring that which would give them immediate symptom relief. Thus, they were able to hold both of these differing explanatory ‘discourses’ according to their needs. The authors suggest that clinicians should therefore be educated in non-Western beliefs.

Finally, the Hearing Voices Network (http://www.hearing-voices.org.uk/) suggests that non-judgemental exploration of the experience of voices is a right of the individual, and that providing a positive framework for the experiences will give great benefit to those who have them. As seen above, for some a biopsychosocial framework will be positive, while for others more traditional cultural or religious explanations will
provide more comfort. The Network also suggests that the education of society as a whole is vital in de-stigmatising the experience. By providing evidence that shows the effectiveness of pharmacological and psychological treatment for psychosis, a biopsychosocial explanation may lose the notion of incurability that is attached to it.

**Conclusion**

In conclusion, the assertion that psychotic experiences are not understandable is a historical relic. Medical explanations outline the biological context in which hallucinations and delusions may occur, but do not consider the content of these experiences. Medical treatment similarly appears to be effective in relieving symptoms in some individuals, but falls short for others and relapse is common (Haddock et al., 1998). Thus a more holistic way of understanding psychosis appears to be necessary. Cognitive therapy that follows from a cognitive model has been found to be effective (Kuipers et al., 1998). Psychodynamic theory similarly focuses on the subjective content of the experiences of the individual. However, there is less evidence to support that psychodynamic treatment is effective.

The importance of considering the meaning of the experience to the psychotic individual has been outlined in the second half of the essay. It appears that an individuals' appraisal of what it means to be having the experiences is very important in determining their impact. In some cultures and religions, holding a positive explanation for the experience renders it non-distressing. In other cultures holding a spiritual or magical explanation in associated with better outcome and quick recovery. The statement that a psychotic experience is 'meaningless' is therefore rejected.

Clearly psychotic experiences are understood in vastly different ways, and different ways of understanding them gives them different meanings. As Casseem (n.d.) points out, they are "A mystery to be lived" (see website), and as such may be associated with extreme distress or with positive outcome. It is vital then that a clinician who comes into contact with a 'psychotic' individual must first consider whether treatment is necessary. If it is then they must use an approach which has both empirical support, and that takes into account the meaning of the experience to the individual.

*Adult Mental Health Essay*
References


Adult Mental Health Essay


Adult Mental Health Essay


Adult Mental Health Essay


Adult Mental Health Essay


What role do clinical psychologists have in the assessment and treatment of people with learning disabilities who have been sexually abused? How can they assist in the prevention of such abuse?

August 2004 - Year 1
People with Learning Disabilities Essay
Introduction

The lives of people with learning disabilities are characterised by difficulties in understanding and communicating, and often by a reliance on others for physical and emotional support. Brown (1997) suggests that these factors, together with a lack of sexual knowledge and negative expectations of sexual options, contribute to an increased vulnerability of this population to become targets for sexual abuse. In addition to these individual vulnerabilities, many people with learning disabilities will either live in a group setting or attend day services with other people with learning disabilities. White, Holland, Marsland and Oakes (2003) suggest that the physical environment and culture of these settings may promote abuse, through the existence of abusive regimes and the improved access to potential victims for both staff and client perpetrators of abuse.

The extent to which sexual abuse of people with learning disabilities is occurring is unclear, with variation seen depending on research methodology and definitions used. Estimates of prevalence range from 8% to 58% (Turk and Brown, 1993) of the learning disabled population. Whatever the exact prevalence it is a significant problem, as demonstrated by the findings of a large scale incidence study carried out by Turk and Brown (1993). If their results were extrapolated to cover the population of Britain, 940 new cases a year would be expected, and Brown, Stein and Turk (1995) suggest that this is likely to be an underestimate.

The role of the clinical psychologist in this area is multifaceted. This essay will first explore the work that may be directly undertaken with clients. Assessment of people who claim to have been sexually abused may involve investigating if it has occurred, as well as assessing the nature of the abuse and its impact on the individual. Judgements of ability to consent and capacity to testify are also considered. Client level interventions are discussed: firstly, reactive interventions which address psychological outcomes for victims of abuse, and secondly preventative interventions which address individuals’ vulnerability to be a victim of abuse. The role of the clinical psychologist in working with learning disabled perpetrators of abuse is also addressed.

The second part of the essay will discuss the role of the psychologist at a broader level. It is argued that abuse is promoted by a lack of definition of what constitutes abuse...
and by inadequate service provision. It is also supported by assumptions of asexuality or sexual promiscuity in people with learning disabilities, or by the belief that they will not suffer psychological consequences of abuse. Thus a clinical psychologist has a role in informing policy and service development, as well as challenging negative and erroneous beliefs and assumptions, particularly where they will have a direct impact on people with learning disabilities. This can be achieved through education, consultation and support, as well as building up a body of research in this under-researched area.

Finally, consideration will be given to the impact of working in this sensitive and potentially distressing area, and the personal and cultural issues that may arise through this work.

For the purposes of this essay, abuse is conceptualised using the comprehensive definition provided by Brown and Turk (1992). This defines contact abuse as when a perpetrator touches, masturbates or penetrates certain parts of the victim's body (e.g. anal or genital areas), or requires the victim to do the same to them. It defines non-contact abuse as when a perpetrator looks at certain parts of the victim's body, harasses them, exposes themselves indecently, or forces them to watch pornography. It is non-consensual, in that the victim withholds consent, is unable to give it, or there is a barrier to consent such as power imbalance, or the use of threat or force.

Role in assessment

Impact of abuse

A clinical psychologist may be asked to assess the likelihood that abuse has occurred, or to determine the impact of known abuse. This is made difficult by the fact that there is currently little research to suggest what psychological or behavioural consequences of abuse may be seen in a learning disabled population (Sequeira and Hollins, 2003). However, Sequeira, Howlin and Hollins (2003) provide some useful information from a case controlled study. They found that individuals who had been sexually abused showed more irritability, lethargy and hyperactivity, as well as more sexualised and self-injurious behaviours than a control group. More of them met diagnostic criteria for psychiatric diagnosis such as depression and hypersomnia, and they
had more clinical symptoms of post-traumatic stress disorder. As well as these symptoms, which are similar to those seen in abused adults and children without learning disabilities, the learning disabled group also showed significantly more stereotypical behaviours than a control group. While these findings are important in highlighting areas that should be assessed, it is important to note that this research does not imply a causal relationship and is one of only a few pieces of research in this area. Replication and further exploration in this area will consolidate these findings.

The level of learning disability of the victim will determine the way in which the process of assessment of these areas is carried out. Some clients may be able to communicate their feelings or disclose what has happened to them, and this can be facilitated using creative methods such as pictures, symbols, or drama. For individuals with limited communication ability, behavioural indicators of abuse may be used. These have limited reliability as they involve an outside person interpreting the meaning of behaviours, and there are problems of inter-rater reliability as to what constitutes a particular behaviour. Despite these difficulties, Fenwick (1994) describes a case where a systematic assessment of an individual's behaviour took place, and the data gathered sufficiently supported a conclusion that although a traumatic event had clearly taken place, it was not clear if it had a sexual element. The assessment involved ward staff recording incidents of inappropriate sexual behaviour and behaviours associated with post-traumatic stress disorder and depression. A baseline level was gauged using information gathered from the parents, and consideration was given to the presence of other stressors.

Capacity to consent

A clinical psychologist may be asked to advise a court if an individual had the ability to consent to a sexual encounter. Although the final decision about capacity will be made by the court, an 'expert' opinion will influence that decision. The role of assessing capacity is particularly important when the perpetrator argues that the encounter(s) were consensual and therefore not abusive. This argument cannot be used when a man has had sexual intercourse with a woman who has a 'severe' learning
disability, as she is considered to be unable to give consent under any circumstances (Sexual Offences Acts 1956 and 1967). However, when the defendant has a mild or a moderate learning disability, it can be a matter of some debate.

There are a number of areas that should be assessed in order to determine an individual's capacity to consent. Measures such as the Socio-sexual Knowledge and Attitudes Test (Wish, McCombs and Edmonson, 1979) can be used to determine if a person has sufficient understanding of the sexual act and its possible consequences, as well as the appropriateness of particular behaviours. The Weschler Adult Intelligence Scale – Third UK Edition (WAIS-III; Weschler, 1999) can be used to determine whether their learning disability is such that they are deemed 'severely' learning disabled and thus unable to give consent. It can also be used to guide a decision as to whether they have sufficient cognitive ability to remember and understand information, problem solve, and consider the consequences of different courses of action. As well as cognitive abilities, an individual's social skills should be assessed. For example, Gudjonsson (1992) found that individuals with learning disabilities are vulnerable to acquiescing, being misled, and complying with instructions or ideas, and these characteristics would all impact on ability to consent.

This 'functional' approach to considering consent is favoured over approaches which judge the 'sensible-ness' of decisions made or make blanket judgements about groups of people (Murphy and Clare, 1997). However, it is important that it is not used to support the over protection of people with learning disabilities by expecting them to make fully thought-through decisions regarding sexual encounters that are not necessarily seen in the general population.

Capacity to testify

Disclosures made by clients are likely to be subjected to high levels of scrutiny within a court setting, and a clinical psychologist may be asked to assess whether an individual is able to give an accurate testimony. Beail (2002) describes how the Gudjonsson Suggestibility Scales (Gudjonsson, 1984, 1987, in Beail, 2002) are used to make this determination by assessing whether semantic information presented verbally is
remembered, and whether it is resistant to leading questions and pressure. However, he argues that this method of assessment underestimates the ability of people with learning disabilities to be reliable witnesses, as they are reporting on events they have experienced, which will be more deeply encoded and stable against pressure to change. Beail (2002) also highlights the importance of considering the nature of the police interview in determining the reliability of a testimony, as pressurising an individual will increase their likelihood of acquiescing. Promisingly, Joyce (2003) found that a significant proportion of referrals to a Psychology service were for assistance with an investigative interview, which suggests that there is an awareness that the statement of a learning disabled individual can be credible if they are interviewed appropriately.

An individual's ability to cope with the pressures of being in court can also be assessed, and it may be necessary to recommend that measures are taken to make the experience of court as unintimidating as possible. For example, Green (2001) describes how a victim preparing to take her case to court was able to meet court officials, practise standing in the witness stand, and practise asking for questions to be repeated before the trial.

Role at a client level

Reactive

As discussed above, sexual abuse has a significant impact on the psychological wellbeing of individuals with learning disabilities. Historically, approaches to distress in this client group have tended to be behavioural or pharmacological. Although they may suppress symptoms such as challenging behaviour and anxiety they do not recognise that the individual may need to express a strong emotion. There is a growing awareness that one-to-one therapy is possible with this group, with adaptations of session length and regularity, and in the presentation of information and ideas. Consideration of an individual's memory, capacity for abstract thinking, understanding of boundaries, and consent to therapy is also necessary (Moss, 1998).

Moss (1998) describes the use of a cognitive behavioural approach with individuals who have been sexually abused. Anxiety management strategies such as
relaxation or distraction can be taught through imitation or visual instructions, and graded exposure to abuse-related stimuli can be used to desensitise individuals. Alternatively, RESPOND, a psychoanalytically based service, suggest that a therapist has a fourfold role: as a witness to believe what has happened, as a protester to state that what has happened is wrong, as a nurturer to provide consistent support, and as a translator to help them make sense of what has happened to them (Corbett, Cottis and Morris, 1996). Brown (1997) describes a role of a therapist which can be conceptualised as an 'advocate.' As well as helping a person make sense of their experience personally, the therapist may act as their advocate in explaining their thoughts, feelings and needs to those caring for them, while respecting the confidentiality of personal information.

Although there is a growing body of evidence as to the effectiveness of cognitive behavioural (Lindsay, 1999) and psychodynamic (Beail, 1995, in Hollins and Sinason, 2000) therapy with this client group, there is currently little or no research which considers the use of these therapies with individuals who have been sexually abused (Moss, 1998). Therefore, although recognition of the possibility of one-to-one therapy in this client group is growing, there is still a long way to go. Indeed, Sequeira et al. (2003) found that 61% of their sample of abused individuals had received no formal psychological therapy. This may be because evidence of its effectiveness is required before government funding is allocated, or it may reflect a lack of knowledge amongst potential referrers that this type of intervention may be appropriate.

In the area of child sexual abuse, there is a significant amount of evidence suggesting that support of parents and alleviation of their distress is an important factor in alleviating symptoms in children (Saywitz, Mannarino, Berliner and Cohen, 2000). O’Callaghan, Murphy and Clare (2003) describe the impact on the parents of their child with learning disabilities being sexually abused. They blamed themselves for exposing their child to abuse and for not responding to the indicators quickly enough. Feelings of guilt and anger, as well as depression and a loss of trust in statutory authorities were also seen. This research, as well as the growing literature on the use of family therapy with families with a child with a learning disability (Goldberg, Magrill, Hale, Damaskinidou, Paul and Tham, 1995), suggests that this approach could also be used.

People with Learning Disabilities Essay
Preventative

As well as offering reactive interventions, clinical psychologists can work to prevent abuse from occurring by addressing areas of individual vulnerability. For example, McCabe, Cummins and Reid (1994) found that people with learning disabilities had lower levels of sexual knowledge than those without a disability, which may lead to a lack of confidence in taking control of their own body and sexuality. Indeed they found that 36% of their participants believed that someone else was responsible for deciding if they have sex. McCarthy (1996) reports that in her experience of working with women with learning disabilities sexual pleasure is rarely reported, with many women having 'difficulty understanding the very concept' (p123). Sex education programmes have an important role to play, and packages such as Sex and the 3Rs (McCarthy and Thompson, 1993) can be used to promote discussion and learning about the act of sex, safe sex, issues of consent, and the fact that sexual activity can be pleasurable for both parties.

Khemka (2000) suggests that individuals with learning disabilities are at greater risk of exploitation because of their limited ability to make decisions in interpersonal situations in which abuse may arise. This is attributed to a cognitive difficulty in weighing up costs and benefits of different courses of action, as well as low confidence in decision making, and a perception of having little control over the outside environment. Individuals who received cognitive problem solving training showed an improved ability to make decisions that would minimise abuse, and a greater internal locus of control. Another group received similar training but it was designed to improve awareness of decision making capability, personal values and control, and they showed greater benefits. Although the generalisation of the problem solving skills to ‘real life’ was not assessed, the findings are positive in terms of improving the individual’s sense of self-efficacy.

A final area of vulnerability was highlighted by McCabe et al. (1994), who found that although 73% of their sample of adults with learning disabilities knew that they could say no to unwanted sexual contact, 46% did not know how, and 36% didn’t know what to do if they had been abused. Lee and Tang (1998) describe the use of the Behavioral Skills Training Program (Wurtele, 1986, as cited in Lee and Tang, 1998), to address this issue.
with female children with learning disabilities. This programme involves seeing, modelling and practising responding verbally in abusive situations, getting away from these situations, and telling someone about the abuse. The children showed greater knowledge of sexual abuse and better self-protection skills than a control group, and the skills were maintained after 2 months. However, many of them remained inconsistent in the use of these skills and it was not possible to gauge the extent to which they would be generalised. This was successfully addressed by Miltenberger, Roberts, Ellingson, Galensky, Rapp, Long & Lumley (1999), who carried out a similar programme which also included in situ training.

Role with perpetrators

Turk and Brown (1993) found that 42% of the perpetrators of sexual abuse in their survey were male service users. A number of explanations have been put forward for this high percentage. People with learning disabilities may be less able to 'cover up' their actions, or may have more access to potential victims (McCarthy, 1996). Charman and Clare (1992) suggest that men with learning disabilities have poor knowledge of the laws and social rules relating to sexual behaviour and so carry out abusive acts without understanding the psychological and legal consequences. This may in part be due the fact that services currently demonstrate 'gross mismanagement of risk with sparse attempts at treatment' (Thompson, 1997, p135), such that 'minor' incidences often provoke no reaction and men with learning disabilities receive mixed messages about what is acceptable or not. Following on from this hypothesis, Charman and Clare (1992) ran an educational group for men with learning disabilities who had committed sexual offences. There were indeed gaps in their knowledge about laws, some members had difficulty identifying fear in a picture of a woman being victimised, and some were unclear about consent and the right to withdraw it. Unfortunately the authors did not determine whether attending the group improved the individuals' knowledge, or indeed whether the lack of knowledge was linked to their inappropriate behaviours. However, they suggest that men with learning disabilities have the right to have this knowledge, and felt that the group was a useful way for people to begin to address their offences. McCarthy (1996) suggests
that all sex education for males should include education as to the right of sexual partners to not be exploited as well as considering their own rights.

A clinical psychologist may be involved in reactive intervention with perpetrators of sexual abuse, with one goal being the prevention of reoffending. A care plan should be developed which outlines the supervision needs of the individual, but it should also include plans for the assessment of their psychological and social needs, and consideration of their activity level. Support should be provided in these areas where necessary.

**Roles at a broader level**

Much of the research into preventative interventions at a client level was carried out with individuals with mild learning disabilities. Ways to enable more disabled individuals to act assertively and understand whether behaviour is acceptable or not should be explored. However, it may be that for these individuals more responsibility needs to be taken at a staffing or service level. Unfortunately, research suggests that there are major shortcomings in current service provision. For example, Turk and Brown (1993) found that the services they studied had inadequate policies in place for addressing the issue of sexual abuse. The majority of cases were raised by the disclosure of the client, which highlights the issue of how and if abuse is detected in those who do not or cannot report it. Records of abusive incidents, if made, tended to be vaguely worded or ambiguous, which limits their usefulness in court proceedings and lessens the possibility of monitoring clients vulnerable to being abused or abusing. Finally, in just under half of the cases reported, no action was taken against the perpetrator, giving the message to both perpetrator and victim that sexual abuse is acceptable and normal. Clinical psychology has a role in influencing those who make policy decisions to ensure they minimise the possibility of abuse, improve its identification, and ensure appropriate steps are taken when it is suspected or discovered.

Hogg, Campbell, Cullen and Hudson (2001) suggest that for policies to be effective staff must be aware of their responsibilities and be able to recognise and understand sexual abuse and the contexts in which it may occur. They therefore ran a
staff training course covering a broad range of topics, including definition, indicators and consequences of abuse, as well as information about their role and the procedures to follow in cases of abuse. After the course staff showed improved knowledge, in some cases from an initially very low level, and had greater confidence in their ability to act appropriately if the issue arose. Although the impact on practice was not assessed, it is likely that this improvement in knowledge would have a positive impact on service delivery.

As well as addressing issues of limited knowledge, the training was designed to change any staff attitudes which would increase the likelihood of abuse being ignored, accepted or perpetrated. The importance of influencing staff attitudes is highlighted by Wardhaugh and Wilding (1993), who describe a perception of people with learning disabilities as being 'less than human'. This could lead to a misguided justification of abuse of people with learning disabilities where they are thought not to suffer, or are thought to be of lower status so do not deserve respect. Even the more benevolent but equally misguided attitude that people with learning disabilities are childlike may promote abuse, as staff members may be unwilling to accept that potentially abusive sexual behaviour is occurring. Training that challenges such beliefs is therefore vital.

White et al. (2003) suggest that as well as targeting perpetrators, the multi-faceted context in which abuse occurs should be addressed. They highlight the importance of competent and available management, adequate staffing levels and a consistent team. They also suggest that a system should be open to external monitoring and evaluation. Wardhaugh and Wilding (1993) describe a dangerous relationship between organisational structure and abuse, in which staff that feel powerless in the system assert the power they have over clients in an abusive way. This may also be seen in clients, whereby vulnerable clients become targets for other clients attempting to gain a sense of control over their situation. A clinical psychologist working in a service that they feel is abusive or is at risk of promoting or sustaining abusive behaviour has a responsibility as a 'whistle-blower' to the appropriate level of management. They can also offer systemic understanding and intervention to a team, or guidance at a management level as to how to create a therapeutic and effective team.

People with Learning Disabilities Essay
Thus far consideration has been given to the role of the psychologist within the caring systems in which people with learning disabilities live. However, the attitudes seen within broader society will also have an impact on their lives. Podell, Kastner and Kastner (1996) found that undergraduates perceived a learning disabled female victim as being less likely to have been harmed than a non-disabled female when she had acted in an ‘encouraging’ way in an abusive sexual encounter, and that she was less responsible for her actions. They also found that learning disabled perpetrators of abuse were perceived as less responsible for their actions than non-disabled perpetrators. These views would have an impact on the verdict if these participants made up a jury or were working in the judicial system. A clinical psychologist may therefore have a role in educating people as to the ‘normality’ of the emotional needs and responses of people with learning disabilities, as well as the impact of their cognitive limitations on their functioning.

**Personal considerations**

Beliefs and assumptions about people with learning disabilities, and about issues of sexuality vary between cultures. Research and literature with reference to anything other than a white western cultural background is extremely limited, but very valuable. For example, the sexual abuse prevention programme described by Lee and Tang (1998) was carried out in Hong Kong. They describe a background of sexual abuse as a taboo in Chinese culture, and a suppression of sexuality which may impact on people’s comfortableness with discussing sexual experiences, including abusive ones. They report that the western training programme was successfully used within this population. However, they do not describe whether they encountered problems with resistance of parents or services, or suggest how they may be resolved. Miles (1996) reviews the issues that arise in Pakistan, and highlights the fact that ‘public discussion of...sexual abuse and the sexuality of mentally handicapped people is unwelcome in Pakistan, as in some other Asian and Muslim nations’ (p263). Sex education is thought to be at best unnecessary and at worst encouraging. This is sometimes resolved by offering ‘modesty education’, which covers personal hygiene, bodily changes and appropriate social
behaviour. He suggests that an informal and slow approach is the most effective way in working with people from a culture with these strong beliefs. Cambridge and Mellan (2000) also emphasise the importance of considering the rights, preferences, health and safety of the individual as well as being sensitive to their cultural background. As well as considering the assumptions and beliefs of clients and staff teams, Podell et al. (1996) suggest that we as psychologists are not immune to the views they found in society that people with learning disabilities are less responsible and less ‘harmable’ than non-disabled people. We should therefore consider the impact of our own beliefs and assumptions on our work.

The emotions that are provoked by working in this potentially distressing area should also be considered. People working with issues of sexual abuse may experience feelings of sadness or anger that abuse has taken place, or shock or disgust at the nature of the abuse. Treading the tightrope between restricting an individual’s freedom and exposing them to an unacceptable level of risk is potentially very stressful. Decisions and clinical judgements are made that are likely to have a large impact on the lives of clients, and the awareness of this responsibility is daunting. There is also a backdrop of awareness that one's own actions may be subjected to a high level of scrutiny if a case goes to court, and that there is a potential of prosecution. McCabe et al. (1994) suggest that a comprehensive and team approach is necessary in order that responsibility is shared. It is also vital that feelings and emotions are acknowledged, as they may affect relationships with clients or within a staff team, as well as impacting on individual well-being. Supervision is vital in addressing the ethical and personal issues that arise. A clinical psychologist may offer supervision to care staff or other professionals, but also has the responsibility for ensuring they themselves access supervision from peers or specialists.

**Conclusion**

This essay has demonstrated that a clinical psychologist can take a number of roles when working with people with learning disabilities who have been sexually abused. This may be at an early stage, where cases of suspected abuse are being
investigated, or assessment of the impact of abuse is necessary. Clinical judgements of an individual’s capacity to consent, or to take part in a court case may be required. It may also be necessary to offer psychological interventions to victims of abuse. As well as reactive work, preventative work to protect what is a very vulnerable group may also be carried out by a clinical psychologist. This may be at an individual level with potential victims or perpetrators of abuse, or at a service level by addressing the contexts in which abuse occurs.

It has been shown that there are many shortcomings in current practice that mean that individuals with learning disabilities are not being sufficiently protected from the risk of sexual abuse. Brown and Thompson (1997) suggest that the lack of a clear definition of what constitutes sexual abuse is acting as a barrier to proper assessment in cases of abuse, management of these cases, and the provision of clinical intervention. There is also a significantly limited research base as to the nature of the issues that surround sexual abuse, and the effectiveness of interventions intended to address these issues.

As well as contending with limited service provision for issues of sexual abuse, people with learning disabilities exist within a society in which they are given little respect. As Moss (1998) states, ‘We only protect the things we value’ (p180), so the low self-esteem of this group may lead to negative expectations of what life should be like. In particular, people with learning disabilities are often not seen as sexual beings, and so have little understanding of sex, or low expectations of it. McCarthy (1996) describes ‘grey areas’ of sexual experience which arise from this. She interviewed women with learning disabilities and found that they gained no pleasure from sex, and many experienced discomfort and pain. However, they continued to engage in sexual activity to satisfy men’s wishes, and for secondary gain such as the self-esteem of being in a relationship or material possessions such as cigarettes. Whether this is abusive or not is a matter of personal opinion, but it is unarguably a sad reflection of the reality of the sexual lives of women with learning disabilities.

Although the picture painted is negative, the research that does exist is hopeful as to the potential effectiveness of work in this area. The shortcomings and issues that have been highlighted will surely provoke action at a government level, as well as a growing
awareness in people who work with individuals with learning disabilities and the broader society. Psychological interventions and new ways of working have been developed and found to be effective. An encouraging article by Green (2001) includes the reaction of an individual to the successful bringing to justice of her abuser: ‘If I hadn’t gone to court, it would all still be in my head – now it’s gone and clear’. It is towards these outcomes that a clinical psychologist should strive.
References


People with Learning Disabilities Essay


People with Learning Disabilities Essay


“Divorce is bad for children”. Critically discuss with reference to the literature on the psychological effects on children of divorce and parental conflict.

November 2004 - Year 2
Child and Family Essay
Introduction

The divorce rate in Britain has increased steadily since the beginning of the twentieth century. The Office for National Statistics (n.d., a) found that in 1999, there were 13 divorces for every 1000 married people, as compared to 0.1 in 1901-1905 (Rodgers & Pryor, 1998). This growing divorce rate has been mirrored by an increasing volume of research about the impact of divorce on children. This is clearly an important area of study, considering that in 2003 just over 153,000 children had experienced their parents’ divorce (Office for National Statistics, n.d., b). In this essay the many varied outcomes of divorce for children that have been reported will be considered. These vary from extremely negative (e.g. higher use of mental health services and shortened life spans, Larson, Larson & Swyers, 1999) to positive (e.g. increased sense of independence, Amato, 1987). Similarly some researchers argue that divorce will cause ‘psychic trauma’ to a child, suggesting that it plays a central role in their development (Wallerstein, 1991), while others argue that it should be ‘decentred’ and considered alongside other ‘pressing concerns’ that young people experience (Flowerdew & Neale, 2003). Descriptions of the conclusions drawn as well as methodological issues which may call these into question will be outlined.

Much of the research has found that the impact of divorce varies according to the presence or absence of mediating factors. One such factor is verbal or physical conflict in the parental relationship, which is proposed to have both a direct effect (Moffit & Caspi, 1998) and an indirect effect on children, for example through the impact it has on the parent-child relationship (Amato & Sobolewski, 2001). A second factor that impacts on the outcome of a divorce is the presence of support for the child through inter-familial relationships including step-family relationships, as well as at a wider community level. In addition, divorce will have different meanings and impacts on children of different ages and stages of development. These three factors will be explored in the second part of the essay. Other factors have also arisen in the literature, for example gender and personality of the child, and changes in financial and social status. The research provides complex and sometimes conflictual evidence regarding the impact of these and it is therefore not possible within the constraints of this essay to discuss them in detail.
Rather than defining divorce as 'Bad' or alternatively 'Good', the final section of the essay will consider the challenges that arise for a child in the context of their parents divorcing, and draw together the factors which may aid or hinder the overcoming of these challenges. Understanding divorce as a process of change is felt to be more useful than considering it as a discrete event which can be judged as having a positive or negative impact.

**Outcomes**

**Large scale longitudinal studies**

A substantial amount of information in this area has been generated through large scale longitudinal studies. A key researcher is Judith Wallerstein, who was involved in the California Children of Divorce Study. This study followed children over a period of 25 years following their parents divorce when they were aged between 3 and 18. This research was carried out using a psychodynamic theoretical framework, whereby clinical interviews were carried out with children at a number of stages. Ongoing feelings of depression, sorrowfulness about ‘emotional and economic deprivation’, anger, worry and resentment are reported (Wallerstein, 1991). Behaviours such as engagement in multiple short term sexual relationships and aggression as well as underachievement are also described. In addition, Wallerstein (1991) highlighted the presence of a ‘sleeper effect’ which means that the full impact of divorce is not experienced until the child goes on to begin their intimate relationships, when they will have extreme anxiety about betrayal or not being loved. However, the research also highlights that for some these negative effects are not seen, with participants reporting pride in their greater maturity and independence and the researchers seeing them as ‘competent people’ (Wallerstein, 1991). Protective factors that accounted for these positive outcomes were thought to be a close relationship with one parent or the inner resources of the child.

Significant criticisms have been levelled against the research methodology used in this study. The families involved were largely white, middle class and educated, and they were recruited by offering counselling in return for participation. The children were screened for psychological disturbance but the parents weren’t and between 15-20% of
them were ‘severely disturbed’ (Elliott, Ochiltree, Richards, Sinclair & Tasker, 1990). This is clearly a skewed sample. A second criticism is of the conclusion of causality that has been reached. There was no comparison group until the final follow up (Wallerstein & Lewis, 2004) which makes it hard to conclude that the outcomes would only be seen in a population of children of divorced parents. There was no measure of the nature of the parents’ relationship pre-divorce and the divorce process, and there is also an assumption that no other life events occurred over the course of the study. All of these may provide a different account for the outcomes seen. Finally, the papers have a negative and somewhat blaming tone. For example, a description is given of ‘parental failure to sustain love and commitment’ (Wallerstein, 1991, pp.354).

A second researcher who has contributed significantly to the literature on divorce is E. Mavis Hetherington, through her involvement in the Virginia Longitudinal study of Divorce and Remarriage. Again, this used a narrow population of white middle class families although comparison groups of non-divorced families were used. Data was gathered from interviews and questionnaires with family members, teachers and peers, as well as observations at home and school. The effects of remarriage were also considered. Hetherington (2003) describes that in the two years immediately following divorce, most children showed more non-compliant behaviour, anxiety, depression, and difficulties in social relationships than those from non-divorced families. After this time, these problems resolved for many children, although for some they endured. She also found evidence for a delayed effect where there was a greater level of early sexual activity and delinquent behaviour in adolescent children of divorced parents. Hetherington (1989, 2003) found that children could be grouped into ‘clusters’. Six years after divorce, these could be labelled 1) ‘aggressive insecure’; 2) ‘opportunistic competent’; and 3) ‘caring competent’. Children from remarried families who had experienced high levels of conflict in the family were overrepresented in the ‘aggressive insecure’ group which was characterised by behavioural problems and unpopularity amongst peers. Children from divorced families were overrepresented in the ‘opportunistic’ group. They were popular and high in self esteem, and tended to be oriented to adults and peers in power. They tended to have had a close relationship with only one parent and had used conflict
between their parents for their own gains. Girls from single-mother headed families were over-represented in the ‘caring’ group. They too were high in self-esteem and popular, but had more stable friendships and often befriended neglected children. They had often had to assume familial responsibilities at a young age and had been encouraged to be independent. Similar clusters were seen eleven years after divorce with the addition of a ‘competent at a cost’ group, who appeared similar to the ‘caring competent’ group, but had lower self-esteem and higher anxiety. They too were found to have had greater responsibilities as children, but the demands placed upon them were felt to have been too high.

Studies of adult attachment style

Although these two large scale projects were quite different in their approaches, both discussed the presence a ‘sleeper effect’ of divorce which is only seen when adolescents begin to establish intimate love relationships. This has been considered from an attachment perspective (Hazan and Shaver, 1987) whereby children’s ‘internal working models’ of themselves and others are thought to lead them to develop secure or insecure attachment styles which are related to the relationship styles seen in adulthood. Hayashi and Strickland (1998) looked at the attachments that young adults’ had both with their parents and in their love relationships. They found that there was no relationship between parental divorce and these attachments. However, young adults’ insecurity in their current love relationships could be predicted by protracted interparental conflict and security was predicted by growing up with an accepting parent or parent-substitute.

Walker and Ehrenberg (1998) only included adolescents with divorced parents in their study. They found that a significant number of them described insecure attachment styles, and that this was related to their perceptions of why their parents divorced. Insecurely attached individuals were more likely than secure individuals to report overt anger between their parents, being involved in conflict, and extramarital affairs. Securely attached individuals tended not to emphasise any one reason for their parents divorce. These studies taken together suggest that the context of divorce and the individual child’s perception of it are more predictive of adult attachment styles than divorce itself.

Child and Adolescent Essay
Children’s self-report

A criticism that has been levelled at the research in this area is that it does not include the voices of the children who have experienced divorce. Moxnes (2003) highlighted the importance of research of this type, suggesting that the concerns of adults do not necessarily reflect the concerns of children. She interviewed 8-18 year olds and found that the relationship they had with their parents was key in many of the accounts. Most children did not report that changes in family structure were the most troubling part of divorce, but rather the lack of understanding or help from their parents in managing these changes. The majority of children reported a positive outcome of the divorce in terms of an improved relationship with their residential parent, who they felt they knew better and respected more. Negative outcome was associated with a ‘role-reversal’ of parent and child and a loss of respect for the parent. Another key issue raised by children was the extent of their involvement in the decision making around divorce. Children who felt that issues of visitation and changes of residence were a shared family concern fared better than those who blamed their parents and had no sense of control in their situation.

Flowerdew and Neale (2003) suggest that research that does not directly consult the child risks characterising them as passive receivers of outcome. They interviewed 11-17 year old children in divorced families and found that they gave ‘broadly positive’ accounts of the divorce associated transitions, for example recognising that they had developed increased resources for coping with change. When transitions were problematic it was because the pace of change was fast, they were experiencing a number of transitions at once, or they came at a time when they did not feel able to cope with them. A number of children actually questioned the focus of the research study, suggesting that more interesting changes were occurring to them outside of family life. One such participant stated ‘I think it’s strange to be singling people out to talk about this...It’s not awkward for me but I do feel it’s unnecessary’ (pp.158). This can be contrasted with the statement made by Wallerstein (1991), that the children in her study ‘showed strongly that they continued to regard their parents divorce as the major formative experience of their lives’ (pp.353). Clearly there is much to be gained by talking to a non-clinical sample of children experiencing divorce.

Child and Adolescent Essay
Mediating factors

Conflict

Regardless of the methodology used, one point on which much of the research in this area agrees is that the level of conflict in the parental relationship has a significant impact on the well-being of the children. This has been seen in terms of behavioural and emotional problems in the short term as well as long-term attachment difficulties (e.g. Hetherington, 2003; Walker & Ehrenberg, 1998). Gohm, Oishi, Darlington and Diener (1998) carried out a large scale cross-cultural study and found that the association between conflict and adult children’s life satisfaction and affective experiences was consistent across gender and culture. Moxnes (2003) found that in her interviews with children, parental arguments or violence appeared to be the most difficult theme that arose, arousing feelings of sadness and anger.

Clearly these findings are very robust. Indeed, Gohm et al. (1998) found that the level of marital conflict was more strongly related to adult children’s life satisfaction than marital status. For some this may suggest a conclusion that if conflict within a marriage is high, then the children will do better if the parents divorce. However, Hetherington (1999) warns against such an assumption, and suggests that it is important to consider 1) the nature of the parental conflict and 2) whether divorce will result in a lessening of conflict. These factors are considered below.

Firstly, in considering the nature of the conflict, Hetherington (1999) suggests that conflict about or involving the child and physically violent conflict are the most detrimental. Blow and Daniel (2002) provide a useful way of understanding the experience of the child who is aware that their parents’ conflict is about them, describing how they are central to the dispute yet they are ‘utterly powerless’ to influence it. Moffitt and Caspi (1998) considered the impact of inter-parental violence, highlighting the fact that witnessing parental aggression in early childhood is related to the development of conduct problems and discussing routes by which this may occur. It may have a direct effect, in that children learn that violence is an acceptable and effective way of resolving differences and exerting control. Alternatively, it may generate extreme stress in a child which they communicate verbally or behaviourally. Finally, it may
disrupt the quality of parenting that the child receives. It is worth noting that all of these routes would still have an effect even if the child did not directly witness the violence. At the other end of the spectrum, Cummings and Davies (2002) found that the degree to which conflict had been satisfactorily resolved for both parents was proportionally related to a reduction in children’s distress.

Secondly, in considering the effect of the divorce on the conflict, Hetherington (1999) suggests that it is a mistake to think that divorce will result in a reduction of conflict in a relationship. In fact, immediately post-divorce it is likely that discussions around parental roles and responsibilities and financial issues will be taking place, which are likely to be emotional if not conflictual. Amato, Loomis and Booth (1995) found that this factor was vital in predicting outcome for children. When divorce was associated with a move to a more harmonious setting, children showed the same levels of adjustment as those with harmoniously married parents and significantly fewer emotional and behavioural problems than those with highly conflictually married parents. For these children, divorce had a positive effect. However, when divorce was associated with increased levels of conflict and stress, children fared less well even than children with married parents who were highly conflictual. For these children, divorce had a negative impact. Hetherington (1999) suggests that this may be because when conflict occurs within the context of a marriage both parents can act as a support to the child, whereas a single parent may be under too much pressure to offer such support.

This research clearly highlights that while conflict does indeed have a negative impact on children, the extent of this varies according to its nature and the outcome.

Interfamilial relationships

In a longitudinal study, Amato and Sobolewski (2001) found no direct relationship between divorce and marital discord on the psychological well-being of the child 17 years later. Instead, these effects were mediated by the quality of the relationship between the parent and the child both at the time of the divorce and when the child was an adult (see diagram). They suggest that marital conflict and divorce may affect parenting quality and the ability of parents to be supportive of their children as they grow up.
Figure 1: Arrows indicate a significant relationship between factors
(Simplified from diagram in Amato & Sobolewski, 2001)

This assertion is supported by Hetherington (2003) who found that parenting quality typically deteriorated after a divorce, becoming less authoritative and more characterised by coercion and lack of communication. However, this was relatively short-lived and resolved as the parent adjusted to the divorce. Clearly a divorce will impact on the parent-child relationship in some way, although this is not always negative. For example, on the NCH website (www.itsnotyourfault.org) children state how divorce has had a positive impact on their relationship: 'When you’re not together all the time, it can sort of make it better when you do see each other'.

As well as considering parent-child relationships, Hetherington (1989) also highlighted the role of other family members, describing how grandparents can be a useful resource in offering emotional and practical support to the divorced parent. Siblings were also seen as a potential supportive resource, although rivalry and aggression between siblings was not uncommon.
Stepfamilies

For many children who experience divorce, the subsequent negotiation of relationships within a step-family will be necessary. ChildLine (www.childline.org.uk) report that in 2000/2001 they received over 15000 calls from children to talk about family relationships, many of these involving step-family issues. These included jealousy about time and money spent on the step-parent or step-siblings and guilt about liking parents’ new partners. On the website one child reports difficulties with being disciplined by her step-father: ‘He seems to think he can tell me what to do, but he hasn’t got the right. He isn’t my real Dad’. Hetherington (1989) found that this complaint isn’t uncommon: while in non-divorced families, closeness of the parents and joint involvement in child-rearing was related to a positive parent-child relationship, the opposite was seen in step-families. Step-father’s involvement in parenting was related to high levels of conflict between the child and both their natural mother and the step-father. This relates to the finding of Moxnes (2003) that those with residential step-parents coped better than those with non-residential step-parents. Although living with a step-parent is potentially a closer relationship, children had had more involvement in the negotiation of how the step-parent became involved in the life of their home, and were consequently more satisfied.

As Hetherington (1989) states, it seems that step-parents who initially make no attempt to shape their step-child’s behaviour are best accepted by them. However, she found that the behaviour of the step-parent is only one of the factors involved in determining a child’s adjustment to a new family. She describes significant gender differences, whereby sons were more distressed when living with their single mother, but daughters had significantly more problems when their mother remarried. She suggests that for the sons, their relationship with their mother is so poor that there is nothing to be lost by her remarriage. However, for daughters who have established a good relationship with their mother, the addition of a step-father is likely to threaten this relationship.

Although children clearly have difficulties in accepting changes in their family relationships, Moxnes (2003) found that children could also recognise the potential benefit of the acquisition of a step-family, for example through increasing family income or by providing emotional support for their parent.
Cultural context

As well as considering the mediating effects of family relationships on the impact of divorce, it is also important to take into account the cultural context in which the divorce occurs. Elliott et al. (1990) suggest that 'it is the attitudes to divorce that colour views of the consequences for children' (pp.309). They propose that the dominance of the negative findings of large scale research may contribute to an unnecessarily negative view of divorce held by society. Indeed, cognitive theory suggests that it is not the event itself that causes distress, but the meaning of that event to the individual. It follows that divorce may have a different impact depending on the beliefs held by the individuals involved as well as those that are held in their cultural context. Unfortunately, much of the research in this area has been carried out using a white Western population but a few studies exist that support this hypothesis.

Cohen and Savaya (2003) found that divorced Muslim Arab citizens of Israel who were disinclined to perceive divorced persons as bad parents and spouses and as socially deviant were better adjusted to their divorce. These beliefs are contrary to the social stereotypes held in this community, and the authors suggest that the better adjustment may be because they are part of a more accepting sub-group of the community, or they may have internalised the beliefs of their culture to a lesser extent. Although this study was carried out with adults experiencing divorce, it could be postulated that children of divorced parents will also be affected by internal or external cultural influences.

Gohm et al. (1998) considered the impact of divorce on children in countries with differing divorce rates, suggesting that these may reflect varying levels of normality and therefore acceptability of divorce. Interestingly they found that in countries with a low divorce rate, there was no significant difference between the life satisfaction of adults of divorced parents and adults of married parents. Conversely, in countries with a high divorce rate, adults with divorced parents were less satisfied with life than their counterparts with married parents. These unexpected results may reflect different levels of dissatisfaction that had to be reached before a marriage could be considered 'over' whereby in countries with low levels of divorce, the marital difficulties may have been more evident to the children hence they felt relief when the marriage dissolved. Gohm et
al. (1998) also considered the differences in impact of divorce on children in individualist and collectivist cultures. They found that living in a collectivist culture appeared to act as a ‘buffer’ against the negative effects of divorce and remarriage seen in the individualist cultures. They suggest that this occurs due to the presence of social support for the mother and children.

Age

A final factor that has been considered in the research is that of the age of the child when divorce occurs. Clearly children of different ages have very different needs, and it therefore follows that any disruption caused by a divorce would have a different impact according to the stage at which these disruptions occur.

Pruett and Pruett (1999) considered the impact of divorce on children at a preschool age. They describe how these children are at a developmental stage which is typified by a need for familiarity and stability. However, consistency may be compromised by practical or emotional changes associated with a divorce. Using semi-structured play interviews they assessed under-6 year olds’ understanding of divorce. They found that the children had developed understandings based on what they had been told as well as through overheard conversations and things seen on television. Key issues that arose were of sadness and loss: ‘Divorce is when your Mum and Dad hate each other and your family is dead’ (pp.1547). Fear of abandonment or separation was seen in games about being kidnapped or lost, and there was a sense of confusion. Jenkins and Buccioni (2000) found that five-year olds are more likely to understand conflict and separation in a self-blaming way rather than believing it is about divergent goals, which is clearly more distressing.

Robey, Cohen and Epstein (1988) considered an area of distress for slightly older children of 8-12. They found that children hold a theory that ‘positive regard [e.g. attention, recognition] is a divisible substance of limited supply’ (pp.2). They may therefore perceive a newly single or a newly married parent to have new demands on them which necessarily reduce the amount of positive regard ‘left’ for them. Indeed, children of divorced parents rated the ‘non-recipient’ of positive regard in hypothetical
triads as more distressed by this than children of non-divorced parents did. Their experiences of their parents going through a divorce may have given them supportive evidence for their theory.

Interestingly, the children in this research did not rate mothers in the hypothetical situations as experiencing the same deprivation as children would. They authors suggest that they view their mothers as ‘suppliers’ of affection as opposed to ‘consumers’. If this is the case then older children who are more aware of the need of their parents for affection may be more acutely aware of the emotional distress that their parents go through in divorce. Amato and Sobolewski (2001) suggest that the significance of divorce for older children and adolescents may also centre on the fact that their parents are less available at a time when they are making big decisions regarding education or career. They may require emotional support in going through puberty, or financial assistance, both of which may be limited by the process of divorce.

Challenges

Divorce clearly has a very different impact on children depending on many contextual factors. Rather than judging the impact as negative or positive it is perhaps more useful to consider the challenges that arise for children in the context of their parents divorcing. Wallerstein (1983) suggests that when a child’s parents divorce, they have to master six inter-related hierarchical ‘coping tasks’ in addition to facing the normative challenges of growing up. The first of these is ‘Acknowledging the reality of the marital rupture’, in which a child will need some level of understanding of the changes occurring and be able to separate this from their imagined reality. As Pruett and Pruett (1999) found, children ‘hungered for trustworthy information regarding divorce’ (pp.1548), suggesting that open and honest communication between parents and children is vital and may help to alleviate feelings of fear and denial. The second task described is ‘Disengaging from parental conflict and distress and resuming customary pursuits’, which Wallerstein suggests is necessary in order that a child can safeguard their own identity. This may be made more difficult if a child has had to relocate and therefore make new friendships, and support and encouragement is essential. The third task is

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Resolution of loss, which includes loss of one parent from the family, the loss of the familiar and maybe material losses. Amato and Sobolewski (2001) suggest that positive involvement of both parents in children's lives following divorce should be promoted, and this indeed would reduce the sense of loss of a parent. Related to this is the fourth task of Resolving anger and self blame, which Wallerstein suggests is made more difficult by the fact that the loss is the result of a voluntary decision which may lead to resentment and blame on the part of the child. This may be made worse if blame also exists in the parental relationship, and it may be necessary to resolve this through mediation such as that described by Blow and Daniel (2002). The fifth task described is Accepting the permanence of the divorce, which can be seen to closely relate to the tasks described above. Kurdek and Siesky (1980) found that children were more likely to accept their parents' divorce as final if they understood it in a clear and non-blaming way in terms of psychological separation. The final task is Achieving realistic hope regarding relationships through developing a willingness to 'take a chance' on trusting and loving while knowing about the uncertainty of relationships. It may be that seeing a parental model of compromise and empathy in spite of differences would support the mastery of this task. When considering this model, the suggestion made by Moxnes (2003) that 'extensive parental co-operation' is the most important protective factor for children of divorce is very relevant: parent-child and interparental communication would help to achieve mastery of each of the tasks described.

Conclusion

This essay has described a large amount of research that has been carried out to determine the effects of parental divorce on children. Longitudinal and cross sectional studies have highlighted short and long term negative effects with increased emotional and behavioural difficulties in children whose parents have divorced. However, some of these studies reach questionable conclusions considering that there are limitations of generalisability due to narrow samples and selection criteria, and there are also issues around determining causality. Studies where children reported on their experiences of divorce themselves showed that they struggled when they felt unsupported or uninvolved.
in the negotiation of changes surrounding the divorce. However, broadly positive accounts were given, highlighting improved relationships with parents and improved ability to cope with change. In fact, some children minimised the significance of the divorce to their lives, suggesting that it had had a negligible impact.

When considered in more detail, research evidence suggests that a number of factors mediate the impact of divorce on children’s well-being. For example, the presence of conflict, particularly violent conflict or that involving the child increases the likelihood of distress. Other factors act as buffers, for example a positive parent-child relationship or a supportive and accepting cultural context. The age of the child at the time of divorce may also affect the nature and extent of its impact. Finally, the fact that a divorce may lead to the subsequent creation of a step-family has been discussed, and the particular issues that arise as a result of this have been considered.

The assertion that ‘Divorce is bad for children’ does not allow for this complexity so clearly described in the literature, including evidence of positive outcome for children. However, as Amato and Sobolewski (2001) state, ‘Because divorce is common and widely accepted...does not mean that its consequences for children are benign’ (pp.918). It is therefore concluded that it is more important to understand the challenges that a child of divorced parents will face. As Selina (n.d.) describes, the outcome of her parents’ divorce was that she ‘had to manage’. It is perhaps of greater clinical significance to consider not what the impact of divorce is, but to develop an increased body of research exploring how to increase children’s resources and ability to master these challenges.
References


Child and Adolescent Essay


Discuss how psychological theory and therapy can make a contribution to working with issues of loss and bereavement in relation to older people.

To what extent do they accommodate issues of social and emotional context and issues of cultural diversity and difference?

August 2005 - Year 2
Older People Essay

NB. I have written this report in the first person as I feel that this style better supports self-reflection. I use the term 'older' as it has been defined in the studies I cite, so age cut-offs vary from 55 to 65.
**Introduction**

Grief has been described in many ways, from the basic definition of an ‘emotional response to loss’ (Raphael, 1984) to the symbolic description of a ‘hole inside that hurts’ (Bennett and Bennett, 2000). In this essay I will explore the experience of loss for older adults, focussing particularly on the experience of widowhood. Firstly I will outline the range of psychological and physical responses to widowhood in older adults that have been reported in quantitative and qualitative research.

In the second part of the essay I will consider the role of psychology in working with people who have experienced bereavement. This has been widely debated and questioned. Until the 1980’s, traditional theories of grief were widely used yet remained unsubstantiated with evidence (Wortman and Silver, 1989). Since then, numerous existing models have been applied to bereavement, as well as new theories being developed. It is beyond the scope of this essay to discuss these theories in depth, but I will present a brief outline of relevant models, as well as some challenges to the assumptions of the traditional theories.

Next I will explore some specific areas to which these theories have been applied with older adults, and the implications that they have for psychology input. I will consider how social context relates to bereavement outcomes. I will also discuss gender differences in responses to bereavement, and the impact of religion and existential factors on the experience of bereavement. Finally, I will present the views of widows and widowers themselves obtained using qualitative research approaches. From their own experiences they suggest what service input could be useful or unhelpful for bereaved people, which is vital information to add to the discussion about the role of psychology in this area.

**Responses to widowhood**

Research findings highlight an enormous breadth of psychological responses to widowhood in older adults. Qualitative studies exploring this experience have found that widow(er)s describe feelings of shock, sadness, anxiety and loneliness. They also discuss physical issues that began after the death of their spouse, for example, nausea, headache,
fatigue, and chest problems. Reminders of the loss such as significant dates and objects were especially hard to face and particular difficulties were reported with learning new skills, socialising in a world of couples ("even the birds are in twos", Bennett and Bennett, 2000, p243), health problems and financial worries. As well as these negative responses, widow(er)s also spoke of positive experiences. Some felt a sense of relief after many years of caring, others found some enjoyment in their new independence, and some gained confidence having learnt new skills and abilities (Anderson and Dimond, 1995; Rodgers, 2004; Bennett and Bennett, 2000). These descriptions are relatively consistent across all three studies, despite differences in cultural (White British, African American, White American) and religious (Mormon, Christian, non-religious) backgrounds of the interviewees.

Quantitative studies support this qualitative research, finding that bereavement is significantly related to feelings of depression, shock, anger and anxiety (e.g. Carr, 2004a) as well as illness and somatic symptoms such as headache, pain and nausea (e.g. Stroebe, Stroebe and Hanson, 1993). A different type of response is described by Xavier, Ferraz, Trentini, Freitas and Moriguchi (2002), who found that bereaved and grieving Brazilian older adults showed a higher occurrence of cognitive difficulties (memory, attention and language) than a non-bereaved group. A small number of researchers highlight a risk of suicide in bereaved older adults (e.g. Osgood, 1985, in Horacek, 1991). Interestingly, this area is somewhat under-researched, which may relate to a social taboo about suicide or to an ageist assumption that this group would not make such a decision. In the qualitative studies described above, only Bennett and Bennett (2000) describe what the authors name 'carelessness for life' in some widows. However, this was not suicide ideation, but a feeling that 'life doesn't matter', which related to reckless behaviour, illness, and loss of appetite.

It appears that some responses to widowhood are consistently seen in a number of cultural contexts. It may therefore be fair to expect similar experiences regardless of age. However, Horacek (1991) suggests a number of factors that mean that older adults may be differently affected by widowhood. Firstly, they are likely to be experiencing 'multiple losses', so that as well as losing their spouse, they may have lost friends or
relatives, and experienced loss of health, of income and roles. Secondly, they may suffer from societal expectations related to their loss, for example as death is more common in old age, people may expect older adults to be less upset by the death of their spouses as it was supposedly more anticipated. Thirdly, they may have fewer resources and supports to cope with a loss, with more physical difficulties and smaller social networks. Finally, some responses to bereavement such as confusion and cognitive difficulties may be mistaken for cognitive decline and even dementia, which could lead to inappropriate service responses.

**Psychological theories applied to bereavement**

For many years psychologists have attempted to make sense of these responses to bereavement. Freud (1917, from Horacek, 1991) developed an early theory of bereavement from a psychodynamic perspective. He understood love as an attachment of energy to the loved person. When the person dies these energy resources remain invested in them, causing grief responses. He suggested that it was important to sever this attachment in order to regain these energy resources, which could then be invested in other relationships. This could be achieved by ‘working through’ the grief by reviewing the past and dwelling on memories of the dead person. Lindemann (1944, from Horacek, 1991) also emphasised the importance of breaking the bond with the deceased, and described three stages of grief – shock and disbelief, acute mourning, and resolution of the process. He stated that this should take one or two years, with the initial grief responses lasting for four to six weeks. These ideas led to a number of stage theories of grief being developed (e.g. Bowlby, 1980, from Horacek, 1991).

A number of challenges to traditional theories such as these have been made. For example, Stroebe, Gergen, Gergen and Stroebe (1992) suggest that the concept of ‘breaking bonds’ to the deceased does not take into account cultural or historical context. They cite examples of different contexts in which retaining a bond to the bereaved is expected and encouraged, for example, through religious rituals in Japan and within the romantic era in Western culture. Similarly, Marwit and Klass (1995) found that their bereaved Western participants described a number of different roles that a deceased
A person continued to have in their lives – as a role model, giving guidance in specific situations, helping to clarify values, or remaining an important part of the survivors’ memories of their own life. In contrast, Stroebe et al. (1992) describe the Hopi Indian culture, in which the deceased are forgotten as quickly as possible as contact with death is to be feared. They conclude that dictating whether ties should be severed or retained without taking context into account is unhelpful.

Another challenge that has been made is to the idea that grief *can* be resolved. Lund (1989) reviewed studies of older widow(er)s and concluded that ‘there may never be a full resolution’ (p220). Bennett and Bennett (2000) quote a widow who stated that “You can’t spend years with someone and then just cast them aside” (p248), and suggest that bereavement should therefore be likened to an amputation. This analogy recognises that while the loss of a loved one can be coped with and adjusted to, it cannot be ‘resolved’.

Wortman and Silver (1989) provide a comprehensive review of these and other arguments, all of which relate to an underlying criticism of theory that dictates what is ‘normal’, and therefore what is pathological. Clearly these traditional theories are at best limited, and at worst lead to potentially damaging expectations being placed on the bereaved. More recently, several other theories have been applied to bereavement, which I outline below (see Bonanno and Kaltman, 1999, for a detailed discussion).

**Attachment theory**

Although the stage model of grief developed by Bowlby (1980, from Horacek, 1991) has been criticised, his understanding of grief in relation to attachment theory is valuable. He likened bereavement to separation anxiety, suggesting that behaviours such as protest, anger, and rumination about the dead person are an attempt to regain proximity to the ‘lost object’.

**Cognitive stress theories**

The cognitive stress perspective suggests that a life event is stressful because the perceived demands of the situation outweigh the perceived coping resources of an
individual (Lazarus and Folkman, 1984). Bereavement itself is stressful, but is also likely to relate to ‘secondary stressors’ such as financial difficulties and changing roles. Stroebe and Stroebe (1987) suggest that when a partner dies the survivor will also lose coping resources, namely the support previously provided by the deceased.

Social-functional approach
Emotion theorists suggest that the expression of emotion achieves functional ends. For example, anger helps to externalise blame, and sadness evokes helping responses in others. However, if experienced to an extreme or prolonged degree they may lead to less functional outcomes, for example causing rejection from others. Keltner and Bonanno (1997) found support for the latter part of this hypothesis for bereaved individuals, where strangers felt more frustrated viewing bereaved individuals who showed only negative emotion as compared to those who also laughed.

Trauma perspective
This perspective emphasises the meaning of the traumatic event, so bereavement is thought to challenge survivor’s core assumptions about themselves, the world, and other people. Janoff-Bulman (1992) suggests that three assumptions are held within Western society – that the world is benevolent, that the world is just and meaningful, and that the self is worthy. When someone dies, the survivor’s sense of control is threatened, and they are faced with the ‘terror of meaninglessness’. This perspective suggests that talking about the loss will enable cognitive restructuring and meaning-making, which reduces the impact of the trauma.

Dual Process Model (Stroebe and Schut, 1999)
This model characterises bereavement as being made up of two stressors – restoration orientation and loss orientation. Restoration orientation involves attending to life changes and dealing with these, and loss orientation involves avoiding or denying these restoration changes, ruminating about the deceased and crying. People ‘oscillate’ between the two processes, and this is necessary for adjustment over time. However, problems may occur
if people oscillate between processes without any control, or if people remain ‘stuck’ in one process to the detriment of the other.

**Social context**

The relationship between social support and bereavement responses has been extensively researched, with hypotheses that arise from several of these theories being tested. For example, a cognitive stress theory of bereavement predicts that social support will reduce the negative impact of bereavement by ‘buffering’ the stress that is caused by the loss. However, in a review of literature, Stroebe, Stroebe, Abakoumkin and Schut (1996) found only limited evidence supporting this hypothesis. In contrast, an attachment theory of bereavement predicts that social support cannot compensate for the loss of an attachment figure, and so will not reduce distress. Stroebe et al. (1996) found that while social support did have an impact on the degree of social loneliness felt by bereaved individuals, it did not affect their emotional loneliness, which gives support to the attachment hypothesis. Further, the effect of bereavement on depressive and somatic symptomatology was mediated entirely by emotional loneliness. Although carried out with a middle-aged population, this research has important implications for provision of services for bereaved older adults. In my clinical work with older adults, I have indeed had a sense that for clients who have experienced multiple bereavements, a referral to a day centre would not come close to filling the gap these bereavements had left. In addition, being aware that I will leave my placement in six months makes me concerned about the effects of creating a new attachment relationship with a client, only for them to lose it soon afterwards.

While the Stroebe et al. (1996) study appears to fit with my experience, it is important to consider the findings of slightly different studies - those exploring the relationship of pre-existing levels of support with bereavement outcomes. Norris and Murrell (1990) found pre-bereavement ‘embeddedness’ in a social network reduced the likelihood of depression in older bereaved widow(er)s, which supports a ‘buffering’ hypothesis. Li, Liang, Toler and Gu (2005) also found that pre-existing social support acted as a buffer against the negative effects of widowhood in Chinese older adults, but
they highlight an important cultural dimension to their findings: only pre-existing support from adult children had this effect, and not that given by friends. They attributed these findings to cultural factors: in Chinese culture friends are peripheral to the lives of elders, with much more emphasis placed on filial responsibility, which is somewhat different in Western culture, where social contact with non-family members for older adults is more common. These findings suggest that an important role for psychology services could be in a preventative capacity. Working to increase or strengthen the social support of older adults before bereavement has occurred may reduce the likelihood of it resulting in severe distress. It would be important to take cultural factors into account, for example, by considering whether it is more appropriate to work with family or a wider social network.

A number of researchers have considered where emotional support for bereaved individuals comes from. For example, some widow(er)s interviewed by Anderson & Dimond (1995) chose to talk to family members about their loss, while others talked to friends and others to members of the clergy. Walter (1996) suggests that the process of grief may be aided by talking to others who knew the deceased person in order to build up an understanding of who the person was. He highlights that this exchange of memories and discussion or debate about the dead person forms part of Jewish tradition. It also seems similar to the ‘storytelling’ that Rodgers (2004) suggests is an important aspect of grieving for African American widows.

There seems to be mixed feelings about emotional support provided by professionals. Rodgers (2004) found that some widows they interviewed found it helpful to talk to a professional about their loss. However, Walter (1996) claims that bereavement counselling is ‘a poor second best’ to talking to people who knew the dead person, and suggests that instead of providing counselling it may be more useful for professionals to help the bereaved identify and contact such people. The widows in the Bennett and Bennett (2000) study also suggest that counselling is not necessarily appropriate: ‘I didn’t want counselling, I wanted friendship’ (p246).

For some individuals, however, emotional support from professionals may be the only viable option. They may not have a social network to offer such support, or even if they do have they may not feel able to use it for fear of burdening people (Anderson &
Dimond, 1995). In addition, the social functional perspective of grief suggests that members of a social network may find it difficult to offer such support to a widow(er), particularly if they are displaying pervasive negative affect, so an initially supportive network may withdraw over time. It is worth noting that professionals are not immune to the feelings of frustration and desire to withdraw predicted by this model, and these issues should therefore be carefully considered in supervision by those who work in this field.

Whether emotional support is provided by a social network or by a professional, a consistent message given by people who are bereaved is that it is not useful or comfortable to be told how to behave. The judgemental nature of the traditional psychological theories appears to exist in society as a whole, and one widow reflected that when she was grieving ‘there was too many people telling you what you should do’ (Bennett and Bennett, 2000, p247). Stroebe and Schut (1999) suggest that as well as taking a non-judgemental stance themselves, psychologists have an important role in educating bereaved people about the wide variety of grief responses that are seen. This may reassure them that whatever their experience, it is normal in its uniqueness.

Nature of the marital relationship

The findings about the relationship of social context to bereavement outcome should be considered in the context of the nature of the spousal relationship before widowhood. A number of researchers have explored the impact of the death of a spouse with dementia on the surviving caregiver. Caregiving is a chronically stressful role, and one that has been associated with depression, low self-esteem and anxiety, and poor health (Gallant and Connell, 1997). Caring for someone with dementia has been likened to a ‘living bereavement’ (Light and Lebowitz, 1989), in which the person with dementia is slowly ‘lost’ to their spouse, although they remain physically present. Various hypotheses can be made – from a trauma perspective this process of ‘living bereavement’ could make the actual death easier, as it is not unexpected. The cognitive-stress model suggests that the death results in a reduction in day-to-day stressors and responsibilities, and will therefore lead to some positive responses to the bereavement. However, this
model also suggests that survivors are experiencing a loss in the context of being under extreme stress, which may make them less able to cope with it.

Support for the final hypothesis is given by Robinson-Whelen, Tada, MacCallum, McGuire and Kiecolt-Glaser (2001), who found that even four years after the death of their spouse, former caregivers did not differ from current caregivers on measure of depression or loneliness. This related to continued intrusive thoughts about caregiving, although it was reduced in those with more social support after the death of their spouse. Bond, Clark and Davies (2003) found somewhat different results. Former caregivers showed increases in levels of social activity after the death of their spouse, and improvements in their physical and mental health. Unlike the Robinson et al. (2001) study, all of these caregivers had admitted their spouses to permanent institutional care before they had died. This could be seen to support the trauma hypothesis, in that the relinquishing of care meant that the spouses had already begun to grieve the loss of their partner before they had actually died. Both studies highlight that input from services may be useful in increasing levels of social support available both before and after the death of the spouse.

Other researchers have considered how the quality of the marital relationship affects subsequent bereavement responses. The cognitive stress hypothesis suggests that the more support there is within the relationship, the more distress there will be if it is lost. This was indeed found to be the case both in a Western (Carr et al., 2000) and a Chinese (Li et al., 2005) population, where individuals who depended on their spouse had higher level of anxiety and depression when bereaved. Utz, Carr, Nesse and Wortman (2002) suggest that individuals with lower socioeconomic resources and no children should be specifically targeted in outreach support efforts. Indeed, factors such as these may make the individuals more dependent on their spouse, and therefore more vulnerable to the negative impact of bereavement.

An interesting adjunct to these findings is provided by Carr (2004b) who found that although bereavement for these dependent individuals led to anxiety and depression, they also experienced an increase in self-esteem following the death of their partner. This positive outcome occurred as individuals were forced to take on new responsibilities, and

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began to recognise previously unknown capabilities. It is important to consider this in terms of clinical input – it may initially seem appropriate to put outside support in place for widow(er)s who appear to be distressed by increased responsibilities. However, this could contribute to feelings of helplessness, and it may be more important to allow someone to learn new skills. Indeed, a widow interviewed by Anderson and Dimond (1995) felt from her experience that after a loss ‘you find out that you can do things’.

**Gender and bereavement**

Several research studies have found gender differences in experiences of grief. Much of this indicates that widowers have higher levels of psychological distress (Umberson, Wortman and Kessler, 1992) and higher mortality and suicide rates than widows (Stroebe and Stroebe, 1983). A number of explanations for this have been explored. For example, van Grootheest et al. (1999) hypothesised that men and women would be affected differently by 1) changing roles, whereby men would experience more change as they took on household responsibilities; and 2) support given, whereby women would be more supported due to larger and more emotionally supportive social networks. They found that widowed men did indeed spend more time doing housework than their married counterparts, but this did not relate to levels of depression. They received less emotional support than their married counterparts, suggesting that this type of support was principally obtained from the marital relationship. For both men and women, receiving emotional support related to lower levels of depression. In addition, men did receive less practical support than bereaved women did after the death of their spouse. However, receiving practical support actually related to increased levels of depression. van Grootheest et al. (1999) also predicted gender differences related to 3) financial security, whereby women would experience a more significant drop in income as a result of bereavement. In fact, in this group widows did not have a lower income than widowers, although this could be due to the extensive social security system in the Netherlands where the study was carried out. Nevertheless, satisfaction with income contributed significantly to depression scores for both men and women, which suggests
that this could be a more significant issue in places with a less effective social security system or where women are more financially reliant on men.

It is important to note that there was also a significant main effect of widowhood on depression for both men and women, suggesting that factors other than support and changing roles are important to explaining this relationship. However, this research highlights a number of areas for consideration in providing intervention. It appears important that emotional support is in place for both genders, and it may be that men in particular do not receive this from their social network as a matter of course. This may in part be related to the fact that older men have fewer male peers due to their lower life expectancy.

Schut, Stroebe, de Keijser and van den Bout (1997) considered the direction that this support could take. They offered grief counselling to men and women which either focussed on the open expression of emotion or on addressing the problems associated with the bereavement. These approaches follow from the loss orientation and the restoration orientation processes described in the Dual Process Model (Stroebe and Schut, 1999). They found that men showed a reduction in their distress when input about emotion expression was provided, and that women did when problem solving input was provided, but neither sex benefited from the other treatment. They suggest that this input provided their clients with ‘skills’ that were traditionally associated with the opposite gender, thus expanding their coping capacity.

**Religious and existential factors**

Brown, Nesse, House and Utz (2004) describe a growing amount of research that highlights the benefits of religion in coping with bereavement, although there is also some evidence to the contrary. They relate this to attachment theory, suggesting that a secure attachment to God may compensate for or replace the lost attachment relationship. In their study they found that widowed participants found increased importance in religion and attended church more frequently after the loss of their spouse. This increased religiousness was associated with decreased levels of yearning, anxiety, anger, shock and despair, and intrusive thoughts. However, it was not related to levels of depression.
Anderson & Dimond (1995) found that the predominantly Mormon older widowed people they interviewed found their religious beliefs a useful source of support to them. People prayed to God for help to cope, and many believed that this help had been given. They also were comforted by the belief that they would be reunited with their spouse in another life. Believing that a death was God's will, and that the deceased was in a better place seemed to make the death acceptable. The latter comments seem supportive of a trauma perspective, whereby religion enables widowed people to find meaning in the loss. Indeed, in the qualitative studies I described earlier, the non-religious group (Bennett and Bennett, 2000) was the only group to describe feelings of anger and guilt. These may result from attempts to make sense of the bereavement by blaming others or oneself.

Of course, people can develop a sense of meaning in life in a non-religious way. Fry (2001) considered the relationship of existential factors such as personal meaning (e.g. sense of order, reason for existence) with psychological well-being following bereavement in older adults. He found that there was indeed a correlation, with those who had more sense of personal meaning showing greater well-being. As a result of these findings he suggests that bereavement counsellors should attempt to increase 'purpose for life' in their clients, perhaps by working with them to develop and strengthen roles in their life.

Existential factors such as these may mean that the experience of bereavement is different for older and younger people. Anderson and Dimond (1995) found that the older widows they interviewed were able to take comfort in the fact that their spouse had had a long and full life, making statements such as 'we've had a wonderful life together'. The death may therefore present less of a challenge to the 'just world' assumption than it does for younger widows, who may feel unfairly deprived of sharing their life with their spouse. Another existential factor that may differ according to age is highlighted by Ballhausen Footman (1998) who suggests that grieving for someone else involves mourning your own mortality. For older adults who are already aware that they are coming to the end of their life span, it may be that a spouse's death provokes more of a concern about the end of their own life.
Advice from older widow(er)s

In considering what input should be provided to older widow(er)s, those who have been through the experience themselves can provide a valuable insight as to what they found helpful and unhelpful. Bergstrom and Holmes (2000) carried out a detailed analysis of advice given by this group for adjusting to and coping with the loss of a spouse. These widow(er)s described contrasting reactions to bereavement – the desire to withdraw and 'feel sorry for yourself' versus the need to 'live life', and 'do or think about something else'. The advice they gave advocated the latter, and discouraged the former. This 'lay theory' of bereavement is strikingly similar to the dual process model described by Stroebe and Schut (1999), although it demonstrates that this group feels that the 'restoration orientation' process is more important. Contrasting findings are cited by Anderson & Dimond (1995) where widow(er)s suggested that staying at home would not necessarily be 'feeling sorry for yourself' but instead was a good opportunity to 'think things out', and remember positive memories, which is similar to the 'loss orientation' process.

The widow(er)s in Bergstrom and Holmes' study (2000) also advised to 'continue' with life as it had been before, 'getting back into things', suggesting that the sense of normality that this provides is comforting and helpful. This is useful to consider in work with clients, in that expecting bereaved clients to engage in new activities in order to address issues of loneliness may not be helpful. The other focus of advice related to the passage of time, with recommendations such as 'take it one day at a time', and that 'time...makes it easier'. This too is backed up by research evidence (e.g. Stroebe et al. 1996) that negative responses to bereavement do decrease over time.

The advice given by widow(er)s tended to be qualified with statements such as 'I know what worked for me' and 'everybody is different'. Perhaps as professionals we should learn from this way of presenting guidance and be honest about our ability to offer educated suggestions rather than 'the answers'. Indeed, one participant reflected that 'You don't know [what it feels like] until you walk in my shoes' confirming that, as described earlier, taking the position of an expert may not be welcomed.
Conclusion

In this essay I have described how psychological theories can usefully contribute to an understanding of the many and varied ways that bereavement is experienced in older adults. Traditional models have led to unhelpful and unrealistic expectations being placed on the bereaved, but more recent models that allow for difference provide a framework which outlines where psychological input may be appropriate. For example, the cognitive stress and attachment perspectives emphasize the necessity to consider a widow(er)s social context. They highlight a role for psychology in helping increase support for older people as a preventative measure. They also suggest psychological support may be helpful for people who find it difficult to access support from a social network, for example men and caregivers. The trauma perspective complements these models, and underscores the importance of considering how existential factors such as personal meaning may affect bereavement outcomes. It suggests that psychological input could support the process of meaning-making that occurs after a loss.

A vital role for psychologists in this area is psycho-education. The experience of bereavement for many widow(er)s is needlessly complicated by pressure to ‘do it the right way’. This pressure may be from within, or from others around them. Historically it has also been applied by psychologists who have developed theories that have dictated what responses are ‘so normative that their absence is...offensive’ (Lindstrøm, 2002, p17). Stroebe et al. (1992) therefore suggest that it is important that widow(er)s are educated as to the different forms that grief takes. In fact, psychology as a profession perhaps has a responsibility to society as a whole to dispel the unhelpful myths about bereavement it has played a part in creating.
References


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Case report summaries
Cognitive Behavioural Therapy with a 35-year old lady presenting with complex needs, including anger management problems and relationship difficulties.

Presenting problems
Ms Cox was referred to the CMHT by the CAMHS that has ongoing involvement with her son. She reported that for the last three years she had been having regular angry outbursts, manifested in verbal or physical aggression towards others, physical aggression towards her property, and self-harm. She also reported relationship issues: she had broken up a 13 year relationship with a physically and emotionally abusive man five years previously but still felt under threat from this man. Her current partner was supportive, but she was finding it difficult to ‘tolerate’ the relationship. Finally, Ms Cox reported distress, shame and confusion related to recent memories of sexual abuse by her father. In addition, she was drinking 20 cups of coffee a day.

Assessment procedure
- The assessment was carried out using structured behavioural interviewing techniques (Kirk, 1989). Initially a broad assessment of her current problems was carried out, and the focus of future sessions was agreed. She stated that she was not ready to discuss her abuse, so a second session focussed on assessment of her relationship difficulties, anger and risk.
- Ms Cox was asked to complete an anger diary.
- Ms Cox was somewhat ambivalent about whether her aggression was a problem. It was therefore not felt appropriate to use a formalised anger questionnaire.

Formulation
Ms Cox’s aggressive episodes were formulated using the Novaco (1994) model of anger. Her angry outbursts have environmental triggers such as slow service in shops, which lead to angry cognitions (e.g. I’m being disrespected, I don’t care what happens) and physiological arousal. Her behavioural response to her anger (i.e. physical or verbal
aggression) reinforces the cognitions and prolongs the arousal. These episodes take place within the environmental context of social deprivation and fear of her ex-partner.

The cognitive conceptualisation model of J. Beck (1995) can be used to understand her extreme responses to environmental triggers. Her childhood experience of sexual abuse, and her more recent experience of an abusive relationship have led her to develop core beliefs that people are untrustworthy, and that she is worthless. These beliefs have led to a conditional assumption that she must show people she is strong or they will take advantage, and also that she must only rely on herself. This means that situations in which she feels disrespected lead to aggressive outbursts. In addition, she interprets her current partners supportiveness as an attempt to control her, so it feels uncomfortable.

**Intervention**

The intervention was guided by Howells (1998).

- Detailed exploration of her aggressive outbursts was carried out to improve her understanding of the links between environmental stressors, thoughts, physical sensations, aggression and outcome. In addition, the impact of her experiences of abuse on her thoughts and feelings now was discussed.
- To improve her control of her physiological arousal, a progressive muscular relaxation tape was provided. She was given information about the effects of caffeine, and was encouraged to cut down her intake.
- Psychoeducational materials about anger were provided.
- Alternatives to her angry cognitions were discussed, for example ‘Maybe this person has other problems’.
- With regards to her relationship issues, we identified Ms Cox’s belief that accepting support means being exposed to manipulation, and discussed how this impacts on her relationship now.

Ms Cox’s feeling that others can’t be trusted and that she must cope on her own affected her engagement in therapy: she stated ‘I don’t want to be...understood’ at one point. Her...
background level of environmental stress acted as a barrier to progress as she found it difficult to find time to complete homework or read literature, and was often distracted by problems in sessions. In addition, Ms Cox often was visibly physically aroused. To manage risk, it was important she did not feel too challenged in the sessions, and it was agreed she could take 'time out' if necessary.

**Outcome**
Ms Cox reported that the most beneficial aspect of therapy for her was to have some time to focus on herself and consider her difficulties. She described a number of occasions when she had used the relaxation technique of slow breathing to avoid becoming aggressive. She also spontaneously developed a coping strategy of going somewhere cold for time out as this reduced her physiological arousal. In addition, she reported using alternative cognitions to reduce her anger effectively. In her relationship she began to manage her time so that she had time for herself, her children and for her partner, perhaps indicating a new belief that you can have space for other people and yourself within the context of a relationship.

Ms Cox did not complete her anger diary. She reported that she still became angry or aggressive 3 or 4 times a day at the end of therapy. She had informally monitored her caffeine intake, and had reduced it from 20 cups of coffee a day to 7.

After this input Ms Cox was referred to a Clinical Psychologist as she was keen to continue psychological work.

**Evaluation**
On reflection, Ms Cox could be understood as being in the Contemplation stage in the Stages of Change model (Prochaska and DiClemente, 1982). She made a number of contradictory statements over the course of therapy about her aggressive behaviour, and although she worked hard within sessions she did little outside them.
It is interesting that Ms Cox reported that the therapeutic relationship was one of the most important factors in therapy for her. I was aware of a time limitation to the therapy and was therefore eager to 'get through' a programme of work, becoming frustrated at frequent lack of focus. It may have been useful to have had a discussion early on in therapy about our expectations.
People with Learning Disabilities case report summary

Behavioural work with a staff team to manage the challenging behaviour of a 46-year-old man with moderate to severe learning disabilities

Presenting problems
Mr Parker has learning disabilities, and lives in 24 hour supported accommodation with four other residents. He was referred to the Behavioural Support Service for input regarding his ‘challenging behaviour’: (1) verbal and physical aggression towards staff, clients, and property; (2) head banging; (3) continual requests for food followed by complaints of sickness; (4) undressing in communal areas of the house; (5) refusing to leave the house for activities, or refusing to leave activities.

Assessment procedure
• Case notes review
• Face-to-face interviews with support workers
• Functional Analysis of Problem Behaviour interview (O’Neill, Horner, Albin, Storey & Sprague, 1990) carried out with two staff members.
• ABC charts
• Observation of Mr Parker using momentary time sampling
• Risk assessment

Formulation
Emerson (2001) highlights that behavioural and pharmacological interventions are considered ‘best practice’ for work with challenging behaviour, so a behavioural formulation was developed.

Mr Parker’s challenging behaviours occur in situations where other residents are getting attention, or when changeovers are happening. His behaviours usually lead to staff members giving him attention, thus reinforcing them. However, staff also find him
wearing and view his behaviours as 'attention seeking' so sometimes ignore him, leading him to escalate his behaviours to gain their attention.

They can be understood against a background of vulnerability factors:

- Mr Parker’s childhood was characterised by ‘persistent verbal aggression and occasional violence’ between his parents and sometimes directed towards him, so he may have vicariously learnt aggressive behaviour.
- He has suffered numerous bereavements: his father and three of his five siblings died during his childhood, his mother died in 1998, and his sister died in 2001.
- He has difficulty communicating his feelings verbally so he may demonstrate them through his behaviour.
- His difficulties with receptive communication are likely to make him frustrated and confused.

Protective factors are Mr Parker’s ability and motivation to initiate social interactions with staff.

**Intervention**

Emerson (1998) recommends implementing multi-component intervention packages to reduce the frequency of challenging behaviours

The assessment findings and formulation were fed back and discussed with the staff team, with the aim that greater understanding would challenge their negative view of him as ‘attention seeking’. Ideas about how to reduce the frequency of the behaviours were brainstormed in order to foster a sense of joint responsibility for the intervention. Two themes arose: (1) Reward appropriate behaviour, don’t respond to inappropriate behaviour; (2) If Mr Parker is getting attention anyway, he won’t need to be challenging to get it.
Guidelines were developed for responding to challenging behaviour, e.g.:

- Say no firmly when he is acting aggressively and leave the room for a short while. When he has finished acting in this way engage him in an enjoyable activity
- Have set ‘snack times’ and if he asks outside these time offer a healthier alternative
- If he takes off his clothes inappropriately don’t give him a bath. Say no, explain why, and help him to dress. Give him a bath at the planned time
- Before a trip make sure Mr Parker knows where he is going and that he will come back. If he refuses to go, don’t spend too much time trying to persuade him, and don’t take him later. Engage him in an enjoyable activity.

A rota was put into place where staff gave Mr Parker attention for an hour each. This would ensure that staff didn’t get ‘burnt out’ but that a staff member was available to engage with Mr Parker when he initiated it.

Targeted behaviours were monitored for two weeks then a review meeting was held. Staff reported no problems in following the guidelines, but discussion arose about what constituted ‘inappropriate’ behaviour. Staff agreed to follow the guidelines and monitor Mr Parker’s behaviour for a month. Telephone contact was made twice with no problems reported. A final review was then held.

Outcome
It was difficult to establish a baseline frequency of behaviour during the assessment phase. Staff reported feeling unable to indicate what ‘usually’ happened, few ABC charts were filled in, and staff members often missed meetings.
However, the monitoring sheets that were filled in while the guidelines were being followed show a reduction in the frequency of most of the behaviours over the course of the seven weeks:

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Child and Family Case Report Summary

Working in an integrative way with a seven year old boy and his family to address his anxiety

Presenting problems
James was referred by his GP to the Primary Care Child and Family Psychology Service regarding difficulties that had lasted for about two years. He cried and clung to his mother when she dropped him at school, although settled quickly when she left. At home he was verbally challenging towards his mother and aggressive towards his two-year old sister. James was 'preoccupied with death', repeatedly asking if his father was going to die. Finally, his father had severe OCD and there were concerns that James was mimicking some of his behaviours.

Assessment procedure
- I interviewed James’ mother, Ms Young, using a generic Child and Adolescent Mental Health Service assessment
- I created a genogram with Ms Young and James, noting particularly close or strained relationships.
- I used the Spence Children’s Anxiety Scale (SCAS: Spence, 1998) with James and his mother in an unstandardised way
- Completed the Trust’s Brief Risk Assessment
- Class observation and discussion with class teacher

Formulation
I initially formulated James’ difficulties using a cognitive-behavioural model. Two years previously there had been a lot of changes in the family – James’ sister was born, his grandmother died, and his father had a period of severe depression. He had therefore experienced a lessening of parental attention, loss of a family member, and anxiety about his father. These experiences led him to think ‘something will happen to someone when
I’m not there’ when he is dropped off at school or his father leaves the house. To manage these anxious thoughts he moans and cries, which his mother responds to by giving him attention, thus reinforcing the behaviour. His oppositional behaviour can also be understood as a way of communicating his anxiety.

Another way James copes with his anxious thoughts is by asking a lot of questions about death. His parents are concerned that these repeated questions are a sign of him ‘inheriting’ his father’s OCD, so avoid answering them. In addition, when Mr Felton was particularly depressed there may have been valid concerns within the family about him harming himself, giving another motivation to avoid discussing anxiety-provoking issues. This avoidance raises James’ anxiety level, thus increasing his need for answers.

I later reformulated the difficulties using a narrative framework. The family gave a ‘problem-saturated account of family life’ (White and Epston, 1990). The marital relationship was described as ‘strained’ and unsalvageable and James was unmanageable. There was also anxiety about heredity – Mr Felton was becoming like his Dad by using alcohol to cope with problems, and James was inheriting Mr Felton’s OCD. In addition, the family externalised Mr Felton’s OCD, calling it Fred. Fred was powerful, uncontrollable, and shameful, and therefore kept a secret from the children.

**Intervention**

Following the cognitive-behavioural formulation, I created a football pitch rewards chart where James had to score a target number of goals ‘against worry’ by attending school without crying and clinging. If he reached an agreed target then his parents would extend a family trip, for example to include a takeaway. I also encouraged Ms Young to become firmer when leaving James. After four weeks, James showed me that he had consistently got the maximum number of goals. I congratulated him for winning the league and asked him what skills he used to do it, who else had been on his team, and what tricks ‘worry’ used to try and beat him. We created a collage with post it notes, covering up worry’s tricks with the skills and team members.
In relation to James' repeated questioning, I shared my formulation with Ms Young as to the maintaining effects of ignoring James' questions. She decided to use a new strategy of giving detailed answers, and found that her concerns that this would 'make things worse' were unfounded. Giving full answers in fact led to James asking fewer questions.

I enabled therapeutic conversations with the family where we explored alternative stories about their functioning. Discussion about the history of Mr Felton and Ms Young's relationship highlighted how they had 'fought the world together', and they reflected that nowadays other families often called on them for support. Discussion about their relationship with James allowed Ms Young to bring up her resentment that she bore the sole responsibility for discipline, and her sense of exclusion from the close relationship Mr Felton had with James. Following this conversation, Mr Felton began to take a more active role in disciplining James, and both parents began to see themselves as a mutually supportive 'unit' again. Over the course of the intervention James' parents reintroduced 'family time', in which they enjoyed activities together. Finally, I introduced discussion about 'Fred' and his influence on the family. Through questioning about ways that he had managed Fred in the past, Mr Felton described that he had found cognitive-behavioural therapy useful. The alternative story of Fred being controllable was therefore strengthened. The mysteriousness of Fred was challenged by providing the family with information about OCD.

Outcome

The family reflected on the change they had seen in James. He began to talk more with them about his everyday concerns at school, as well as his frustrations with his sister. Ms Young and Mr Felton felt that this was because he saw them as more 'solid' and able to cope with his problems. James agreed that he had become braver about talking about things that worry him, and said this is because he is 'getting older and older'. In our final session, the family told me about their plans for a summer holiday, which demonstrates a new story of hopefulness about their future as a family. I repeated the SCAS (1998) with Child and Family case report summary
James in an unstandardised way. His responses seemed to demonstrate an increased willingness to think about anxiety provoking issues. The family and I felt that they did not need further input so the case was closed.
Older Adult case report summary

Neuropsychological assessment of a 78-year old woman reporting memory difficulties and unusual experiences of seeing and hearing things

Presenting problems
Mrs Foster was referred by a Consultant Psychiatrist at a CMHT for Older People. He requested a neuropsychological assessment to help inform a diagnostic decision with regards to Mrs Foster’s memory difficulties, which related to instances of losing things, word-finding problems, and getting confused about paying in shops. She also reported ‘frightening experiences’ of seeing and hearing unusual things, and having disturbed sleep. She had noticed these difficulties since moving in with her son three years previously.

Mrs Foster had a CT brain scan which showed ‘no significant abnormalities’. An EEG showed an ‘abnormal record’, relating to ischaemic disease. On examination by the Psychiatrist no gross focal neurological deficits were found.

Assessment of personal history and current circumstances
Mrs Foster left school at seventeen with Cambridge School Certificates and retired at sixty having worked in clerical and PA posts throughout her life. She was widowed thirteen years ago, after which she lived alone for ten years. She moved to live with her son and grandson three years ago, and finds it very stressful. The house is cluttered, and there are frequent arguments between family members. She planned to move in the near future.

Mrs Foster has no psychiatric history and did not show signs of depression, scoring 0 / 4 on the short-form Geriatric Depression scale. She has high blood pressure and osteo-arthritis. She has glaucoma in both eyes, has had cataracts removed from both eyes, and wears glasses.

Older People case report summary
Neuropsychological assessment

The following assessments were administered:

- Weschler Test of Adult Reading to predict pre-morbid level of ability.
- National Adult Reading Test -II to predict pre-morbid level of ability.
- Weschler Adult Intelligence Scale-III to assess general intellectual functioning.
- Logical Memory test from Weschler Memory Scale-III to assess immediate and delayed verbal recall.
- Rey Complex Figure to assess visual-spatial ability and immediate and delayed visual recall.
- Faces subtest of WMS-III to assess visual recognition ability.
- Trail Making Part A to assess cognitive processing and motor speed, and Trail Making Part B to assess rule shifting ability.
- Controlled Oral Word Association Test to assess verbal fluency, and animal naming test to assess semantic fluency.
- Hayling sentence completion test to assess response initiation speed and response suppression ability.
- Brixton spatial anticipation test to assess rule detection and ability to shift.

Mrs Foster showed a number of significant difficulties in her cognitive functioning relative to her predicted pre-morbid ability. In particular she showed impairment of executive functioning, perceptual organisation and speed of processing. In terms of memory, her ability to encode, store, and retrieve visual and verbal abstract information was impaired. However, when information had meaning, such as a story or faces, her performance was much improved. She also benefited from the structure of recognition tasks as opposed to recall. This pattern of memory deficits suggests that she has difficulty in organising information throughout the memory process, which fits with her executive functioning impairment.

Older People case report summary
Outcome

The pattern of impairments seen was consistent with Lewy body dementia. In particular prominent deficits in fronto-subcortical and visual spatial skills were seen, and memory impairment was secondary to executive functioning difficulties. In addition, Mrs Foster reported some experiences of seeing unusual things to the Consultant Psychiatrist, which could be visual hallucinations. However, she did not show motor features of Parkinsonism and there was also no clear evidence of fluctuating cognitive function and alertness during the assessment sessions.

The pattern of impairments was also consistent with vascular dementia. Difficulties were seen in memory, visual-spatial functioning, and executive functioning skills, with executive dysfunction more significant than memory impairment. Although no sign of ischaemic change was seen on the CT scan, abnormality was seen in the EEG which was stated to ‘probably relate to ischaemic disease’. Mrs Foster also has high blood pressure, a vascular risk factor. It was hard to confirm a relationship between cerebrovascular disease and cognitive impairment. Although there was no recorded history of a stroke, the onset of symptoms did occur at a specific time, which may relate to a cerebrovascular accident. However, at around this time she moved into her son’s house: she may have been unknowingly coping with impairments in her previous home and only became aware of them when she moved into the unfamiliar and somewhat chaotic surroundings of her sons house. Alternatively, the high levels of stress in her current home may be impacting on her cognitive ability.

The impairments were not consistent with Alzheimer’s disease. Mrs Foster’s memory benefited from structure and meaning, and she was better at recognition than recall tasks. Her semantic knowledge as assessed in the Similarities and Vocabulary tasks was relatively preserved. In addition, cerebral atrophy was not seen on the CT scan.

Older People case report summary
Recommendations
Clearly Mrs Foster had significant cognitive impairment relating to underlying organic changes. Dementia with Lewy bodies or vascular dementia were likely explanations, so I made the following recommendations to help inform the decision:

- Monitoring by a community psychiatric nurse to determine whether visual hallucinations are present, and assess the nature of the unusual experiences Mrs Foster reports.
- Monitoring by a CPN and repeat neuropsychological assessment in 9-12 months time to determine whether deterioration in cognitive functioning occurs, and if this is a gradual or stepwise process
- Referral for an MRI scan

I also made some suggestions about ways to manage Mrs Fosters difficulties:

- Input from a CPN to monitor her mood, and her ability to carry out day-to-day activities, particularly when she moved from her current home into a flat.
- The use of strategies to compensate for cognitive impairment, for example clearing workspaces and getting all the ingredients out before cooking, using a calendar for appointments, paying by card in shops.
Specialist placement - Traumatic stress service case report summary

Using a cognitive-behavioural approach with a 45-year-old man with post-traumatic stress disorder following torture in an Iraqi prison

Presenting problems
Mr Hakim was referred to the specialist trauma service for psychological input following experiences in Iraq. In 1980 he was imprisoned and tortured and members of his family were killed. When he was released he came to live in England. He returned to visit Iraq in 2004 and had a serious car accident there. Following this he has had a number of problems: (1) after initial difficulties falling asleep, nightmares about prison wake him every half hour, so he only has four hours sleep a night; (2) he has frequent flashbacks of his time in prison, which cause strong anxiety symptoms including dissociation; (3) he feels constantly alert and has an exaggerated startle response to loud noises; (4) he easily becomes agitated; (5) he feels hopeless, worthless, has little energy, and does not enjoy anything. He has suicidal thoughts and has made a number of suicide attempts; (6) he has severe back, joint and leg pain which makes it difficult to walk and stand.

Assessment procedure
I interviewed Mr Hakim over three sessions and he completed an activity and sleep diary. He completed the Post-traumatic stress disorder Diagnostic Scale (Foa, 1995) and the Beck Depression Inventory (Beck, 1978). His responses showed that he met all the DSM-IV criteria for a diagnosis of PTSD, which was in the moderate-severe range, and his depression score placed him in the severe range. I also carried out a risk assessment.

Formulation
Mr Hakim’s difficulties were understood within the Ehlers and Clark (2000) cognitive model of PTSD, in which symptoms are said to persist when a traumatic event and its sequelae are processed in a way that produces a sense of current, serious threat:

Traumatic stress case report summary
• His memory for his traumatic experiences has not been integrated into his autobiographical memory, so has no time reference or context. As such it is easily triggered by reminders.
• His hyperarousal and exaggerated startle response to noise were learned during his time in prison, where he was constantly unsafe.
• In prison he developed the capacity to dissociate to cope with the torture. This has become an involuntary and unpleasant response to feelings of anxiety, and also prevents the elaboration of the traumatic memory.
• His appraisal of his symptoms is that he is mad and cannot control himself.
• The severity and longevity of his symptoms make him feel he won’t recover.
• His pain acts as a trigger for his intrusive memories and feelings of hopelessness.
• He withdraws from others to avoid upsetting them. This means he has little to distract him from his thoughts and memories, and limited potential for social support.
• When anxious he leaves the house, at all times of day and night. This contributes to his feeling that he cannot control himself.
• He ruminates and watches television to try and find meaning in his experiences. This prevents him from engaging in other aspects of life, keeps his focus on threat-based information which triggers intrusive memories, and prevents the memory from being integrated.
• His suicide attempts are attempts to control or end his overwhelming feelings and experiences.
• Since his car accident he is unable to use the previously effective coping strategy of working to distract himself from his difficulties.

**Intervention**

• Anxiety management through practice of controlled breathing
• Grounding from dissociation with incense and a strong tasting drink.
• Normalisation and psychoeducation regarding his anxiety symptoms and nightmares.

Traumatic stress case report summary
• Encouragement to increase his activity level, using his activity and sleep diary to highlight the relationship between mood, activity, and sleep.

• Management of suicide risk through ongoing monitoring of his mood and suicidal ideation, and development of a plan for use if he felt suicidal again.

• Gathering of evidence to show that he could change and has control over his future.

• Hearing his story, by giving him time and space to talk about his experiences

Outcome
Mr Hakim found that controlled breathing helped him relax, but he found it difficult to use when feeling very anxious. Burning the incense in his room reduced the amount of time he took to calm down after nightmares from ninety to forty-five minutes. He no longer walked outside at night to calm down, and felt more in control of making the decision not to leave.

In our final session he chose not to repeat the formal assessments but subjectively his mood remained significantly depressed, and he continued to report frequent and disabling symptoms of PTSD. However, he reported that he had found the sessions helpful, and planned to re-engage in therapy when he returned from a trip to Iraq. This suggests that he believed there was some possibility of change.

Evaluation
This work was very challenging. Mr Hakim’s hopelessness was pervasive, and I found it frustrating and infectious. It was also anxiety provoking and exhausting to contain and manage Mr Hakim’s extreme emotions within the sessions, which included panic, despair, and anger. Good supervision was therefore vital: it allowed me to debrief, explore my own emotions, consider my expectations for outcome, and discuss dilemmas.

It was also useful to read the work of Herman (1992), who describes responses to trauma in victims of torture. For example she conceptualises hopelessness as a response that is learned following experiences of unsuccessful attempts to gain control. She highlights
that recovery is a slow process, in which the therapeutic relationship is vital. Her model includes a safety stage, in which people learn to understand and control their environment and themselves. Her reflections resonated with my experience, which was reassuring.

It was also important to consider cultural issues. As a younger white British female, I was aware that we may hold different beliefs about his problems and the role of professionals. I also wondered if he felt I would be unable to understand his experiences.

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Traumatic stress case report summary
Placement summaries
Adult mental health placement summary

Dates: 15 October 2003 – 26 March 2004
Supervisor: Momotaj Islam
Base: Tooting and Furzedown Community Mental Health Team,
      Springfield Hospital, Tooting, London

Client group:
- Range of presenting issues: depression, OCD and health anxiety, panic, agoraphobia, gender issues, anger, cognitive impairment
- Age range 22-68
- Range of cultural backgrounds, including Asian Hindu, White British Catholic, Black British Christian.

Assessments:
- A number of formal tools used: Weschler Adult Intelligence Scale-III, Weschler Memory Scale-III, Beck Depression Inventory-II, Maudsley Obsessive Compulsive Inventory, Beck Anxiety Inventory
- Generic screening assessment interview
- Initial assessment for therapy interview

Interventions:
- Co-facilitated ‘Looking After Yourself’ group on inpatient ward. Psycho-educational group about mental wellbeing, including sessions about nutrition, exercise, sleep etc.
- Work predominantly using cognitive-behavioural model. Also used behavioural and counselling models.

Other experiences
- Training - Child protection, Risk, Change in the NHS, Cultural awareness.
- Completed audit of the cost of not having clinical rooms on site
- Attended away day

Placement summaries
People with learning disabilities placement summary

Dates: 7 April – 24 September 2004
Supervisor: Dionne Joseph
Base: Lewisham Team for Adults with Learning Disabilities, Catford, London

Client group:
- Range of presenting issues: anger, anxiety, sexual issues, challenging behaviour, parenting skills, dementia, cognitive impairment
- Age range: 19-89
- Range of cultural backgrounds, including Albanian, White British, Black Caribbean.
- Varied living arrangements: 24-hr supported accommodation, independent with outreach support, parental home

Assessment:
- A number of techniques used: interview, momentary time sampling, ABC charts
- Variety of measures used: Assessment of Cognitive Deterioration in People with Learning Disabilities, Early Signs of Dementia Checklist, Assessment for Adults with Developmental Difficulties, Questionnaire on Social and Sexual Knowledge, Assessment of Challenging Behaviour, Weschler Adult Intelligence Scale - III

Interventions:
- 1:1 input predominantly using cognitive-behavioural model. Also used counselling, behavioural, and systemic models and ideas.
- Worked with staff groups to develop behavioural management plans and giving information about dementia and support for people with memory problems

Other experiences
- Ran training day for staff team ‘Understanding and coping with bereavement’
- Acted as a consultant for a Day Centre running a ‘Men’s Day’ and a ‘Woman’s Day’, providing education about sex and personal care
- Attended away day
- Training: Clinical risk assessment
- Observation of duty social work department, funding panel, psychiatry clinical meeting, outpatient clinic, allocations meeting, partnership board meeting

Placement summaries
Child and family placement summary

Dates: 13 October 2004– 24 March 2005
Supervisor: Paula Vincent
Base: Early Intervention Service, Kennington, London

Client group:
- Range of presenting issues: low self-esteem, history of bullying, anger, behavioural difficulties, attentional difficulties, depression, autism, separation difficulties, anxiety
- Age range: 2-18
- Many clients from deprived social backgrounds

Assessment:
- Carried out using assessment interview with child and/or parent, and school observations
- Variety of measures used: Weschler Intelligence Scale for Children–III, Weschler Preschool & Primary Scale of Intelligence–III, Beck Depression Inventory–II, Weschler Objective Reading Dimensions

Interventions:
- Carried out 1:1 interventions using cognitive-behavioural and counselling models
- Used a number of resources: Anti-Bullying Game, All about Me, Strength Cards
- Worked with parents to offer advice on behavioural management
- Family work using systemic model to address dynamics around anxiety problems

Other experiences
- Met with staff and observed work in Sure Start and developmental assessment service
- Training – Risk assessment, Working with interpreters, Working together to safeguard children

Placement summaries
Older adult placement summary

Dates: 6 April – 23 September 2005
Supervisor: Victoria Hill / Sara Turner
Base: Merton Community Mental Health Team for Older People, Tooting, London

Client group:
- Range of presenting issues: anxiety, memory problems (differential diagnosis), OCD, depression, disinhibition, bereavement, pain
- Age range: 65-91
- Predominantly White British Christian

Assessment:
- Assessment interviews carried out with individuals, couples, and staff members
- Variety of measures used: Penn State Worry Questionnaire, Hospital Anxiety and Depressions Scale, Graded Naming Test, Obsessive Compulsive Behavioural Checklist, Hayling, Weschler Adult Intelligence Scale–III, Weschler Memory Scale-III, Rey Complex Figure, Hopkins Verbal Learning Test, Rey Auditory Verbal Learning Test, National Adult Reading Test, Trail Making, Verbal and Semantic Fluency test, Weschler Test of Adult Reading, Geriatric Depression Scale, Middlesex Elderly Assessment of Mental State, Mini-Mental State Examination, Anxious Thoughts Inventory

Interventions:
- 1:1 work using cognitive-behavioural, narrative and counselling models.
- Work with a staff team giving psychoeducation about cognitive impairment, and using systemic ideas
- Developed and ran a ‘Reducing Worry’ group for four people in day hospital. Focus on cognitive aspects of worry, including identifying and challenging thoughts.

Other experiences:
- Attended two CPD days - gave presentation about chronic pain in older adults, and observed other presentations
- Attended neuroradiology meetings to discuss neuropsychological assessment in relation to CAT scans
- Attended NSF Standard 1 steering group meeting

Placement summaries
**Traumatic stress specialist placement summary**

**Dates:** 12 October 2005 – 24 March 2006

**Supervisor:** Sharif El-Leithy / Ian Robbins

**Base:** Traumatic Stress Service, Tooting, London

**Client group:**
- Most clients had post-traumatic stress disorder, following exposure to a variety of traumatic events: torture, violent assault, rape, domestic violence, car accident, war experiences.
- Additional issues: traumatic grief, depression, conversion disorder, anxiety and suicidality
- Age range: 19-48
- Wide range of cultural backgrounds, including Iraqi, Chechen, White British, Black Congolese, Indian, Kosovan, Serbian, Pakistani, Afghani and Iranian
- Wide variety of religious backgrounds, including Muslim, Christian, and Hindu
- Most clients had English as their second language, so interpreters were often used both in assessment and intervention
- Many were seeking asylum in this country

**Assessment:**
- Predominant form of assessment was interview
- Post-traumatic stress Diagnostic Scale, and Beck Depression Inventory used at screening

**Interventions:**
- Mainly 1:1 work using cognitive-behavioural, narrative and systemic models.
- Also guided by 3-stage model of trauma of Herman (2001)

**Other experiences**
- Presentation of cases in team meeting
- Attended away day
- Training: weekly education session covering assessment, formulation, and intervention in PTSD, and drug treatment for PTSD
Adolescent specialist placement summary

Dates: 5 April – 29 September 2006
Supervisor: Nick Kirby-Turner
Base: Sussex Centre for Children and Young People, Haywards Heath
Horsham Child and Adolescent Mental Health Service, Horsham

Client group:
- Range of presenting issues:
- Age range
- Predominantly White British

Assessments:
- A number of formal tools used:
  - Assessment interview

Interventions:
- Work predominantly using

Other experiences

Placement summaries
Service related research project
Have clients in a Community Mental Health Team had a positive, negative or mixed experience of receiving copies of their correspondence? An audit of client views.

Service Related Research Project – June 2004. Year 1
Abstract

Objective: An audit of client views of the 'Copying correspondence to clients' policy was carried out. The policy was implemented with the aim of enhancing client satisfaction with the NHS service they receive by increasing their involvement in the implementation of their care.

Design: A questionnaire was designed that addressed issues raised by staff and clients who had experienced the use of the policy. Quantitative and qualitative responses were elicited.

Setting and participants: The audit took place in an outer-London Community Mental Health Team (CMHT). Forty-one clients were deemed appropriate to take part by their keyworkers, and 38 of them chose to do so.

Results: Less than half of the clients were aware of the policy, although most had received copied letters. The majority (78.9%) reported generally positive feelings about it. Some clients reported changes of feelings towards staff and their care. For the majority this was in a positive direction, but for some it was negative. A minority of clients reported difficulties understanding their letters, problems with the accuracy or issues of disagreement with the information given, inability to ask questions about letters, and issues of confidentiality.

Conclusions: The results provide support for the continued implementation of this policy. However, the concerns of staff in this area do reflect genuine issues that arise, and it is recommended that these are addressed with clients on an individual basis. The findings must be interpreted cautiously due to the use of a non-standardised measure and a possibly skewed sample.
Acknowledgements

I would like to thank the staff in the Community Mental Health Team for their comments at the early stages of the project, and at a later stage their involvement in recruitment of clients and administration of questionnaires. I would like to thank my University Research Supervisor for their help and advice, and a number of fellow Trainee Clinical Psychologists for their suggestions and support.
Introduction

In 1999 the Mental Health National Service Framework was put into place to ‘help drive up quality’ in the Mental Health services provided by the NHS and to ‘remove the wide and unacceptable variations in [service] provision’. An External Reference Group including professionals and service users was set up to help the development of this framework. They stated that services should offer high quality treatment and care, offer choices to clients to promote independence, be non-discriminatory and demonstrate accountability. They suggested that service users and their carers should be involved in the planning and delivery of their care to ensure that these standards are being met.

Following these guidelines, a commitment is made in the NHS Plan (2000, Paragraph 10.3) that ‘letters between clinicians about an individual patient’s care will be copied to the patient as of right’. This results from the recognition that while patients have the right to access their medical records, in practice the communication between professionals is not available to them. A Working Group was convened in 2001 to draw together knowledge and research findings in current copying correspondence initiatives. The Working Group Report (2002) highlights the reported benefits, including the written records acting as ‘aides memoires’, error correction by patients, improved patient satisfaction, and an improved patient – clinician relationship. The financial implications were considered in some initiatives and generally found to be minimal.

Limited data is available about the implementation of the policy in the area of mental health. Harris and Boaden (2003) found that the majority of clients at an anxiety clinic felt that the policy is a good idea. They reported feeling in control of future treatment, and wanted to continue receiving letters. Interestingly, although they expected to be better informed as a result of reading a letter they in fact did not show an improved understanding of their condition and treatment. Another study in the area was carried out by Hughes (unpublished), who found that adults under the care of a Community Mental Health Team (CMHT) were generally satisfied with the policy, and felt better informed rather than angry or upset as staff had expected. The main improvement they wanted was

Service related research project
in the accuracy of information in the letters. In contrast to these generally positive findings, Harris and Boaden (2003) report on the findings of a survey of users of Mental Health Services in Bolton. Half had found letters difficult to read and understand, and most had found it difficult to contact professionals about their concerns. The majority reported concerns about confidentiality.

Members of the outer-London CMHT where this audit was carried out highlighted their concerns about the implementation of this policy in the area of Adult Mental Health. They cited examples of when clients had been upset or angry when they disagreed with information in the letters they had received. Some team members felt they were 'holding back' from openly communicating tentative hypotheses about their clients, as they were concerned about the impact these may have on the client. Finally, staff were concerned about confidentiality. The team suggested that a review of the impact of the policy on clients would determine the prevalence of the se problems and give ideas about how they could be resolved. Gaining an understanding of how clients feel about receiving letters may also determine whether this policy should be reviewed at a higher level. This monitoring of client views of the policy follows the recommendations of the Good Practice Guidelines (Department of Health, 2003), that suggest that 'From time to time, it will be helpful to check with patients how they feel about copied letters, perhaps as part of patient surveys' (Paragraph 5.8).
Aims and hypotheses

The policy was implemented to enhance user satisfaction. However, some pilot studies and clinician experience suggest potential negative outcomes. This audit aims to determine whether a standard of satisfaction has been met, and to determine the regularity of occurrence of negative outcomes. The following hypotheses are made:

- Awareness: All clients should be aware of the policy. The required procedure is that they should be given an information sheet about it, including the option to opt out, at their first meeting.
- General feelings: The majority of clients will report positive feelings about the policy.
- Ability to read and understand: All clients should be able to read and understand their letters, but some will report difficulties.
- Error or disagreement: There should be no errors in letters and no comments made that are disagreed with without prior discussion with the client. However, it is expected that incidences will be reported.
- Opportunity to ask questions: All clients should be able to ask questions about their letters, but some will report that they have not been able to do so.
- Change in feelings towards staff and service: The majority of clients will report that their feelings about the staff and services have changed for the better.
- Confidentiality: There should be no occurrences of confidentiality breaches, but this will be an area of concern for some clients.
Method / Procedures

Participants
A random list of 60 clients who had been under the CMHT for at least three months was generated using Microsoft Excel. Keyworkers agreed to complete the questionnaires with their clients and 12 were returned. It was agreed that they could select appropriate clients in order to gather more data. Twenty-one more were returned, and a further five were completed by clients on an inpatient ward. Three clients approached these ways were unwilling to take part.

Of the 38 participating clients, demographic data was given for 27. Sixteen (59.3%) were female. The average age was 42.3 (Range: 24-65). In terms of ethnic background, 77.8% (n=21) described themselves as White British, 14.8% (n=4) described themselves as Asian and 7.4% (n=2) described themselves as Caribbean-Black British. Psychiatric diagnoses were unavailable.

Questionnaire
A 12-item questionnaire was designed (see Appendix 1). Two questions assessed awareness of the policy, using a Yes / No response format. One question asked how many letters they had received. If they hadn't received any then only questions 4 and 12 were asked.

The questionnaire considered general feelings about the policy, ability to understand letters, incidences of error or disagreement, the impact of receiving letters on clients’ feelings about staff and their care, and confidentiality. In each area there was a question requiring a response indicating degree or nature of feeling (e.g. Good / Ok / Bad) or frequency (e.g. Yes – all of them / Yes – some of them / No – not at all). There was also a ‘Not sure’ option. Open-ended questions then gave an opportunity to expand on answers, following the recommendations of Stallard (1996).
Items were generated by expert sampling through discussion with CMHT clinical staff, and from research evidence (Harris and Boaden, 2003; Working Group report, 2002). The final questionnaire was approved by two Clinical Psychologists and CMHT clinical staff, which indicates that it has some content validity. Due to limited resources and a small sample size it was not possible to assess other types of validity or reliability.

**Procedure**

Most clients were approached by their keyworker and given an information sheet outlining the policy and the implications of choosing to take part or not (see Appendix 2). For those who agreed to take part the questionnaire was either carried out by the keyworker or, with prior agreement, by the author over the telephone. With the clients on the ward the ward manager made the initial contact. Clients were given the opportunity to ask questions and a contact number was given.
Results and analysis

Awareness and experience of policy

Sixteen clients (42.1%) were aware of the policy. Four (10.5%) knew that they could opt out. A two-tailed z approximation binomial test showed that these proportions were significantly less (n=38, p<0.0001) than the standard that 100% of people should be aware.

Graph 1: The number of letters received by clients

Nine clients (23.7%) had not received any letters. The majority (n=18: 47.4%) received between one and three (see Graph 1)
General feelings about the policy

Graph 2: Answers to Question 4

Do you think receiving letters about your care is a good or a bad thing?

Number of clients

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Thirty clients (78.9%) felt the policy was a good thing (see Graph 2). The main reason given was feeling informed and involved. Other benefits reported included having insight into professionals’ opinions, correcting inaccuracy and aiding memory.

Three clients (7.9%) reported thinking it was a bad idea. The remainder reported both positive and negative feelings. Negative comments made included concern about the impact of receiving distressing information, and problems caused by receiving incorrect information. As one client noted this ‘could cause problems of low self esteem – it may make you feel you’ve made a mistake’. Another concern was about the content of letters being ‘watered down’: ‘You question whether they’re holding back’.

Qualitative responses made across the whole questionnaire were coded as ‘Positive’, ‘Negative’, and ‘Not classified’. They were coded according to whether they said...
something positive or negative about the policy, clients' experiences of it, the NHS, or staff members. 'Not classified' comments had no connotations in either direction, or could be seen in both ways. Twenty-four of the 105 comments made were given to an independent Trainee Psychologist to code. Cohen's Kappa was calculated as 0.68, which Fliess (1981) suggests demonstrates 'good' inter-rater reliability. Sixty (57.1%) of the comments made were positive. Thirty-one (29.5%) were negative. A two-tailed $z$ approximation binomial test indicated that these proportions differ significantly from a .50 / .50 split ($n=91$, $p<0.005$), with significantly more positive comments made.
The following questions were only asked to clients who had received copies of letters (n=29)

**Ability to read and understand information**

Graph 3: Answers to Question 5

![Bar Graph]

Graph 3 shows that 72.4% (n=21) of clients reported having been able to read and understand all their letters. None had been unable to read any. The main comments made were about difficulty with long or technical words, and problems taking in large volumes of information (see Appendix 3: Table 2).
Accuracy of information

Graph 4: Answers to Questions 6 and 7

Nine clients (31.0%) reported that they had received letters that said things that weren't true. The same proportion reported that they said things they disagreed with (see Graph 4).

Table 3 (Appendix 3) shows that clients' responses to these incidences played a large part in determining their outcome. As one client noted 'There was an error...I rang the keyworker and it was dealt with – imagine if [I] hadn't understood...You may not know to [address] it'. Another said that they had not addressed the issue and 'left [them] to get on with it. I put it to one side and tried not to dwell on it'.

Service related research project
Opportunity to address issues raised by receiving the letters

Graph 5: Answers to Question 8

Have you been able to ask questions?

Thirteen clients (44.8%) reported having been able to ask questions about all of their letters (see Graph 5). Interestingly, three people who hadn’t asked questions commented that they hadn’t thought to do so (see Appendix 3: Table 4)
Change of feelings towards staff and service

Graph 6: Answers to questions 9 and 10

As Graph 6 shows, 24.2% (n=7) of clients reported their feelings about staff changing for the better. The comments in Table 5 (Appendix 3) show that clients value openness and being heard or understood. One client spoke positively about a Doctor who ‘commented I pray a lot...I’ll always remember it – he was nice, friendly, compassionate’. Four clients (13.8%) reported their feelings about staff changing for the worse. The main reason reported for this was being given conflicting information.

Thirteen clients (44.8%) reported their feelings about their care changing for the better, with reasons for this including the feeling of a team approach. Three (10.3%) reported feelings changing for the worse, for reasons of misdiagnosis and having to cope with distressing information (see Appendix 3: Table 6).
Confidentiality

Graph 7: Answers to Question 11

Twenty-seven clients (93.1%) clients reported that their letters had not been opened by anyone they did not want to (Graph 7). One client felt the Private and Confidential stamp drew unnecessary attention to the letter while another felt it was useful to know it was important (see Appendix 3: Table 7). One client raised concern about confidentiality in question 4.

Response rate to qualitative questions

Questions 4 and 12 were asked to 38 clients, and questions 5-11 were asked to the 29 who had received letters. From this total of 250 opportunities for comments to be made, none were made on 155 occasions (62%). A two-tailed z approximation binomial test showed that this proportion differed significantly from a .50 / .50 split (n=250, p< 0.001), with significantly more occasions when comments weren’t made than when they were made.

Service related research project
Discussion

A majority of clients had received copies of correspondence but only a minority were aware that they had done so because of a policy, and less knew that they could opt out of the system. Clients may be more inclined to become involved in their care if they are aware that this policy exists to empower them to do so. Staff should therefore be reminded of the policy and the procedure that should be followed.

Both the quantitative and qualitative data support the hypothesis that a majority of clients have positive feelings about the policy. Interestingly, the hypothesis that the majority of clients would have more positive feelings towards the staff as a result of receiving letters was not supported, as most clients reported that their feelings were unchanged. However, most of those clients who reported that their feelings had changed reported change for the better. Similar results were seen with feelings towards the service. These findings should be fed back to the staff team as they are likely to be more motivated to implement a policy that is well received by clients.

Most clients reported having been able to read and understand all the letters they had received although, as hypothesised, problems were reported with understanding the language or with the volume of information given. This matter should be considered on an individual basis, and could be resolved by simplifying language or by using clinical time to go through and explain reports with clients.

As hypothesised, some clients reported that their letters contained errors or points of disagreement. This was only seen in a minority of cases and some were minor inaccuracies and mistakes that were rectified. The fact that this was the main concern of staff perhaps reflects the fact that angry or upset feedback from clients is memorable. The Good practice guidelines (Department of Health, 2003) highlight that staff concerns of this nature are valid and common, but they should not mean the policy is not implemented. They suggest that ‘there should be no new information in the letter that might surprise or distress the patient’, and that sensitive and contentious issues should be
discussed with the patient prior to the letter being sent. One client reported on the effective use this strategy stating that ‘We had discussed it earlier so there were no surprises’. Another client reported that ‘It is helpful to know but not easy to live with’, showing that it is not the professional’s role to protect a client from being distressed by sensitive information, but they should help them manage their feelings about it. This way of working should be encouraged, as well as ensuring the factual detail in all letters is checked.

Only 51.7% of clients reported that they had been able to raise questions about the letters they had received, which supports the hypothesis made. Unfortunately the wording of the question (‘Have you been able to ask questions about the letters you have received’) means that the responses are difficult to interpret. Some clients may not have had questions while others may have had them but didn’t feel able to ask them. Indeed, one client stated that ‘people don’t like to change what they write’, suggesting a feeling of helplessness. The issue of whether clients feel empowered to use the information they are given to exercise control over their care is an important area for further research.

Finally, the standard of confidentiality was close to being met, with only one clear breach reported. One client reported concerns in this area, which was far fewer than expected. Clearly, as Harris and Boaden (2003) also found, ‘user and professional view about the user isn’t necessarily the same’. The use of surveys such as this to determine users’ views directly is therefore vital in effective service monitoring.

These findings were fed back to the service in order that they could use them to inform their use of this policy in the future (see Appendix 4).

A key drawback to this study is the method of recruitment. Random selection proved unfeasible so the sample obtained may not be representative of clients under the CMHT. The majority of clients approached agreed to take part, so any sampling bias that exists would come from the willingness of clinical staff to recruit individuals. The demographic
data shows that roughly equal numbers of male and females clients of a broad range of ages participated, and their ethnicity roughly represents that of the target population of the CMHT (Census, 2001 & 2002). However, clients with particular psychiatric diagnoses may have been deemed inappropriate to take part, which would negatively impact on the generalisability of the findings.

A second drawback is a possible response bias. Significantly more positive than negative comments were made. This may reflect a generally positive feeling towards the policy or it may reflect an unwillingness to give negative feedback. This was seen by Stallard (1995), who found that non-responders to a postal satisfaction questionnaire evaluated a service they had been involved with more negatively than responders. The 62% of occasions in this audit where clients did not make comments may therefore reflect hidden negative feeling.

Lastly, although the results obtained are useful for this service, the questionnaire was non-standardised so the reliability and validity of the findings cannot be determined.

A final important finding of this audit was that many of the clients who took part in it gave very positive feedback about being involved. They reported that they appreciated having their views about service issues of this type elicited. Thus the process of carrying out a satisfaction survey may in itself improve a clients' satisfaction with the service that they receive.
References


Service related research project


Appendices.

Appendix 1: Questionnaire

Interview questions

(Please circle response given)

1) Before being given the information sheet, did you know that there is a policy in this Trust that means that you receive copies of all letters relating to your care? Yes / No

2) Did you know that you have the option to choose not to receive these letters? Yes / No

3) About how many copies of letters between people involved in your care have you received? (not including appointment letters)

4) a) If you have received letters - do you think receiving copies of letters about your care has been a good or a bad thing? Good / Ok / Bad / Not sure

b) If you haven't received letters – do you think receiving copies of letters about your care is a good or a bad idea? Good / Ok / Bad / Not sure

Any comments? Are there any reasons why you think it is a good or bad idea?

5) Have you been able to read and understand your letters?

Yes - all of them / Some of them / None of them / Not sure

Any comments? What has been easy or difficult to understand?

6) Have the letters you have received said things that aren't true?

Yes - all of them / Some of them / None of them / Not sure

7) Have they contained anything you disagree with?

Yes - all of them / Some of them / None of them / Not sure

Any comments? If yes, what did you do? How was it handled by the team?

Service related research project
8) Have you been able to ask questions about the letters you have received?
   - Yes – all of them
   - Some of them
   - None of them
   - Not sure

   Any comments? If yes, how did you do this? Were they answered?

9) Has receiving letters from the people involved in your care changed the way you feel about them?
   - Yes – I feel better about them
   - Yes – I feel worse about them
   - No – not at all
   - Not sure

   If yes, what have these changes been? Can you give any examples?

10) Has receiving letters made you feel differently about your treatment / care?
    - Yes – I feel better about it
    - Yes – I feel worse about it
    - No – not at all
    - Not sure

    If yes, what have these changes been? Can you give any examples?

11) Have any of your letters been read or opened by anyone you didn’t want to?
    - Yes – all the time
    - A few times
    - No
    - Don’t know

    Any comments? What happened? How did you feel about it?

12) Do you have any comments, suggestions or questions about the policy?
Appendix 2: Information sheet

Did you know...

You should be getting copies of all the letters that people involved in your care send to each other. This is part of the NHS Plan (2000).

If you would rather not receive these copies, you can ask anyone involved in your care. They can arrange for it to be stopped.

I am interested in seeing if you have had copies of letters. If you have, I am interested in what you feel about getting them. This may be good, bad, or a mixture of both.

The information you give me will be used to see how people feel about this new way of working. I can see if any changes should be made.

I would be very grateful if you are willing to answer a few questions. Please be honest - your name and any other information about you will NOT be recorded or used at any time.

- Trainee Clinical Psychologist

Please contact me on [redacted] if you have any questions.

Service related research project
### Appendix 3: Qualitative comments

Table 1: Qualitative responses made to questions 4 and 12

<table>
<thead>
<tr>
<th>Theme of comment</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>POSITIVE</strong></td>
<td></td>
</tr>
<tr>
<td>Feeling of being informed / involved</td>
<td>13</td>
</tr>
<tr>
<td>Insight into professional opinion</td>
<td>6</td>
</tr>
<tr>
<td>Helpful</td>
<td>4</td>
</tr>
<tr>
<td>Memory aide</td>
<td>3</td>
</tr>
<tr>
<td>Opportunity to correct inaccuracy / discuss disagreement</td>
<td>3</td>
</tr>
<tr>
<td>Feeling of empowerment</td>
<td>3</td>
</tr>
<tr>
<td>Desire to continue / start receiving letters</td>
<td>3</td>
</tr>
<tr>
<td>It’s good because I have the right to have the information</td>
<td>2</td>
</tr>
<tr>
<td>Professionals are more accountable for what they say</td>
<td>2</td>
</tr>
<tr>
<td>Can share the information with family</td>
<td>1</td>
</tr>
<tr>
<td>Reassurance that I’m not crazy</td>
<td>1</td>
</tr>
<tr>
<td>No secrets</td>
<td>1</td>
</tr>
<tr>
<td><strong>TOTAL:</strong> 42</td>
<td></td>
</tr>
<tr>
<td><strong>NEGATIVE</strong></td>
<td></td>
</tr>
<tr>
<td>Makes you think about it too much</td>
<td>2</td>
</tr>
<tr>
<td>Incorrect information may have a negative impact on self esteem</td>
<td>2</td>
</tr>
<tr>
<td>May impact on what they write – watering down</td>
<td>2</td>
</tr>
<tr>
<td>I should have been informed about the policy</td>
<td>1</td>
</tr>
<tr>
<td>Concern regarding confidentiality</td>
<td>1</td>
</tr>
<tr>
<td>Started receiving letters but isn’t happening any more</td>
<td>1</td>
</tr>
<tr>
<td>May cause anxiety and stress</td>
<td>1</td>
</tr>
<tr>
<td><strong>TOTAL:</strong> 10</td>
<td></td>
</tr>
<tr>
<td><strong>NOT CLASSIFIED</strong></td>
<td></td>
</tr>
<tr>
<td>Important to consider financial implications</td>
<td>3</td>
</tr>
<tr>
<td>May be inappropriate if you’re unwell</td>
<td>2</td>
</tr>
<tr>
<td>Impact on relationship – negative or positive</td>
<td>1</td>
</tr>
<tr>
<td><strong>TOTAL:</strong> 6</td>
<td></td>
</tr>
<tr>
<td>No comments made Question 4</td>
<td>10 people</td>
</tr>
<tr>
<td>Question 12</td>
<td>16 people</td>
</tr>
</tbody>
</table>

Service related research project
Table 2: Qualitative responses made to question 5

<table>
<thead>
<tr>
<th>Theme of comment</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>POSITIVE</strong></td>
<td></td>
</tr>
<tr>
<td>It was straightforward</td>
<td>2</td>
</tr>
<tr>
<td><strong>TOTAL:</strong></td>
<td><strong>2</strong></td>
</tr>
<tr>
<td><strong>NEGATIVE</strong></td>
<td></td>
</tr>
<tr>
<td>It was hard to read long / technical words</td>
<td>4</td>
</tr>
<tr>
<td>It was hard because I have problems with concentration</td>
<td>2</td>
</tr>
<tr>
<td>It was impossible</td>
<td>1</td>
</tr>
<tr>
<td>Handwriting in notes was difficult to read</td>
<td>1</td>
</tr>
<tr>
<td><strong>TOTAL:</strong></td>
<td><strong>8</strong></td>
</tr>
<tr>
<td><strong>NOT CLASSIFIED</strong></td>
<td></td>
</tr>
<tr>
<td>I needed my glasses</td>
<td>1</td>
</tr>
<tr>
<td><strong>TOTAL:</strong></td>
<td><strong>1</strong></td>
</tr>
<tr>
<td>No comments made</td>
<td></td>
</tr>
<tr>
<td><strong>TOTAL:</strong></td>
<td><strong>18 people</strong></td>
</tr>
</tbody>
</table>

Table 3: Qualitative responses made to questions 6 and 7

<table>
<thead>
<tr>
<th>Theme of comment</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>POSITIVE</strong></td>
<td></td>
</tr>
<tr>
<td>We had discussed it earlier so there were no surprises</td>
<td>1</td>
</tr>
<tr>
<td><strong>TOTAL:</strong></td>
<td><strong>1</strong></td>
</tr>
<tr>
<td><strong>NEGATIVE</strong></td>
<td></td>
</tr>
<tr>
<td>There were minor inaccuracies</td>
<td>2</td>
</tr>
<tr>
<td>Felt upset about mistakes but did not address it</td>
<td>2</td>
</tr>
<tr>
<td>Addressed but no action taken by staff member</td>
<td>1</td>
</tr>
<tr>
<td><strong>TOTAL:</strong></td>
<td><strong>5</strong></td>
</tr>
<tr>
<td><strong>NOT CLASSIFIED</strong></td>
<td></td>
</tr>
<tr>
<td>Addressed and inaccuracies were rectified</td>
<td>2</td>
</tr>
<tr>
<td>Forgot to address inaccuracies</td>
<td>1</td>
</tr>
<tr>
<td><strong>TOTAL:</strong></td>
<td><strong>3</strong></td>
</tr>
<tr>
<td>No comments made</td>
<td></td>
</tr>
<tr>
<td><strong>TOTAL:</strong></td>
<td><strong>20 people</strong></td>
</tr>
</tbody>
</table>

Service related research project
Table 4: Qualitative responses made to question 8

<table>
<thead>
<tr>
<th>Theme of comment</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>NOT CLASSIFIED</td>
<td></td>
</tr>
<tr>
<td>Didn’t think to try to ask questions</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>TOTAL: 3</td>
</tr>
<tr>
<td>No comments made</td>
<td></td>
</tr>
<tr>
<td></td>
<td>TOTAL: 25 people</td>
</tr>
</tbody>
</table>

Table 5: Qualitative responses made to question 9

<table>
<thead>
<tr>
<th>Theme of comment</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>POSITIVE</td>
<td></td>
</tr>
<tr>
<td>Felt understood and valued</td>
<td>4</td>
</tr>
<tr>
<td>Value openness</td>
<td>3</td>
</tr>
<tr>
<td>People seem more approachable</td>
<td>1</td>
</tr>
<tr>
<td>It helped me to improve</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>TOTAL: 9</td>
</tr>
<tr>
<td>NEGATIVE</td>
<td></td>
</tr>
<tr>
<td>Receiving conflicting information was confusing</td>
<td>3</td>
</tr>
<tr>
<td>It can create more problems</td>
<td>1</td>
</tr>
<tr>
<td>Makes people seem interfering</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>TOTAL: 5</td>
</tr>
<tr>
<td>No comments made</td>
<td></td>
</tr>
<tr>
<td></td>
<td>TOTAL: 19 people</td>
</tr>
</tbody>
</table>

Service related research project
Table 6: Qualitative responses made to question 10

<table>
<thead>
<tr>
<th>Theme of comment</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>POSITIVE</td>
<td></td>
</tr>
<tr>
<td>Demonstrates team approach</td>
<td>3</td>
</tr>
<tr>
<td>Feeling of being informed</td>
<td>1</td>
</tr>
<tr>
<td>Feeling of equality and forming a working alliance</td>
<td>1</td>
</tr>
<tr>
<td>TOTAL:</td>
<td>5</td>
</tr>
<tr>
<td>NEGATIVE</td>
<td></td>
</tr>
<tr>
<td>Misdiagnosis has a negative impact</td>
<td>1</td>
</tr>
<tr>
<td>It's difficult to take distressing information</td>
<td>1</td>
</tr>
<tr>
<td>TOTAL:</td>
<td>2</td>
</tr>
<tr>
<td>NOT CLASSIFIED</td>
<td></td>
</tr>
<tr>
<td>You should particularly be given the name of your medication</td>
<td>1</td>
</tr>
<tr>
<td>TOTAL:</td>
<td>1</td>
</tr>
<tr>
<td>No comments made</td>
<td></td>
</tr>
<tr>
<td>TOTAL:</td>
<td>21 people</td>
</tr>
</tbody>
</table>

Table 7: Qualitative responses made to question 11

<table>
<thead>
<tr>
<th>Theme of comment</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>POSITIVE</td>
<td></td>
</tr>
<tr>
<td>Private and confidential stamp highlights it's importance</td>
<td>1</td>
</tr>
<tr>
<td>TOTAL:</td>
<td>1</td>
</tr>
<tr>
<td>NEGATIVE</td>
<td></td>
</tr>
<tr>
<td>Private and confidential stamp draws unnecessary attention to it</td>
<td>1</td>
</tr>
<tr>
<td>TOTAL:</td>
<td>1</td>
</tr>
<tr>
<td>No comments made</td>
<td></td>
</tr>
<tr>
<td>TOTAL:</td>
<td>26 people</td>
</tr>
</tbody>
</table>
Appendix 4: Feedback to service

Dear [Name],

Thank you very much for coming to our team meeting to feed back the results of your research project on copies of correspondence to clients.

The team are interested in the results of this and I have suggested that our Clinical Governance Department may also be interested in seeing a copy as part of their monitoring of the service clients receive from us here.

Best wishes with the rest of your training.

Yours sincerely,

[Name]

Acting Team Manager
Research Log Checklist
<table>
<thead>
<tr>
<th></th>
<th>Research Log Checklist</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Formulating and testing hypotheses and research questions</td>
</tr>
<tr>
<td>2</td>
<td>Carrying out a structured literature search using information technology and literature search tools</td>
</tr>
<tr>
<td>3</td>
<td>Critically reviewing relevant literature and evaluating research methods</td>
</tr>
<tr>
<td>4</td>
<td>Formulating specific research questions</td>
</tr>
<tr>
<td>5</td>
<td>Writing brief research proposals</td>
</tr>
<tr>
<td>6</td>
<td>Writing detailed research proposals/protocols</td>
</tr>
<tr>
<td>7</td>
<td>Considering issues related to ethical practice in research, including issues of diversity, and structuring plans accordingly</td>
</tr>
<tr>
<td>8</td>
<td>Obtaining approval from a research ethics committee</td>
</tr>
<tr>
<td>9</td>
<td>Obtaining appropriate supervision for research</td>
</tr>
<tr>
<td>10</td>
<td>Obtaining appropriate collaboration for research</td>
</tr>
<tr>
<td>11</td>
<td>Collecting data from research participants</td>
</tr>
<tr>
<td>12</td>
<td>Choosing appropriate design for research questions</td>
</tr>
<tr>
<td>13</td>
<td>Writing patient information and consent forms</td>
</tr>
<tr>
<td>14</td>
<td>Devising and administering questionnaires</td>
</tr>
<tr>
<td>15</td>
<td>Negotiating access to study participants in applied NHS settings</td>
</tr>
<tr>
<td>16</td>
<td>Setting up a data file</td>
</tr>
<tr>
<td>17</td>
<td>Conducting statistical data analysis using SPSS</td>
</tr>
<tr>
<td>18</td>
<td>Choosing appropriate statistical analyses</td>
</tr>
<tr>
<td>19</td>
<td>Preparing quantitative data for analysis</td>
</tr>
<tr>
<td>20</td>
<td>Choosing appropriate quantitative data analysis</td>
</tr>
<tr>
<td>21</td>
<td>Summarising results in figures and tables</td>
</tr>
<tr>
<td>22</td>
<td>Conducting semi-structured interviews</td>
</tr>
<tr>
<td>23</td>
<td>Transcribing and analysing interview data using qualitative methods</td>
</tr>
<tr>
<td>24</td>
<td>Choosing appropriate qualitative analyses</td>
</tr>
<tr>
<td>25</td>
<td>Interpreting results from quantitative and qualitative data analysis</td>
</tr>
<tr>
<td>26</td>
<td>Presenting research findings in a variety of contexts</td>
</tr>
<tr>
<td>27</td>
<td>Producing a written report on a research project</td>
</tr>
<tr>
<td>28</td>
<td>Defending own research decisions and analyses</td>
</tr>
<tr>
<td>29</td>
<td>Submitting research reports for publication in peer-reviewed journals or edited book</td>
</tr>
<tr>
<td>30</td>
<td>Applying research findings to clinical practice</td>
</tr>
</tbody>
</table>
Major Research Project
Exploring identity in older adults with chronic pain: an interpretative phenomenological analysis

Naomi Dawkins

Submitted July 2006
Abstract

Objective
Chronic pain is a significant issue for many older adults. Although they make use of coping strategies, they also face a number of barriers to intervention. Not least is the limited amount of research specifically focussing on people over 65 years old. One area that research in chronic pain has recently explored is identity, which has implications for pain management. The aim of the current study was to improve understanding of identity in the context of ageing and chronic pain.

Method
The study used an Interpretative Phenomenological Analysis (IPA) approach. Nine people (age range: 65-81) with chronic pain who attended a pain clinic in Surrey were interviewed.

Themes
Participants experienced pain as threatening to identity. They used cognitive and practical strategies to manage this, thereby retaining a constant sense of self. Their experiences of pain were affected by age-related factors: age was used as an explanation for pain, which had varied emotional implications; age in itself posed a threat to identity; participants were exposed to ageism, sometimes internally generated; and pain was one of multiple problems in their lives. Finally, participants discussed pain in relational terms, describing struggles for control and attempts to develop a tolerable relationship with it.

Implications
The themes are discussed in relation to existing theories of identity, development, and acceptance. Implications for clinical assessment and intervention are highlighted, and areas for further research are outlined. It is noted that findings should be considered in the specific context of the research, and are not generalisable.
Introduction

Chronic pain has been defined in pragmatic terms as ‘pain that either persists beyond the point at which healing would be expected to be complete, or that occurs in disease processes in which healing does not take place’ (Clinical Standards Advisory Group, 1999/2000; pp.2). This description also notes that chronic pain can be experienced in the absence of evidence of tissue damage, and that it may be accompanied by ‘severe psychological and social disturbance’. Williams and Erskine (1995) highlight that this ‘disturbance’ is a crucial factor in the understanding of chronic pain, giving examples of its negative influence on family relationships and financial status through loss of work.

Currently the majority of research about chronic pain is focussed on under 65 year olds. Bressler, Keyes, Rochon, and Badley (1999) suggest that this is because of a drive to reduce the cost to society of chronic pain through lost working days in younger adults. Compared to this, improving the quality of life of older adults is deemed a lower priority. Although there is a great deal of variability in estimates of prevalence in over 65 year olds, research suggests that at least 13% and at most 83% have a pain problem (Bressler et al., 1999; Fox, Raina, & Jadad, 1999). The current study therefore aims to explore the experiences of this under-represented but clearly significantly affected group, and the introduction will begin with a discussion of existing literature in this area.

The focus of the research is identity in the context of chronic pain, an area of ‘psychological and social disturbance’ that has recently attracted research interest. Historically pain was understood as an alarm system, in which receptors in different parts of the body relayed pain signals to the brain, signifying damage. However, Melzack and Wall (1965) challenged this understanding in their development of the gate control model of pain. This model suggests that the experience of pain is influenced by subjective, affective, cognitive, and behavioural factors, which mediate the effects of information received from pain-receptors in the body. The relationship between chronic pain and identity is one such factor that has been found to influence the experience of the pain.
Following the discussion of pain in older adults, literature about identity in the context of chronic pain will be reviewed.

The third relevant area of research that will be discussed brings together the areas of identity and ageing. Both qualitative and quantitative studies have explored how age-related changes affect people's sense of identity, and have considered ways in which the tension this causes is managed. Finally, the rationale for carrying out a study incorporating all three areas of interest will be outlined. An extensive literature search found only one study which considered identity in people with chronic pain who are also ageing. It is therefore hoped that this study will be valuable in informing clinicians working with this client group.

**Pain and ageing**

**Prevalence**

The UK has an ageing population. Over the last thirty years the proportion of the population aged 65 and over has increased from 13% to 16% (National Statistics Online, 2005). Life expectancy has increased, and is predicted to continue to rise. Boys born in 2004 are expected to live to 77 (69 in 1970) and girls to 81 (75 in 1970). However, statistics show that although people have been living for longer, these extra years are not necessarily healthy ones – life expectancy has been increasing at a faster rate than healthy life expectancy. Indeed, in 1981 the expected time lived in poor health for males was 6.5 years and by 2001 this had risen to 8.7 years. In 1981 the expected time lived in poor health for females was 10.1 years, rising to 11.6 years in 2001 (National Statistics Online, 2004).

Thomas and Roy (1999) highlight that ageing does not inevitably result in increased levels of chronic pain, and suggest that there is a greater variability in health and pain status in the elderly than in any other age group. However, they also note that there are increases in the incidence of painful disease in older people and recovery from accidents is slower. In a review of community-based epidemiological studies looking into the
prevalence of pain complaints in people of different ages, Gagliese and Melzack (1997) found mixed outcomes: most researchers reported a peak in middle age followed by a decline, but some reported an age-related increase and others an age-related decrease in pain. More recently, Breivik, Collett, Ventafridda, Cohen and Gallacher (2006) did a telephone survey of 46,394 people within 15 European countries, including the UK. Like the majority of other researchers, they found a peak in reports of pain in the 41-60 age group. Focussing on the prevalence of chronic pain in the elderly, Bressler et al. (1999) found similarly diverse outcomes in their review of studies of back pain in over 65-year olds. The majority of the studies they included were carried out with community samples, and they concluded that the prevalence ‘likely ranges between 13 and 49%’ (pp.1816). Fox et al. (1999) carried out a review of the studies of older adults in residential care and found that prevalence rates varied between 27 and 83%. All of these researchers highlight that methodological issues had a significant impact on findings. For example, Brevik et al. (2006) note that their telephone survey excluded nursing home residents, thus potentially underestimating the prevalence of pain in older adults. Gagliese and Melzack (1997) also suggested that studies may not take into account variability in likelihood of reporting pain. Although it would be useful to address these issues to gain an accurate picture of the prevalence of chronic pain, these studies highlight that it is clearly a problem for a significant number of over 65 year olds.

Coping and treatment
A number of studies have explored the ways in which older adults cope with their chronic pain. Using a grounded theory approach, Lansbury (2000) carried out interviews and focus groups with 72 people aged 65 and older. She found that they preferred strategies that were familiar, convenient, inexpensive and self-administered, such as home remedies, massage and the use of distraction through social outings. Non-preferred strategies were prescribed treatment, such as medication and physiotherapy. The 48-86 year old women interviewed in a grounded theory study by Roberto and Reynolds (2002) also used exercise, distraction, and change or reduction in their level of activity, as well as medication. Interestingly, Keefe and Williams (1990) compared the use of coping
strategies in people with chronic pain from different age groups. They asked 88 participants aged 21 and over to report how much they used distraction, self-statements, praying or hoping, catastrophising, ignoring, reinterpretation of pain, and increasing activity, and found that there were no significant differences according to age group. Similarly, Prohaska, Keller, Leventhal and Leventhal (1987) found no age differences in the use of 'passive acceptance' or 'active coping' in response to medical symptoms.

Clearly older adults use a wide variety of strategies to cope with their pain, including cognitive and behavioural techniques of pacing, distraction, and reinterpretation. These techniques and others would be recommended and practised in cognitive-behavioural therapy (CBT). Indeed, a recent meta-analysis of 25 existing studies showed that CBT was effective in improving mood, increasing positive coping strategies, and improving functioning in people with chronic pain (average age 48, median effect size: 0.5; Morley, Eccleston & Williams, 1999). However, although studies have found that CBT is effective in treating affective disorders in older adults (Laidlaw, 2001; Nordhus & Pallesen, 2003), there is very little research looking at the use of CBT for chronic pain with older adults.

One of the few studies was carried out by Ersek, Turner, McCurry, Gibbons and Miller Kraybill (2003) who looked into pain management programmes for older adults. Forty five over 65-year olds either attended a pain self management group or received an educational booklet. People who attended the group showed a greater improvement in self-reported physical role function (the degree to which pain impacted on work and daily activities) and pain intensity after the input had been given. Forty three percent showed clinically significant improvement compared to 13% of the educational booklet group. However, this difference was not seen at a three-month follow up, at which approximately 23% of participants in both groups showed improvement from baseline. After input there were no differences between groups in depression and pain related beliefs. This study therefore suggests that pain management programmes were only as useful as education for this group of older adults. The generalisability of the findings is
limited, in that the participants were not significantly depressed at baseline, which is not representative of many chronic pain sufferers who are referred for pain management. In addition, they were predominantly Caucasian.

In an earlier study, Puder (1988) found no age effect when exploring the effectiveness of a stress inoculation training programme for chronic pain. With 69 participants aged between 21 and 80, he found that regardless of age, a group that attended the programme had significantly less pain-related interference with activity than a wait-list control. They also showed increased ability to cope with pain and decreased use of medication and other treatments. The control group then completed the programme and showed similar significant improvements. All these improvements were maintained at a six-month follow-up, and were seen in all age groups. He concluded that ‘there is every reason to include older adults in these [stress inoculation training] programs’ (pp.207). In another study, Cook (1998) evaluated the effectiveness of a cognitive-behavioural pain management programme for a small group (n=17) of over 60 year olds living in nursing homes. When compared with older adults in a generic supportive therapy group, they reported less pain and less pain related disability after the programme and this was maintained at a four month follow up. These studies provide more promising support for pain management programmes to be offered to older adults, but it will be important for the findings to be replicated with larger numbers. In addition, research specifically focussing on the experience of chronic pain in older adults is necessary to inform the development of interventions that meet their specific needs.

Despite this evidence that older adults make good use of similar coping strategies and interventions to younger adults, a review of existing literature showed that a significant amount of elderly people do not get adequate pain management (Gagliese & Melzack, 1997). A number of studies using grounded theory have highlighted barriers that elderly people describe. These include practical factors such as transport or financial concerns (Davis, Hiemenz, & White, 2002; Lansbury, 2000), deficits in knowledge about their diagnosis and pain management methods (Davis et al., 2002), poor relationships with
health care providers (Davis et al., 2002; Roberto & Reynolds, 2002), reluctance to use both pharmacological and non-pharmacological approaches due to anxiety about side-effects or perceived limitations (Davis et al., 2002; Lansbury, 2000), and issues due to comorbidity (Lansbury, 2000). While some of these barriers have also been found in younger adults (e.g. Giesser & Roth, 1998; May, Rose & Johnstone, 2000), it seems that older adults may have particular difficulties in accessing professional input.

Expectations of ageing

Another barrier to effective treatment that has been explored involves the beliefs and attitudes of healthcare professionals. Historically there has been an erroneous and unsubstantiated belief that older adults feel less pain due to changes in their nociceptor and pain processing system (Thomas & Roy, 1999; Upshur & Wootton, 2003). Harkins and Price (1992) suggest that this would lead to reports of pain being minimised and a lower likelihood of treatment being offered. This was indeed seen in research carried out in Sweden by Blomqvist (2002), who interviewed 52 members of staff (nursing, physiotherapists and occupational therapists) about the older adults they worked with. Content analysis of the frequency of the different responses they made to the older adults’ chronic pain showed that the most common response was doing nothing specific. They explained this with stereotyped views regarding the inevitability of pain in old age, as well as citing lack of time and a reliance on medication as explanations.

Older adults themselves have also reported unhelpful attitudes in healthcare professionals. The women with chronic pain interviewed by Davis et al. (2002) reported feeling that doctors had little time for them, with one saying ‘they don’t believe what you say...or pay attention to what you say, because you are getting old’ (pp.124). Lansbury (2000) found that her interviewees reported similar experiences of being disbelieved or rushed through by professionals, which they put down to their age. It is worth noting that the interview questions in this study could be perceived as leading, for example asking ‘Have you come across any barriers to your pain management? e.g. attitudes of healthcare workers?’ Although the interviewees put professionals’ actions down to age, younger adults with
chronic pain have given similar reports of being dismissed (May et al., 2000; Werner & Malterud, 2003), so age-related beliefs may not be a complete explanation.

Having a belief that old age equals pain is not limited to health professionals. A number of qualitative studies have shown that older adults themselves hold such a belief, which was linked to an idea that it therefore could or should be tolerated and managed without professional input (Davis et al., 2002; Lansbury, 2000; Roberto & Reynolds, 2002). This has also been seen in quantitative research. For example, Goodwin, Black and Satish (1999) explored the beliefs and attitudes about the painful disease arthritis in 506 community-dwelling over 75 year olds from different ethnic groups. In interviews with these individuals they found a substantial number of people in each ethnic group felt that arthritis was a normal part of ageing, ranging from 41.8% of Black Americans to 62.5% of non-Hispanic White Americans. Other explanations put forward were it being caused by work and the environment, and heredity. Approximately 23% of all participants felt that nothing could be done to make arthritis better, with no group differences seen. These beliefs of ‘normality’ and ‘untreatableness’ were linked with lower utilisation of healthcare services.

A possible consequence of holding such beliefs could be that older adults are missing out on potentially useful interventions. This was considered in a unique study by Rakowski and Hickey (1992). They interviewed 1391 people over 70 years old who had reported functional difficulties as part of a larger study, and found that 72 of them attributed these difficulties to old age. In a follow up four years later, this group had elevated rates of mortality as compared to those who attributed functional difficulties to other things, even when other factors such as health problems, age, gender, and social contacts were controlled for. Unfortunately no measures were taken to explore the presence of mediating factors for this relationship, but the authors suggest that it may relate to self-care and health promoting activities. Indeed, Sarkisian, Prohaska, Wong, Hirsch and Mangione (2005) found that expectations of age-related decline related to lower levels of physical activity among older adults.
A frequently cited study that also explored the implications of attributing health issues to old age was carried out by Prohaska et al. (1987). They gave 334 adults a number of illness scenarios, and asked how they would respond to these. They also asked them whether the symptoms described could be attributed to ageing. They found that attribution to ageing was more likely in older adults and was more frequent if symptoms were mild. It was also associated with a tendency for participants to say they would delay seeking medical treatment. The same was found in the 'field' part of the study, where Prohaska et al. (1987) asked 168 participants seeking medical care about the background to attending the medical centre. As well as having this behavioural impact, Prohaska et al. (1987) found that attributing symptoms to ageing was related to mood, whereby it was associated with a less negative emotional response to the symptoms. Although causality cannot be inferred, it may be that it protected participants from worry, depression, and fear. Although this study did not relate to chronic pain, it highlights that attributions about the cause of pain can have a significant effect on mood and behaviour.

When considering the attributions that older people make about the cause of their pain and related functional disability, Sarkisian, Liu, Ensrud, Stone and Mangione (2001) suggest that it is important to differentiate between people with a new disability and those with life-long or chronic conditions. They highlight that it may be reasonable to believe that a chronic condition will not improve or be treatable in old age but that a new disability may be treatable. They therefore focussed their research on 657 women over the age of 67 who had a disability that had developed in the previous four years, and attempted to determine what individual differences related to a tendency to attribute it to old age. They found that most factors such as mood, education, medical comorbidity, and level of activity were not predictive. Instead, like Prohaska et al. (1987), they found that a key predictor was age itself, whereby older adults were more likely to attribute problems to old age. Indeed, 27% of over 80 year olds viewed old age as the main contributor to functional difficulties, compared to 4% of under 70 year olds. It is worth noting, however, that across all participants arthritis was reported as the main cause of disability. It may be that old age is seen as the cause when a diagnosis has not been
received or when difficulties are not perceived to relate to the disease. Sarkisian et al. (2001) suggest that attributing disability to old age may be a coping mechanism which reduces emotional distress: people manage a situation they feel is unchangeable by 'blaming' old age. It may be that attributing problems to old age is only unhelpful in situations where input could be given to reduce or control symptoms. At other times it relates more to acceptance, which is in fact often seen as a treatment target.

It seems that attributions about the cause of pain are likely to have an impact on the emotional and behavioural responses that are made. In a related piece of research Gibson and Helme (2000) explored locus of control (LOC) in chronic pain. They asked 196 30-95 year old adults attending a pain management programme to complete a number of psychometric measures. They found older adults were more likely to have a chance LOC than younger adults, which may relate to the idea that pain is caused by an unstoppable and unmanageable ageing process. Across the whole sample, having a chance LOC was a good predictor of depressive symptoms and greater pain related interference. Conversely, having an internal LOC was related to lower levels of pain and effective use of coping strategies. The authors note that it is not possible to infer causality from this correlational study. It may be that a chance locus of control results in unhelpful coping strategies, increased pain and suffering. Alternatively, unsuccessful coping leading to greater pain and suffering may lead people to believe less in their own capacity to control the situation.

Summary
Chronic pain is an important issue for a significant number of older adults. Although they make use of many coping strategies, there are a number of barriers to intervention that they face. One potential barrier is an expectation of inevitable decline in old age, which has been found in a number of studies. When such an expectation is held by healthcare professionals it may lead to the denial of adequate pain management for older adults. The implications of older adults holding these beliefs are more complex. Some research has shown that it relates to a delay in seeking potentially useful medical input, and it may also
relate to an external locus of control and the use of unhelpful coping strategies. However, studies have also shown that it can relate to reduced emotional distress, and so attributing difficulties to old age may be protective in situations where medical input has been found to be ineffective.

**Pain and identity**

It has been suggested that chronic pain is ‘a threat to self and identity’ (Crombez, Morley, McCracken, Sensky, & Pincus, 2003, pp.651). For example, this was found in the seminal study by Osborn and Smith (1998) who used interpretative phenomenological analysis (IPA) to explore the experience of chronic back pain. The women they interviewed compared their ‘current self’ to their ‘past self’, which for many was felt to be the ‘real self’ that had been replaced by a false persona. There are numerous theoretical and philosophical constructions of ‘self’ and ‘identity’ (for detailed discussion see Blumstein, 1991; Higgins, 1987; Niedenthal & Beike, 1997; Stryker & Statham, 1985). A comprehensive exploration of the various constructions is not possible here, but it has been proposed that they can be divided into two broad types: those in which the self is defined by connections to concepts of others (interrelated self-concepts) and those in which such connections are not present (isolated self-concepts) (Niedenthal & Beike, 1997). A number of theories of identity of both types have been explored and supported with evidence in relation to chronic pain, and these are outlined below.

Self-discrepancy theory was formulated by Higgins (1987), and it remains widely used and quoted. This conceptualises the ‘self’ as isolated from connections with others, and differentiates between different ‘selves’ an individual has: the ‘actual self’, which is defined in terms of an individual’s *actual* characteristics and attributes; the ‘ideal self’, which includes the features that a person *would like to* have; and the ‘ought self’, which relates to those features that a person feels that they *should* have. Higgins (1987) found that ‘self-discrepancy’, whereby these ‘selves’ are very different, caused distress. Discrepancy between actual and ought selves caused agitation-related emotions such as fear or guilt, and discrepancy between actual and ideal selves related to dejection-related
emotions such as disappointment or shame. Beliefs about these selves were variably available and accessible, which affected how distressing any discrepancies were. A similar theory was proposed by Markus and Nurius (1986), who discuss the idea of 'possible selves'. These represent people's ideas of what they would like to become in the future, described as the 'hoped for' self, and what they are afraid of becoming, described as the 'feared for' self. Possible selves comprise hopes, fears, goals and threats, and provide an evaluative context for the current self. They also act as an incentive for future behaviour whereby action is taken to become a 'hoped-for' self, or avoid becoming a 'feared-for' self, thus resolving the 'self-discrepancy'.

Pincus and Morley (2001) suggested that chronic pain can be understood within a model that incorporates both this self-discrepancy theory and schema theory. In schema theory, schemas are conceptualised as stored bodies of knowledge which affect the encoding and retrieval of information. It is suggested that we have a self schema in which we organise information about ourselves, again an isolated conceptualisation of the self. The model also suggests that we have pain and illness schemas, and distress is thought to occur when our self schema and our pain and illness schemas are 'enmeshed', so that negative information about pain is interconnected with negative information about the self. An example of this would be when someone's pain when walking makes them feel sad that they are not able to shop alone, and fearful of further loss of independence in the future.

Research by Morley, Davies, and Barton (2005) provides support for this model. They asked 89 chronic pain patients to complete self-report measures of depression and acceptance. They were then asked to generate lists of characteristics of their actual, hoped-for and feared-for selves, and judge whether these were dependent on the presence or absence of pain, i.e. enmeshed with pain. They found that depression and lack of acceptance were significantly related to the degree to which the 'hoped for' self is conditional on the elimination of pain, with more distress seen when there was greater self-pain enmeshment. It is important to note that this study used a cross-sectional design, so causality cannot be determined: the hopeless thinking seen in depression may
lead to this enmeshment of self and pain, but alternatively self-pain enmeshment may lead to depression and lack of acceptance. In addition, participants were all under 65, so the findings may not be generalisable across the age range.

An exploration of pain and identity using a different, interrelated conceptualisation of the self was carried out by Harris, Morley, and Barton (2003). The study took a symbolic interactionist stance, suggesting that identity exists in the context of relationships. Roles were seen as external manifestations of social interaction (e.g. I am a wife), and attributes were understood to be internalised representations of the self in relation to others (e.g. I support others). In their study they asked 80 chronic pain patients to report the roles and attributes they had, both currently and prior to the onset of their chronic pain. They found that after the onset of chronic pain, people reported significantly fewer roles and personal attributes, predominantly in the domains of occupation, friendship and leisure. These losses were predictive of scores on self-report measures of depression. It is important to consider the potential that participants idealised the past in their retrospective self-reporting on life before pain, thus emphasising these losses. In addition, the participants were all under 65, and so were still working before the onset of their pain. For older adults with chronic pain this loss of occupational role may have already taken place through retirement, which may change its meaning and emotional impact.

An understanding of chronic pain informed by these conceptualisations of identity highlights some potential areas for clinical intervention. In terms of assessment, Büchi, Sensky, Sharpe and Timberlake (1998) have devised an innovative measure of 'enmeshment', which involves patients graphically representing the relative positions of 'themselves' and 'illness' in their life. In a small-scale study of 26 people with chronic pain, they found that the distance they put between the two was inversely correlated with measures of depression and coping. The authors suggest that this tool may be a useful way to measure therapeutic change. In relation to therapeutic input, although not referring specifically to chronic pain, Higgins (1987) suggests that therapy could target an individual's 'actual self' by behaviourally modifying activity or cognitively modifying.
interpretations of performance. Alternatively it could target ‘ideal’ and ‘ought’ selves by challenging their level or relevance, utility, and reasonableness. This is seen in Acceptance and Commitment Therapy (Hayes, Strosahl & Wilson, 1999), an approach that aims to reduce overidentification with an unrealistic idea of the self, focusing on acceptance of thoughts and feelings, and making behavioural changes.

As seen above, quantitative research has found that a number of theories of the self are helpful in understanding distress in chronic pain. Alongside these studies, it is important to consider qualitative research that is led by individuals with chronic pain, ensuring that theory continues to be grounded in their experiences. One study that did this was carried out in Sweden by Hellstrom (2001). This used an ‘Empirical Phenomenological Psychological’ method to interpret transcripts from interviews with 21 people aged between 24 and 73 with chronic pain. These interviews explored the temporal aspects of participants’ self-concepts, looking at the past, the present and the future. Four factors arose from the data: (1) the distanced foreign body, where participants viewed their body as separate from their ‘self’; (2) maintaining the consistency of self, where people described a struggle to keep characteristics of their past (somewhat idealised) selves alive; (3) the entrapped self, where participants described being trapped both in their bodies and in time, unable to do or plan what they would like to do; and (4) projected selves, where people felt that others, such as friends, doctors and the media, projected and defined their identities. In another qualitative study by Clarke (2001), ‘Jean’ explains how chronic pain is a ‘distraction of your mind or your soul or your inner being’ (pp.457). These rich descriptions help to augment clinicians’ understanding of what threats to identity in the context of chronic pain feel like.

When exploring identity it is important to consider the cultural context of the research in this area. The studies described above have all taken place within a Western culture, and it may be that the theories that have arisen are not applicable in a non-Western context. This was the case in research carried out by Yuki (2003), who asserted that social identity theory was not a useful explanation for collectivistic behaviours among East Asian
participants. Smith and Bond (1998) provide a comprehensive discussion of cultural issues in understanding identity, suggesting that conceptualisations of the self and valued aspects of identity vary across cultures. People from individualistic cultures are said to see themselves as 'independent' and have freedom and self-determination as goals, while people from collectivist cultures are said to see themselves as 'interdependent' and strive for harmonious relationships with others.

Summary
The relatively recent exploration of identity in the context of chronic pain seems to be a useful direction to take in terms of developing therapeutic assessments and interventions, and enriching clinicians’ understanding of the experience of chronic pain. However, awareness of the cultural context of research in this area is vital in considering the applicability of research to clinical practise.

Ageing and identity
The third area of research that relates to the current study is the relationship between ageing and identity. Clarke (2001) explores this in depth, using grounded theory to analyse interviews with 22 women who were over 60 years old. She asked them about the changes in their bodies that had accompanied ageing, their thoughts and feelings about these, and about their concept of beauty and sense of ‘selfhood’. This study specifically focussed on the experiences of white women in Canada, so the experiences described need to be considered with an awareness of their cultural context. A theme that arose in the majority of women was a tension between the ‘inside’ self and the ‘outside’ self. They did not feel their chronological age, and their bodies were seen as mere receptacles for their ‘true’ inside selves. For many, this ‘inside’ self was experienced as continuous throughout their life. Interestingly, some reported having a feeling of shock and disappointment when they were confronted with images of themselves, for example in the mirror, although others had ‘got used to it’. A second theme was the sense of loss and frustration due to physical decline, and a feeling of entrapment. This was often accompanied with a sense of pragmatism, if not acceptance.
and participants also downplayed the importance of the body when compared to the mind. They described a re-evaluation of priorities whereby individuality and personality had become more important than youthfulness, beauty and energy.

Brandtstädt and Greve (1994) describe a comprehensively researched and empirically supported model that can be used to understand the ‘self’ in the process of ageing. This model is closely related to self-discrepancy theory, conceptualising the self as ‘isolated’ i.e. not dependent on relationships with an ‘other’. Brandtstädt and Greve (1994) suggest that the developmental changes that come about through ageing are a threat to identity, but highlight there is little empirical evidence to suggest that older people have problems with self-esteem or well-being. The authors suggest that a positive view of the self is preserved by dynamic processes of assimilation, accommodation and immunization.

**Assimilation** refers to problem-directed action to transform situational circumstances. For example, if an individual experiences physical changes they may attempt to keep fit or use a hearing aid, thus remaining fit, able to socialise, and retaining an appearance of ‘youthfulness’. These actions can only take place when developmental changes are perceived as reversible or controllable. **Accommodation** refers to the readjustment of personal goals and standards so they fit the current situation or emergent constraints. For example an individual may reduce their expectations about the distance they want to walk. Clearly some goals and values will be harder to disengage from than others, particularly those that are felt to be key to the sense of self. Accommodation also involves making self-enhancing comparisons, for example comparing oneself to worse-off people of the same age as opposed to younger, fitter people. The authors suggest that the process of accommodation should not be conceptualised as showing resignation or hopelessness, but instead should be seen as an adaptive (although not consciously reasoned) response to changes that helps to maintain a continuous and positive sense of identity. However, they recognise that premature accommodation may occur, preventing individuals from striving to reach goals that are actually achievable. The final process
that Brandtstädter and Greve (1994) describe is *immunization*, whereby the processing of information about the self is influenced so that discrepant information is defended against. For example people may discredit information from the present as defining them, and instead focus on past accomplishments and characteristics. Similarly, the importance of short-term memory may be devalued, and the value of life experience increased as cognitive abilities change. The women interviewed by Clarke (2001) could be seen to be using this process in their prioritisation of the mind over the body and of personality over energy.

Another way in which identity has been explored in older people is using the concept of possible selves (Markus & Nurius, 1986). Frazier, Hooker, Johnson and Kaus (2000) carried out a 5-year longitudinal study looking at possible selves in adults who were between 55 and 89 years old at the start of the research. They asked 114 participants to generate possible selves at Time 1, and asked them to repeat the task 5 years later. Hoped for and feared for selves in physical and health domains were mostly ‘emergent’, i.e. not present at Time 1, but present at Time 2, while selves in other domains were constant over time. This suggests that both continuity and change in values and important aspects of identity are evident as ageing occurs. Being a longitudinal study, this gives credible evidence for a causal relationship between ageing and change in identity. However, there was significant dropout, with only 40 participants at Time 2, which limits the strength of the evidence.

Following on from this study, Frazier, Johnson, Gonzalez and Kafka (2002) attempted to determine when and why changes in possible selves are seen. They considered two hypotheses: firstly, that normative age-related changes may prompt people to hope for good health and fear poor health. Alternatively, that pathological changes in health mean that illness and disability become important considerations. They asked 151 over 60 year olds to generate hoped for and feared for possible selves, as well as completing self-report measures of general health, locus of control and quality of life. Logistical regression analysis of this data gave support to the former hypothesis, with age being the strongest
predictor of hoped for health-related selves. The oldest adults were more likely to report feared for and hoped for selves in that domain, although those with better physical functioning and emotional well-being were less likely to, highlighting that well being is important too. These findings could lead to an expectation that older adults with chronic pain would have particularly prominent feared for and hoped for selves in the domain of health.

These studies, like many in this area, are limited in that they have predominantly white participants. One of the few studies that considers aspects of identity and ageing in a non-white population was carried out by Waid and Frazier (2003). They recruited 100 over-60 year old Spanish speaking (predominantly Cuban) and non-Hispanic Americans and compared the possible selves that they reported. They found that non-Hispanic participants were more likely to report hoped for selves in the ability/education domain and feared for selves in the physical domain. In contrast, Hispanic participants were more likely to report feared for and hoped for selves in the family domain and feared for selves in the bereavement domain. The researchers suggested that this relates to collectivist and individualist values of self-sacrifice and self-enhancement (respectively). Interestingly, people aged over 75 in both cultural groups were unlikely to report possible selves in the ability and education domains, perhaps highlighting changing priorities and expectations across the lifespan. Alternatively this could be a cohort effect.

Summary
It seems that the process of ageing can be experienced as threatening to identity, for example changing appearance and affecting abilities. Ageing also increases the valence of certain aspects of identity, although this may depend on the cultural context. People seem motivated to retain a constant sense of identity over time, and make use of a number of strategies to do this.
Pain, ageing and identity

Roberto and Reynolds (2002) brought together the three areas of research explored above in their grounded theory study of older women with chronic pain. The women described changes in their involvement in social and individual activities and discussed how this had influenced their sense of identity – it was as if they had ‘become’ different people. For some women, their functional difficulties meant that they could not continue to hold valued social roles, such as volunteer work. Others described changes in characteristics with one person stating ‘I’m a different type of personality’, and another feeling frustrated that she had ‘never been lazy’ yet was now unable to do a number of things. In addition to the changes these women felt themselves, there was also an awareness of the perceptions that others had of them. One woman’s comment that she did not want ‘to be seen as old and whining’ suggests that she does not necessarily identify with this label. The woman described that to avoid these perceptions she had become a ‘very good actor’, thereby not showing her true self. Interestingly, another difficulty that these women faced was having their abilities unrealistically idealised by their children. One stated that ‘they don’t understand that you can’t be the person you used to be’, and another said that her children had a ‘total denial that Mother is getting older’. It seems that these women attributed these changes sometimes to their pain and sometimes to ageing itself.

This study gives a valuable insight into the experiences of women living in the community with chronic pain. Identity was clearly an important issue but it was not the main focus of the study so there was limited exploration and discussion of this area. It is also worth noting that although the authors describe the group as being ‘older adults’ the sample included three women aged between 48 and 52, with the remainder being aged 66-86. It is unclear what contribution the younger women made to the analysis, but it may be that their experiences were somewhat different to the over 66 year olds.

Conclusion

Chronic pain is clearly a significant issue for many older adults, but there is a limited body of research in this area. Studies have shown that there may be aspects of their
experiences that are unique, as well as aspects that are similar to the experiences of younger adults. Concepts of identity have been applied to both chronic pain and ageing, and have important implications for the provision of therapeutic intervention. The aim of the current study is to improve understanding of the particular experiences of older adults with chronic pain, specifically considering aspects of identity. It is hoped that this will contribute to the development of more effective pain-management services for this group.

The choice of a qualitative approach to explore this area was made for a number of reasons: firstly, an exploratory approach will help to enrich clinical understanding of an area that has received little research attention thus far. Secondly, identity as a concept has been explained in many different ways, and this approach will allow a meaningful conceptualisation to emerge from the data rather than imposing a concept. Finally, the study will guide further quantitative and qualitative research in this area, and will help to keep theory grounded in the experiences of older adults with chronic pain.

**Method**

**Rationale for methodology**

Interpretative Phenomenological Analysis (IPA) aims to ‘explore in detail how participants are making sense of their personal and social world’ (Smith & Osborn, 2003, pp.51). It recognises that people’s experiences are mediated by their beliefs, expectations and judgements, and therefore that people can experience the same ‘objective’ condition in very different ways. Within this approach generalised statements about the world are not made, but instead the world ‘as it is experienced by human beings within particular contexts’ is the focus (Willig, 2001, pp.51). IPA recognises that the researcher can never truly access or represent another individuals’ experience, as they are viewing them through their own interpretative lens. It therefore requires that the researcher is reflective about their influence on the research and attempts to reduce its impact. It also requires that the researcher is open about their perspective so that readers are aware of the context of the interpretation of the data.
IPA was chosen rather than other qualitative approaches for a number of reasons. Firstly, the openness in IPA about the researcher's position and the strong emphasis on personal reflection are felt to be important. While the nature of the analysis in IPA is very similar to that seen in Grounded theory, the two approaches differ in where they locate the researcher. In the original empiricist approach to Grounded theory (Glaser & Strauss, 1967) the researcher is positioned as a 'witness' to the 'reality' that they are observing, and their standpoint is considered to be secondary to the data they are collecting and representing (Willig, 2001). This seems to overlook the impact of the researcher's beliefs and values on the research process, and the approach has therefore not been chosen in this study. It is worth noting that the more recent, social constructionist version of grounded theory (Chamaz, 1990) is more like IPA in its understanding that the product of the analysis is the researcher's interpretation of the participant's representation of reality.

Secondly, IPA has been developed as a psychological approach, while Grounded theory has been developed from a sociological tradition. Both approaches can contribute to theory development, but they differ in the emphasis placed on this: Grounded theory has it as a key aim, while IPA has the more modest aim of increasing understanding of the psychosocial world of the individual (which may in turn lead to theory development). The primary aim of the current study is to explore and describe individual experience of chronic pain, and IPA is therefore deemed to be the most suitable approach to use.

Finally, as the goal of the study is to explore experience it is felt appropriate to take the epistemological stance that is held in IPA. This approach assumes that the content of people's narratives gives a meaningful representation to their experience (albeit mediated by language, culture, and socio-political factors), so analysis of the content of interviews is viewed as a valid way of accessing these experiences. This is in contrast to discourse analysis, which follows a social constructionist epistemology whereby language is understood as a behaviour that creates a construction of the world that must be understood in the context of power and culture. Discourse analysis therefore involves detailed and explicit analysis of language and its function (Willig, 2001).
Ethics

Ethical approval for this research study was obtained from three committees: London - Surrey Borders Local Research Ethics Committee, Epsom & St Helier University Hospitals NHS Trust Research & Development Committee, and University of Surrey Research Ethics Committee (see Appendix 1). There were three key ethical considerations, and measures were put in place to address these:

- *The possibility that participants may become distressed as a result of the interview.*
  The interviewer was experienced in managing distress and participants were informed that they were free to withdraw from the interview at any time. A helpline number was also provided for use after the interview.

- *Consent.* A detailed, large print consent form was used and the information sheet clearly stated that deciding not to take part or withdrawing from the research would not affect people’s current or future care.

- *Confidentiality.* All identifying information was removed from interview transcripts and they were stored in password protected computer files.

Participants

Nine people were interviewed for the study. A summary of their demographic information is provided in Table 1. Smith and Osborn (2003) suggest that IPA should involve a ‘fairly homogeneous sample’ (pp.54). Participants in this study are all over 65 and suffering from chronic pain, which are the key aspects of the research question. However, there are differences in other demographic areas, for example pain duration and place of recruitment.

As there are a small numbers of participants involved in IPA studies, random or representative sampling is inappropriate (Smith and Osborn, 2003). It therefore uses purposive sampling, whereby participants are selected for whom the research question will be significant. In terms of numbers, Smith and Osborn (2003) suggest that using six or seven interviews provides enough information to be useful, but not too much as to be overwhelming.
Table 1: Demographic information for participants

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<tbody>
<tr>
<td>Female: Male</td>
<td>8:1</td>
</tr>
<tr>
<td>Age</td>
<td>65-81 (mean and median age 71)</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>All identified as White British</td>
</tr>
<tr>
<td>Marital status</td>
<td>4 widowed, 5 married</td>
</tr>
<tr>
<td>Accommodation</td>
<td>7 in own homes, 2 renting</td>
</tr>
<tr>
<td>Educational level</td>
<td>1 had a degree, 8 left school with a school certificate at around the age of 15.</td>
</tr>
<tr>
<td>Pain duration</td>
<td>4 for 1-5 yrs; 2 for 15 yrs; 3 for 40 - 45 yrs. All participants reporting longer duration also reported deterioration within the past 5 -10 yrs.</td>
</tr>
<tr>
<td>Recruitment route</td>
<td>7 from pain management programme, 2 from TENS clinic</td>
</tr>
<tr>
<td>Diagnosis/es</td>
<td>Rheumatoid arthritis (1 participant); osteoarthritis (2); spondylitis (1), injury caused by accidents (4); disc damage (2); diabetes (1); injury caused by surgery (1); scoliosis (1); no diagnosis (1)</td>
</tr>
<tr>
<td>*Pain rating / 100</td>
<td>50 - 100 (mean 67.5).</td>
</tr>
<tr>
<td>*HADS</td>
<td>Anxiety: 3 - 12 (mean 6)</td>
</tr>
<tr>
<td></td>
<td>Depression: 3 - 12 (mean 6.8)</td>
</tr>
<tr>
<td>*RMDQ</td>
<td>6 - 18 (mean 12)</td>
</tr>
<tr>
<td>*PSEQ</td>
<td>27 - 44 (mean 33.3)</td>
</tr>
</tbody>
</table>

* Information gathered as part of routine screening assessment for the pain management programme, therefore only available for the 7 participants recruited through this route.
HADS: Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983).
RMDQ: Roland Morris Disability Questionnaire (Roland & Morris, 1983)
SEQ: Pain Self-Efficacy Questionnaire (Nicholas, in press)

To be involved in the research, participants had to be 65 years old or above and have chronic pain. Chronic pain was defined according to the Clinical Standards Advisory Group (CSAG, 1999/2000) criteria described above. People with dementia and non-English speakers were excluded from the study. This was because this research method requires that people speak fluently about their experiences.

Potential participants were identified through a pain clinic in Surrey, either by their attendance of an initial assessment for a pain management programme or at an initial consultation session regarding the use of a TENS machine. They were given a covering letter and an information sheet about the research (Appendices 2 and 3), and those who immediately expressed an interest in participating were asked to fill in a consent form (Appendix 4). Otherwise they were asked to contact the pain clinic if they decided they
would like to take part, and were sent the consent form if necessary. With consent, the GPs of interested participants were contacted prior to the interview taking place (Appendix 5). Possible implications of this recruitment strategy for the findings are addressed in the discussion section.

Data collection
Smith and Osborn (2003) suggest that semi-structured interviews are ‘the exemplary method for IPA’ (pp.55). The interview schedule acts as a guide rather than being strictly adhered to, so interesting and unexpected areas that arise can be followed up and explored. The interviewee is therefore given the opportunity to describe their unique experience and plays a part in directing the interview. This leads to richer data, and aids the development of rapport with the interviewer.

Interview schedule
The questions in the interview schedule were developed after discussion with a clinician working in the pain management field with an extensive experience of working with people with chronic pain. It was also discussed with a research psychologist with experience of IPA who provided feedback in terms of the structure and process of interviewing. In addition the existing literature in this area was consulted. The schedule was then presented at a multi-disciplinary team meeting at the pain clinic, and the feedback from this was used to refine a number of questions.

The interview schedule can be found in Appendix 6. In broad terms, it focuses on the impact of chronic pain and ageing on participants’ sense of identity. It begins with straightforward background questions, which were included to make the beginning of the interview less anxiety provoking for the participants. It then goes on to ask about the participants’ social roles and activities, their personality, and their beliefs and values. The impact on these that chronic pain and ageing may have had is then explored. Participants are then asked what they expect for the future in the context of their pain and age. Finally, feedback questions are included to ensure that the process is comfortable.
IPA attempts to reduce the power differential between researcher and participant by eliciting feedback about the interview from each participant and using this to inform further interviews. As such, the interview schedule was revised over the course of data collection to follow up areas of interest that had arisen from earlier interviews. A few practical amendments were also made to improve the clarity of questions and the flow of the interview.

**Interview process**
Participants were interviewed either in a private office at the pain clinic or at their own home, depending on their preference. Interviews took approximately one hour, and afterwards participants were asked to fill in a short demographic questionnaire (Appendix 7). Every effort was made to create a relaxed environment, and to ensure that participants were aware of their right to withdraw. The interviews were tape-recorded and afterwards were transcribed verbatim, with identifying information removed (see Appendix 8 for sample transcript).

**Analytic process**
The idiographic approach to analysis described by Smith, Jarman and Osborn (1999) was used. Firstly the transcript of an interview in which the participant had been particularly rich in her narrative was looked at in detail. It was read a number of times, and thoughts, ideas, associations and connections that arose were noted in the left hand margin. Reading through the transcript again the right hand margin was used to note themes that emerged. These themes were then listed and those that seemed to be connected were clustered together, checking back with the transcript to see that this clustering related to the participant's words. Clusters related to overarching concepts, and these 'superordinate' themes were named. A table of the superordinate and sub-themes including example extracts from the transcript was created.

The first transcript analysed was from an interview with a female participant recruited from the pain management programme who had had chronic pain for 15 years. A
similarly detailed analysis was then carried out with transcripts from a participant from the TENS clinic, a male participant, and one with a more recent onset of pain in order to determine whether similar or significantly different themes arose. They were similar enough to conclude that the sample could be considered ‘fairly homogenous’. The tables of superordinate themes were therefore consolidated, with transcripts re-read in the context of the new themes that arose. The final five transcripts were read looking for instances of these superordinate themes, although the possibility of finding new themes remained open. The process was cyclical, involving repeated re-reading of transcripts and checking for examples of themes in the data. In carrying out the analysis, themes that were relevant to the research question and that were frequently or richly illustrated were particularly focussed on, and those which did not seem to fit or lacked evidence were dropped (Smith & Osborn, 2003).

Quality checks
A number of authors have attempted to develop sets of criteria for the assessment of qualitative research, in order to legitimise qualitative approaches as well as ensuring they are used and reviewed correctly (see Elliott, Fischer & Rennie, 1999; Henwood & Pidgeon, 1992; Yardley, 2000). They are broadly similar, including considerations of fit with data, richness of analysis, reflexivity, usefulness, and coherence.

For the purposes of this study the guidelines developed by Elliot et al. (1999) were used. These highlight that some criteria are shared with quantitative research, such as a relationship to current literature, clear purpose and value, appropriate methodology, ethical conduct, and clarity of presentation. The authors also suggest seven criteria specific to qualitative research. In order to meet these in the current study, effort has been made to be transparent about the research process. For example, information about the demographic background of participants, a sample transcript, and quotations have been included within the report. In addition, it is hoped that the study gives a coherent narrative that is relevant and useful for clinicians. Attempts to meet other criteria of ‘providing credibility checks’ and ‘owning one’s perspective’ are described below.
Providing credibility checks
By carrying out a detailed analysis on four participants it was possible to consider convergences and divergences in the data (Smith & Osborn, 2003) from interviews with participants recruited from the two routes, with both male and female participants, and from those with recent onset and longstanding chronic pain. These analyses suggested that the participant’s experiences were homogenous enough to be analysed as a group.

In the later stages of analysis, a meeting with a clinician with extensive experience of working in the field of chronic pain was held to discuss the emerging themes and their relationship with the data. Discussion about the applicability and usefulness of the findings to clinicians in this field was also had.

A decision was taken to not meet with participants to discuss emerging themes as part of the analytic process. IPA specifically notes the interpretative nature of the analysis, and participants would therefore not be expected to share the interpretative perspective of the researcher. Henwood and Pidgeon (1992) also note that any such discussion with participants would be in the context of power differences between ‘the researcher and [the] researched’, making the value of the outcome of such a discussion questionable. However, ideas about potential themes were checked with participants during the research interviews themselves. Some of these ideas had arisen during the interviews, and some during the process of transcribing interviews and reflecting on their content. Over the course of data collection a few new questions were introduced to the interview schedule to explore these. For example, in later interviews participants were asked ‘Do you see your pain as a significant part of your life? Of who you are?’.

Owning one’s perspective
Over the course of the research a research diary was used to reflect on values, interests and assumptions, and the impact that these may be having on the research. In addition an interview was held with a colleague at the beginning and end of the research process to discuss the research. Some themes from these reflections are outlined in Table 2.
Table 2: Reflections on the impact of the researcher on the research process

During my clinical training I spent six months working with older adults with mental health issues. I also attended a number of lectures about older adults, and read literature about ageing while developing my research question. Many of the topics covered emphasised negative experiences of ageing, including vulnerability to abuse, ageism, institutionalisation and loss. In my interview at the beginning of the research process I discussed with my colleague my desire to help the voice of older adults be heard. This perhaps reflected a belief that older adults are devalued in our society, which I continue to hold. However, also could reflect a somewhat patronising view that older people are passive ‘victims’ in need of help.

This idea was challenged straight away when I arranged my first interview over the telephone. In my diary I noted that ‘speaking to [her] was quite a surprise – she seemed very organised and busy – still working? Not quite the stereotype of an older person in pain I’d expected!’.

Over the course of the interviews I felt heartened by numerous examples of resilience and adaptation in the face of distress from the participants. However, some experiences were not so positive. Participants described situations which left me feeling quite sad, and I perceived some as vulnerable - ‘The interviewee seemed quite fragile – I worried about pushing her’. It was important for me to retain a balanced view of ageing in all of the interviews, following up statements about coping as well as those about restriction and loss.

I have not been affected by chronic pain, either personally or through anyone I know. However, my reading about this topic led me to expect that pain would have an impact on people’s sense of identity. It was important to be open to the possibility that this was not the case for some people. Finally, as a trainee clinical psychologist, my conceptualisations of individuals and the world are influenced by a number of psychological theories, particularly cognitive and systemic. I therefore tried to ensure that I ‘heard’ and responded to experiences that did not clearly ‘fit’ theory. This was perhaps aided by my reading of qualitative papers which demonstrated the complexity of individual experience.
Table 2 (continued):

Over the course of the analysis I attempted to remain open to varied interpretations of the data, as well as checking with others to ensure my interpretations were credible. However, I will still have been influenced by my own beliefs and perceptions both during the interviews themselves and in my analysis. For example, in my interview prior to the research I commented that I hoped the project would not have a negative feel. I may therefore have been biased towards noticing examples of hope and strength in participants’ accounts. In addition, as a white British woman I may have been more open to noticing themes that fit with salient values in my cultural context such as individual empowerment.

Analysis

Three super-ordinate themes arose from the analysis (see Table 3). Appendix 9 shows sections of each participant’s transcripts which fit these themes.

Table 3: Super-ordinate and sub-ordinate themes

<table>
<thead>
<tr>
<th>Super-ordinate and sub-ordinate themes</th>
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</thead>
<tbody>
<tr>
<td>1 Maintaining identity despite pain</td>
</tr>
<tr>
<td>1.1 Stopping doing or keeping going</td>
</tr>
<tr>
<td>1.2 Resisting unwelcome changes in personality</td>
</tr>
<tr>
<td>1.3 Managing others’ perceptions</td>
</tr>
<tr>
<td>1.4 Identity in the past and the future</td>
</tr>
<tr>
<td>2 Pain in the context of ageing</td>
</tr>
<tr>
<td>2.1 Emotional implications of attributing pain to old age</td>
</tr>
<tr>
<td>2.2 Maintaining identity despite age</td>
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<tr>
<td>2.3 Living with ageism</td>
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<tr>
<td>2.4 The significance of pain in relation to multiple problems</td>
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<tr>
<td>3 The relationship with pain</td>
</tr>
<tr>
<td>3.1 A struggle for control</td>
</tr>
<tr>
<td>3.2 Putting up with pain</td>
</tr>
</tbody>
</table>
Themes

1 Maintaining identity despite pain

Pain posed a threat to different aspects of identity, but participants were able to maintain a constant sense of self in spite of this. Pain had the potential to limit what they were able to do, but participants often ‘kept going’, particularly with highly valued activities. Pain also threatened to affect participants’ mood and personality characteristics. However, they were determined not to ‘become’ negative people, and used cognitive strategies of altering criteria for evaluating quality of life and downward comparison to maintain a positive outlook. In order to manage their outward appearance in relationships with others they withdrew or covered up their pain. Finally, they described their identity over time, and were motivated to retain a sense of constancy from the past and into the future.

1.1 Stopping doing or keeping going

June stated that ‘if you've got pain...you automatically stop doing things’, which was indeed the case for all of the participants. They gave many examples of tasks or activities they could not do, and they attributed these limitations to pain. Pain made participants physically incapable of certain things, and related tiredness meant that their range of activity in a day was restricted. In addition, some of the consequences of pain had an indirect impact on activity. For Emma, the pain-related hospital appointments ‘conflict with, with what I would like to do’, while Jill found the equipment she uses for managing pain and disability intrusive:

Can’t even really go out for the day...I’d have to, as well as the wheelchair I’d have to take my stick as well. So it's all sort of inconvenient, you know. Takes the pleasure out of it...spoils it

However, when describing their level of activity, most participants explained that they had not stopped doing things, but their abilities had changed. Instead of walking they ‘tottered’, ‘limped’, or ‘hobbled’, and the amount they could do in a day was reduced:
I can take the every day, although I couldn't do, say, a whole day's physical activity unabated. I couldn't do that. I did do a bit of gardening yesterday (Anita)

The most common response that participants had to the impact that pain had on activity was described as 'getting on' or 'keeping going'. In order to remain active, they had accessed a variety of practical inputs and supports to manage their pain and related limitations (e.g. medication, walking sticks). Penny, Rose, and Bob described that for them staying active served as a distraction from pain. It meant they did not stay at home thinking about it, which would make it worse. For example, Rose continues to sing in a choir even though the seats can be very uncomfortable. As she says:

I thoroughly enjoy it. Takes my mind off it [pain].

For some participants, staying active was more than a distraction technique. The activities they continued were a valuable part of their lives and identities, and giving them up was too great a sacrifice. Penny, Anita, and Mary viewed themselves as people who help others, and Penny went as far as to state that she 'couldn't see any purpose in living' without having something to offer. Similarly, Emma, a professional singer, explained why she continued to work:

it would be very foolish of me to give up, because I don't earn a lot from it, you see, but if I gave up I think it would be wrong...it keeps me, helps me deal with life. Helps me, gives me something to look forward to perhaps. Yes, you know, otherwise what have I got?

In some cases, the importance of retaining independence and continuing these identity-defining activities outweighed the potential implications of being in more pain. Bob, a keen gardener, made this conscious decision:

It does hurt a bit, you know, I must admit. But I don't tell that to my daughter or my son...my son would say you're not coming round, but he doesn't like gardening, and I do.

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And it gives me something to do...the base of the spine [hurts], that's the worst part of it...I've, I have got to do something and if that's what it takes then I will do it.

In some cases it was possible to organise activity or put limits in place in order to keep going, although to a lesser degree. For example, Penny took time to move around when she become uncomfortable staying in one place for work, and Anita and Rose opted out of activity when their pain was particularly bad. Liz was an expert in managing her level of activity:

I don't let my arthritis or back pain stop me doing things but I know how much I...I know my limitations because if I get too tired or do too much I really am in agony

Although participants were keen to keep active, some also reported making conscious decisions to stop doing certain things when they had become too difficult. This may reflect prioritisation, in that they were prepared to drop activities that were less important to them, in order that they could focus their energy and effort into keeping up the more valued activities. For example, Bob used to volunteer in the catering tent at football matches but decided to stop:

I found that I couldn't hold a cup of tea properly...and I thought, it's time to pack up

This change did not seem to pose as much of a threat to his identity as the risk that he may have to stop gardening, and so he did not attempt to 'keep going' with this role. This variability in the significance of activities to participants' self-concepts may have been longstanding. Alternatively, they may have devalued certain activities as a response to the threat of pain.

1.2 Resisting unwelcome changes in personality

Participants described how pain had affected their personality. For some, these changes were seen as transient fluctuations which depended on the severity of the pain. Others
highlighted changes they felt were more permanent. Many participants reported having new characteristics, all of which were seen as negative and unwelcome. For example, Liz felt that her pain had made her 'a bit selfish', because she had to prioritise activity and included things she enjoyed, and Bob, Rose and Jill described a new irritable side to their personality. Five participants described how pain made them feel down and 'depressed'. As well as adding negative characteristics, participants described how pain takes away positive traits, such as confidence and extraversion. It had robbed Bob of a valued part of his personality:

*I've got quite a sense of humour, but it [pain] certainly took it away from me*

Bob also described how his humour had recently started to come back, which made him feel that he could 'go on' with life. Clearly it was an integral part of his sense of self, without which it was hard to see a way forward.

Participants were very aware that pain had the potential of making them become down and short-tempered. These were unwanted and unfamiliar labels, and participants strongly resisted 'becoming' someone they did not want to be: Mary pushed negative thoughts out of her mind, while Rose 'pulled herself up' when she felt low. A common way of retaining positive mood was 'counting...blessings' (Mary). Participants noted what they still had, and the things they were still able to do and enjoy. Some participants made these reflections explicitly, stating that all things considered they had a good life. They chose alternative criteria to physical ability to judge their quality of life, devaluing their health problems and placing importance on security and prior achievements. As June remarked:

*I just consider that I'm lucky. I mean I've got a very, very comfortable [gestures to room]...I have no financial worries whatsoever, um, really my health isn't that bad, alright I'm a bit deaf, I can't remember much and I've got a bad back, but I mean, that's nothing, is it?*
I've fulfilled my function I've raised three smashing sons....I've achieved what I set out to do, and what you're put on earth for, haven't I?

Although these statements could be interpreted as attempts to convince herself without truly believing what she was saying, in fact they seemed to reflect a genuine reappraisal of priorities.

Other participants did not make explicit evaluative comments about their lives, but described how some aspects of their identity remained constant and unaffected by their pain. For example, Anita continued to enjoy art and seemed quite adamant that it had 'no relationship whatsoever' with her pain. Rose described an incident when she gave money to a beggar, showing that her strongly held values and beliefs remained present:

*that's the way I'm made and I don't want to be any different. I've always been kind*

Indeed, having the coping strategy of 'keeping going' described in the 'Doing' sub-theme was in itself a valued and lifelong characteristic for four participants, which Rose recognised as coming from 'the way you're brought up'.

June stated that what she felt like on the inside had not changed, and that this was more important than her outside appearance and ability as defining features of her identity.

*I'm me. Inside I'm exactly the same person*

It was perhaps reassuring for these participants to notice continuity in these aspects of their identity. Pain had not affected every part of them, and reminding themselves of this may have helped them to remain positive in spite of their limitations.

Another way in which participants attempted to stay positive was in their use of downward comparison. Rose explained that this was an important way of coping for her:
you think, well you know there's people worse off than me...that's how I get through, I say, oh, you know, I could be a lot worse.

Participants compared themselves with people with specific illnesses or disabilities, and with people with pain in geographical areas with poorer service provision. In addition, comparisons were made on the basis of age: Jill, June and Penny reflected that their lives as a whole had been 'good', and they had benefited from a full life prior to onset or worsening of their pain. As such, they felt better off than people who had not had such positive experiences prior to health difficulties:

«when I look around and see some people, and I see amputees of 34, 35, and I feel awful [complaining about pain], I've had such a good life (Penny)»

It is interesting to note that Penny reports feelings 'awful' as a result of downward comparison, and this sense of guilt for 'feeling sorry for yourself' was also highlighted by Rose. This strategy therefore may not always be a reliable way of improving mood.

1.3 Managing others' perceptions

Some participants noted that changes in their characteristics had an influence on those around them. They felt guilty that they took their frustration out on close family members, and tried to protect others from these new traits:

«I'm glad when I'm on my own so that people don't really see me like it [snappy]. Because I don't like to be like it in front of people (Bob)»

Five participants also described how they did not let others know about their pain. This was sometimes driven by a belief that people would be bored, annoyed, or simply not interested in hearing about it. For others, it seemed to relate to a concern about becoming 'the type of person that complains'. Indeed, in the interview with Liz she was apologetic.
about talking about pain, highlighting that she was only doing it because it was the remit of the research:

*I tend not to talk about illness to people, you know some people always talk about their aches and pains. I am to you now cause this was the purpose of this visit.*

In their presentations of themselves as ‘non-complainers’, it seemed that being stoic was an important self-descriptor for some participants. It could be that this aspect of their identity was possible to hold onto in the face of pain, and thereby another way to retain a sense of constancy over time. Mary explained that stoicism is a valued family characteristic:

*we never let on, we always push it away, deal with it, and we never moan about it...it's a [surname] trait*

By covering up her pain and quietly managing it she remained recognisable to herself, which seemed to be greatly reassuring.

Although motivated to hide their pain, Rose and Penny also described frustration about having an ‘invisible’ problem. They felt that people did not really understand their difficulties because they could not see them. This was clearly very difficult for Penny who stated:

*sometimes I used to wish I was in a wheelchair because people could physically see*

It may be that although they are reluctant to speak about their pain, they would like others to know about it. Their determination to not complain therefore may deny them potential support.
1.4 Identity in the past and the future

In discussing their current abilities and activities, all of the participants used their 'former' self as a reference point. They talked about what they 'used to' be able to do, and many emphasised how they had been 'so fit and so healthy' (Penny) prior to the onset of their pain. They also described changes in mood and character traits in relation to 'former' personality.

*I used to be, um, very friendly and outgoing, but now...I get very bad tempered and I say things sometimes what I regret afterwards (Jill)*

This 'former' self was invariably described in positive terms, with regret expressed about losses and changes resulting from the pain. As such, it seemed to be viewed as representing the 'true' identity of the participants, and as seen above, retaining aspects of identity from the past was a valued goal.

Clearly participants currently felt far removed from their prior sense of self, and when they looked to the future they anticipated further distance from their 'true' identity'. Many had a 'bleak' outlook, describing a 'dread' of what could happen. For June this was a fear of her pain being more 'intense', while for Jill it was a fear of being 'put in a home'. Other participants were afraid of further decline in ability:

*if I can sort of go on at the moment...the way I am, it doesn't deteriorate, cause that's what's worrying me that it will all deteriorate (Mary)*

Although they had thus far found ways to retain their sense of identity and manage their pain this position seemed to feel tenuous for them, and they were not confident in their ability to face additional challenges. In addition, the potential implications of further change were extreme. Life without activity was felt to be worthless by most of the participants. Liz stated that:

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if I became that I wasn't independent and couldn't do things I'd rather be dead

The ability to 'do things' is clearly a central and defining aspect of her identity, without which she can see no merit in existence. The 'fear' and 'dread' described by other participants perhaps relates to a similar sense that change could potentially wipe out their entire sense of who they are.

To manage this intense fear in relation to the future Liz and Rose take one day at a time and avoid thinking about it. Indeed, Liz seemed to warn me off this line of questioning:

I: What do you think life will be like in your future?

Liz: I don't know and to be perfectly honest I would prefer just to live from day to day...I don't sort of keep thinking about it. Don't want to particularly...block it out, block it out.

In contrast to their active stance in the current management of pain, many participants had an external locus of control when considering the future. Liz and June described themselves as 'fatalistic', suggesting that they felt they had little choice or control about what happened to them. Similarly Bob commented that 'you never know with life do you?', Rose described how she 'just take[s] it as it comes', and Mary's sense is that 'you can only hope can't you?'. These comments could be seen as reflecting a somewhat hopeless feeling amongst participant, but alternatively they may represent a pragmatic choice to deal with problems as they occur rather than planning for an unknown future. They may also represent longstanding coping strategies used by participants, and thereby highlight a further constant aspect of identity.

2 Pain in the context of ageing

Participants experienced pain in the context of becoming older. They all anticipated decline in old age, which for some provided a welcome explanation for their pain.
However, for others the process of ageing itself was threatening to identity and frightening to face, so they used cognitive and practical strategies to retain a sense of constancy. Participants live in a society that holds negative stereotypes relating to old age. Indeed these were held by many participants, which could have implications for their identity and pain management. Participants also reported multiple problems, which either reduced or increased the impact of pain.

2.1 Emotional implications of attributing pain to old age

An expectation of decline in old age was universally held by participants, but it varied in terms of its emotional implications. For some it was presented simply as an unquestionable statement of fact: participants understood their pain as a result of a process that ‘naturally’ (Emma) and ‘inevitably’ (Liz) came about, through ‘general wearing out’ (Anita):

*I'm 74 so therefore I've got aches and pains (June)*

Age was also linked to slowness and limitations in activity. Indeed, even when pain was felt to be the cause of these limitations, the pain was often attributed to ageing:

*I couldn't go and swim seven or eight lengths of a pool, I wouldn't, I couldn't, the pain wouldn't let me do that and I know I would never get out. But it still lets me do things...And, you know, when you're seventy odd you don't expect to do the things you did when you were twenty do you? (Liz)*

This sometimes seemed to be a welcome explanation for pain. Although it did not make it better or offer much hope for the future, it made pain understandable. In addition, lowering expectations for ability meant that they could still be met or even exceeded. Indeed, in evaluating her situation Emma seemed to be reassured by her thought that ‘for my age I'm not too bad I suppose’. This comparison with a stereotypical idea of a more impaired old age helped her to value her remaining abilities.
In contrast, Penny and Mary, two of the youngest participants, found the idea of decline in old age harder to accept. Pain was a scary and frustrating reminder of the ageing process:

"it's quite frightening as you're getting older, that's what's, um, frightening, cause I've always been sort of...tried to be independent and help other people, but er, now it's...not so nice" (Mary)

The expectation of inevitable decline brings with it a sense of lack of control or hope which they perhaps found hard to manage. In addition, as they were younger, they may have felt that change in old age was not yet applicable to them. Interestingly, Penny reflected that things would be different when she felt she was the 'right' age to be experiencing such difficulties:

"Once I do turn seventy next year...I'll probably be able to turn round and I'll probably be a much, a lot calmer, because then I'll be able to turn round and say to people, well I am seventy you know...Because I have said that I will retire at seventy, that I will work till I'm seventy"

For her, pain was bringing about changes before they were 'supposed' to happen, and this discrepancy appeared to contribute to her distress.

Although all participants expected decline in old age, a number of them also expressed the somewhat contradictory view that age itself was not a barrier to activity and achievement. Emma and Penny had plans for old age that suggest they viewed it as a stage in ongoing growth and development. Penny had planned to play sport in the old age Olympics, and Emma had expected to continue to work as a professional singer:

"you don't retire from, from the theatre...I was working towards getting better, and getting more prestigious work, you know, all the time"
Three participants even explicitly denied that age had contributed to their difficulties at certain points in the interviews. This could be seen as a hopeful and empowering perspective to have. However, when plans were not achieved or unexpected difficulties came about, this led to disappointment. Jill recounted a discussion she had with peers about this:

They all say, isn’t it awful when you get old and can’t do this, can’t do that, you know, I said, yes, I said, it’s a shock isn’t it. I said, I didn’t realise it was going to be like this

Clearly the attributions made about pain in relation to age and expectations of old age had varied emotional implications for participants. This may explain why some held seemingly opposing beliefs simultaneously, as they were then able to selectively use and reject them to protect themselves from distress.

2.2 Maintaining identity despite age

Seven of the participants described a discrepancy between their chronological age and the age they felt. They described shock and disbelief about becoming ‘old’ and June went as far as to say she ‘loathed’ it. Chronological age was a label that didn’t seem to fit and for June, Jill and Anita the outward appearance of age seemed to pose a threat to their sense of identity. June managed this by simply avoiding reminders of her age:

I don’t look in the mirror. I can just be me. I can be the me that I’ve always been, my thoughts and what I’m doing, as long as I don't look in the mirror (laughs). It’s depressing!

Bob and Anita responded to the threat by questioning the significance of numerical age. Although they were aware of their age, it was described as a technicality, and was less important than their young ‘attitudes’ and ‘ways’.
I'm old, as I put it. People say you're not old but I am old, I'm 72 years old and that's not young. But...I'm a young man at heart (Bob).

Indeed, Anita went so far as to spurn age as a label, saying 'I don't do age'. This seemed to be partly driven by her beliefs about ageism, and in fact she reported frequently lying about her age in order to be treated fairly.

Rose and Emma were different in that they did not report feeling uncomfortable with their age. Rose viewed it as an irrelevant factor in the formation of her identity stating that 'I don't think it has made much difference as far as me'. Interestingly, they had reported fewer stereotypical pessimistic views about ageing than many participants. It may be that they were less resistant to the process of getting older because it held fewer negative connotations for them.

2.3 Living with ageism
Anita felt deeply that society discriminated against older adults, in relation to healthcare and employment:

I think people over 65 are considered a very grey area of not worthy of helping and dealing with. There's a strong attitude of that in this society.

Only Emma reported an example of this, whereby she felt that singing jobs were offered to younger people than her regardless of talent. In terms of healthcare, four participants described some dissatisfaction with professional input, for example being disbelieved or disregarded. However, they did not attribute this to age discrimination, and clearly it would not be possible to determine whether this was a factor.

A number of participants actually made discriminatory comments about older people themselves. They were described as tending to exaggerate ailments, being undesirable company, and even 'repulsively' ugly. June and Bob made comments about being too
old, with Bob joking that maybe he should be 'put down'. June seemed to agree with this idea that you can outlive your usefulness, stating 'It's old age, we're all living too long, that's the trouble'. Indeed, Liz and June expressed sympathy for me 'having' to carry out interviews with people like themselves:

*fancy...going round interviewing old people...how depressing! (June)*

Holding such negative views about themselves could impact on these participants’ self-esteem. It could also relate to beliefs about being unworthy of professional input, which may lead to lower likelihood of accessing potentially helpful services.

### 2.4 The significance of pain in relation to multiple problems

Pain was not the only issue in participants’ lives. In fact, in comparison to experiences of bereavement it was relatively unimportant. Six participants talked about deaths of loved ones, either in the past or more recently. These had had a major and lasting impact on the participants’ lives. As Jill put it:

*it was never the same after that*

As well as the language used, the way in which these bereavements were talked about highlighted their significance. For example, when asked about the type of person she is, Emma’s first statement was that ‘I was widowed in the war’, suggesting that this is of primary importance for her. Other participants dedicated a significant amount of time in the interviews to describing the lives and deaths of their loved ones. In this respect, the influence of pain seemed to be diminished.

However, other issues also exaggerated the impact of pain by creating an accumulation of problems. Six participants had concurrent health issues, including diabetes, heart and sensory problems, and eight had multiple sites and causes of pain. Three had concerns about their memory, both currently and in the future, where Alzheimer’s disease was
‘dreaded’ (Liz). In addition, some participants were worried about their partner’s health, financial and housing issues, and reported current and historical relationship difficulties.

Liz, Anita, and Bob described how hard it was to deal with more than one problem at once. For Bob, this led to a practical difficulty in keeping on top of a number of healthcare regimes:

there's other things to...contend with. There's so much to remember.

The cumulative effect of numerous problems meant that Liz’s bad back was the ‘final straw’, while Anita described it using a mathematical metaphor:

what I don't want is an addition sum of loads of pain, plus that problem, plus a dilemma I've got about moving possibly next year, etcetera, etcetera, so there is quite a lot buzzing around that will add to tension

Obviously people of all age groups face a variety of issues in their lives, so this sub-theme may be relevant even outside the context of ageing. However, health problems and bereavements are more common in later life, so it may be reasonable to expect that the ‘addition sum’ for older adults would involve more factors than for younger people.

3 The relationship with pain
Many participants described their pain as a powerful ‘other’. They endeavoured to influence this relationship, taking control back from the pain and finding a way to live with it.

3.1 A struggle for control
In describing the impact of pain on their lives, some of the participants used words that evoked a sense of struggle for power with a dominant enemy. Pain did not simply ‘hurt’, but was ‘agonising’, ‘crippling’, and ‘excruciating’. Rose described an attempt to resist
being forced to stop work by pain, but 'it the end it beat me', and Mary said that 'when you're sick and bad you've got to give in to it'. For many of the participants pain was often in control, dictating how time was spent, and demanding attention:

*the pain that's terrible, it knocks you out for a day* (Mary)

However, most participants noted that there was variability in the control that pain exerted, for example Penny gave an account of how the position and dominance of pain in her life had changed over time:

*It did rule my life for about two years. But...it's about the first time I've actually said it, no it doesn't rule me any more. For the last two or three months it has not ruled me any more. But I'm not ruling it yet, it's just part of me.*

Rose and Mary attributed the variability in the relationship with pain to the pain itself. Mary would not know until she woke up whether it would be a 'good day' or a 'bad day', suggesting that she was at the mercy of pain to decide whether to give her respite. Rose described that while she was often able to 'work [her] way through' the pain, at times this wasn't enough and the pain would prevail.

Other participants described how they themselves had influenced the relationship with pain. They tried hard to retain their sense of power by not 'giving in /up' (Mary, Rose and Emma), which required carefulness and planning. They also took concrete control by assertively accessing professional support and input:

*You should insist on, you know, him [your GP] saying more than he wants to say. And...and, um, asking if there's more that he can do* (Emma)

In addition, wrestling control from pain took great determination and strength of will:
I won't let it get the better of me, I just know I won't (Liz)

3.2 Putting up with pain
A number of participants described a relationship with pain that developed over time. They had been through a process of 'learning' (Penny / Jill / June) through experience how to live with pain. This incorporated both concrete management and more abstract ideas about acceptance or tolerance of pain. For example, Penny described that 'all the life that I'd planned has got to be altered around' and also that this required a long process of 'mental adjustment':

I've only just been able to say it to myself. Accepting the difficulty. It was, for two years it was why me?, why this?, why that?, you know, why have I got all this pain?

Some participants talked about 'putting up' (June and Jill) with pain, and getting on with life anyway. Many felt that they had no choice about this:

they said they couldn't do anything so...looks like I've just got to put up with it (Jill)

Although this could be interpreted as a reflecting an unhelpful hopeless stance, it in fact often seemed to be a pragmatic reaction to feedback from doctors that there was nothing that could be done about their pain. As such, these participants had perhaps begun to view and accept their pain as a chronic condition.

A somewhat different account of living with pain was given by June at one point in her interview. Instead of using relational terms she stated that pain was part of herself:

It's part of me now, you see. It's part of me all the time. I'm not in continuous pain but as I say, a single thing like I sit down...on the kitchen chair and get up, oh yes, oh this pain...So it's part and parcel of me now..

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Rather than seeing pain as an 'other', she has incorporated it into her sense of identity. This could have a number of implications, positive or negative. For example, she may feel more comfortable not being involved in a difficult battle with a powerful other, but alternatively integration of pain into her 'self' could feel threatening to her identity.

There did not seem to be a clear association between the duration of pain and the descriptions of living with it that participants gave. Other factors such as expectation of pain in old age and longstanding problem-solving styles may be more important influences on the degree of control and acceptance that is seen.

**Summary**
To conclude, participants experienced pain and ageing as threatening to their identity. They were highly motivated to retain a constant sense of self and used a wide variety of strategies, both cognitive and practical, to achieve this. Doing so was difficult and involved a struggle to develop an acceptable relationship with pain. In their attempts to maintain their identity and manage difficulties, participants showed determination and resourcefulness despite strong feelings of sadness and fear.

**Discussion**
This discussion will firstly outline links and associations between the themes that arose from the analysis and the existing research literature. Following this some methodological issues relating to the study will be explored. Finally, the clinical and research implications of the findings will be considered.

**Discussion of themes in relation to existing literature**

*Maintaining identity despite pain*
It was clear in all the interviews that pain had had a significant impact on participants' lives and identities, both in relation to what they did and their personal characteristics. This adds to the large body of research about the psychological, social and behavioural
effects of pain, and highlights that these effects are also seen in older adults. A significant part of the themes that arose from the analysis related to the maintenance of identity and functioning despite pain. In some ways this was unsurprising, as research has demonstrated that older adults make use of multiple strategies to cope with pain and related limitations (e.g. Keefe & Williams, 1990). It is particularly interesting to note that the semi-structured interview did not actually include questions about the management of threats to identity. This highlights that participants played an integral part in guiding the direction of the research through their unique and sometimes unexpected responses to questions.

Some of the cognitive and practical strategies that they used to maintain a constant sense of identity fitted with the model of ‘the ageing self’ proposed by Brandstätter and Greve (1994). As described in the introduction, this model incorporates three processes: (1) Assimilation refers to attempts to address the unsatisfactory situation in practical ways in order to adhere to original goals. Participants in the current study were indeed motivated to ‘keep going’ with many valued activities that were threatened by pain, and took medication and paced themselves in order to achieve a constant sense of identity; (2) Accommodation refers to making adjustments to personal goals and standards. Again, this was commonly seen in participants in the study. For example, some made conscious decisions to stop doing certain activities (i.e. disengaged from goals) and others lower their expectations for achievements (i.e. set themselves different standards); (3) Immunization refers to making changes to the processing of self-referential information. June demonstrated this by placing importance on her prior achievements and minimising the relevance of her current activity level to the construction of her identity.

Schmitz, Saile and Nilges (1996) also found that an earlier version of this model (including only the accommodative and assimilative strands) was applicable to use in relation to chronic pain. In a study of 120 people with chronic pain they found that flexible goal adjustment (accommodation) was associated with less depression and acted as a buffer against the negative effects of pain and disability on mood. This was not the
case for the use of assimilative strategies. Although this was a cross-sectional study so causality could not be inferred, it seems that accommodative processes may be protective against distress. Many of the participants in the current study were indeed adept in their use of accommodative strategies, which allowed a sense of continuity of identity. Following on from the findings of Schmitz et al. (1996), it seems likely that this was protective against depression.

In addition, Schmitz et al. (1996) suggested that people with chronic pain may go through a process whereby they initially use assimilative strategies such as seeking medical intervention but eventually begin to use accommodative strategies as they find that their ability to change the unsatisfactory situation is limited. However, the authors also highlight that people have a fundamental disposition to use particular strategies, with some more likely to tenaciously pursue goals and others more likely to flexibly adjust them. Again, this is relevant in relation to the current study. It is likely that the ways of coping that participants described represented a stage in an ongoing process of adjustment to chronic pain, but also reflected lifelong styles of managing unwanted situations. This may explain why there was not a clear association between the duration of pain and the nature of strategies that people used to manage related challenges to identity.

Participants also used different strategies depending on the type of activity, showing variability in their determination to ‘keep going’ and willingness to ‘pack up’. This perhaps related to the relative importance of these activities to their identity. Indeed, in a large (n=486) study of self-esteem and identity, Pelham and Swann (1989) found that people’s self-concepts were multifaceted, with different appraisals made for each of their characteristics. Only highly valued characteristics had a significant relationship with self-esteem, for example, people would only feel positive about a test result if they valued academic achievement. In the current study, it could be hypothesized that participants were only willing to drop activities if this did not pose too great a threat to their identity and cost to their self-esteem. Quantitative research testing this theory would help to clarify this issue.
Interestingly, a highly valued characteristic for all of the participants was independence. They ‘kept going’ to avoid losing it, and were fearful of a future without it. According to the cross-cultural research carried out by Waid and Frazier (2003), this may relate to the cultural background of the participants. They were all white British, and may therefore be expected to value individualistic ideas of self-fulfilment and independence. If the study were repeated with individuals from a collectivist culture, pursuit of different goals may be apparent.

One of the most commonly used identity management strategies in the current study was downward comparison, which generally had a positive impact on mood. Brandstädter and Greve (1994) suggest that this is an accommodative strategy and indeed there is empirical support that it is protective against depression (Brandstädter, Wentura, & Greve, 1993). This strategy was also seen by Osborn and Smith (1998), but they found that it tended to reinforce negative feeling. Their participants were uncertain about their prognosis, so instead of feeling lucky in comparison to ‘worse off’ people, they feared that they themselves could end up in this ‘worse’ position. In addition to making downward comparisons, Osborn and Smith (1998) also found that participants made ‘upward’ comparisons with people in a better position than they were. These comparisons were often with people of the same age or older, and they served to emphasise participants’ feelings of loss. This was not seen in the current study.

These differences in use and implications of comparison with others may relate to the different age range of participants in the two studies. Osborn and Smith (1998) interviewed 25-55 year olds, while participants in this study were aged between 65 and 81. It may be that the older participants did not view anyone of their age in an ‘upward’ position to them, either because they had actually experienced peers becoming unwell, or because they had stereotypical expectations of old age. In this way, expectations of decline could be seen as protecting participants from feelings of unexpected or unjust loss. The participant samples also differ in relation to their levels of distress and uncertainty. Unlike the current study, Osborn and Smith (1998) specifically selected

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participants on the basis of high levels of distress and a lack of diagnosis. It may be that
the lack of certainty coupled with distress meant that fears about eventually being in the
position of the ‘worse off’ person were more acute for this group.

A unique downward comparison used by a number of participants in the current study
was encapsulated in the statement ‘I’ve had a good life’. The implication is that some
people experience difficulties without having had a good life before them. This type of
evaluation is clearly only possible when people value what they have already achieved
and experienced in life. Older adults are therefore more likely to be able to make use of
this comparison as they have been alive for longer. It may be that cohort and cultural
factors also affected participants’ use of downward comparison. As well as noticing what
others don’t have, this strategy involves recognising what you do have. ‘Counting your
blessings’ is a biblical concept, and older adults brought up in Britain may be more likely
to have been exposed to Christian teaching than younger people. They may also have
been influenced by the wartime slogan ‘make do and mend’, which emphasises the
importance of valuing and using what you have.

Identity in the past and the future
Consistency in identity over time seemed to be an important goal for participants. They
commonly compared their current identity with their ‘self’ prior to the onset of their pain,
and feared further change and therefore threat to identity in the future. Temporal
dimensions of identity in the context of chronic pain have been widely explored in
psychological research, for example Walker, Sofaer and Holloway (2006) explored loss
of previous roles and identity, Morley et al. (2005) considered future selves, and
Hellstrom (2001) considered both.

It is useful to view this temporal perspective in relation to the concept of acceptance.
Consideration of acceptance is important in the area of chronic pain, as greater acceptance
of pain has been linked to lower levels of anxiety and depression, as well as less
avoidance and disability (McCracken, 1998; McCracken & Eccleston, 2003). Acceptance
of chronic pain has been explained in a variety of ways. One definition is provided by Hayes, Jacobson, Follette and Dougher (1994) who state that to accept means to live in the present rather than rehearsing the past or projecting into the future. Similarly, Risdon, Eccleston, Crombez and McCracken (2003) explored accounts of acceptance amongst lay people and found that some saw accepting loss of self and some saw accepting uncertainty about the future as crucial. According to these accounts, by making comparisons with the past, the participants in the current study may be prevented from fully accepting their pain. However, when thinking about the future many were fatalistic, preferring to live ‘day to day’. This willingness to live in the present and live with uncertainty encapsulates an accepting stance. Participants can therefore perhaps be seen as part way through a process of accepting their pain.

**Pain in the context of ageing**

This theme highlights the importance of being aware of contextual factors that influence the experience of chronic pain and its impact on identity. A number of factors arose that are unique to the older age group, which suggests that simply applying models of chronic pain developed with younger groups to older people is not appropriate. For example, older adults are more likely to have multiple health problems and to have experienced bereavements, which could either exacerbate or reduce the impact of pain. Some of the other sub-themes relating to the experience of chronic pain in older adults specifically are explored further below.

**Emotional implications of attributing pain to old age**

Participants reported that their chronic pain was an inevitable result of their age, caused either through age-related disease or general ‘wear and tear’. Causal attributions such as this can be conceptualised within the common-sense model of illness representation (Leventhal, Idler & Leventhal, 1999). This model posits that illness representations have five attributes: the identity of the disease, its timeline, perceived causes, its consequences, and perceptions of controllability. The content of these attributes is said to relate to the action taken to manage the illness.
The attribution to ageing is likely to relate to a perception of uncontrollability and longevity, because the ageing process cannot be halted (Keller, Leventhal, Prohaska & Leventhal, 1989). However, it is interesting to consider the direction of causality in this relationship. Expectations of pain in old age may have led the participants to believe it is uncontrollable as soon as they experienced it. Alternatively, they may have initially made many unsuccessful attempts to control their pain, and finally concluded that it was uncontrollable. In trying to make sense of this uncontrollability, they then attributed it to old age. It could be that this enabled participants to protect their identity, retaining a sense of independence and self-efficacy: being unable to control pain because it is inherently uncontrollable does not automatically imply deficits in personal capability. For some participants the explanation did indeed seem to be a comfort, perhaps resolving their ‘crisis of legitimation’ (Miles, Curran, Pearce & Allan, 2005). However for others, attributing pain to ageing generated fear. This maybe relates to the implication of uncontrollability, which may be uncomfortable and also incongruous with participants’ perceptions of themselves as able and independent.

In the main, research literature cites attributing difficulties to age as unhelpful, acting as a potential barrier to effective treatment. However, this study highlights that it is important to consider at what stage such attributions are made: when they are seen at the end of a process of unsuccessful control attempts, they could be conceptualised as a form of acceptance. However, ‘accepting’ pain as inevitable may not be appropriate if it is actually possible to control it (McCracken, Carson, Eccleston & Keefe, 2004). In this study it was also interesting to find that participants made varied causal attributions with regard to their pain and limitations. This was also the case in the qualitative study by Roberto and Reynolds (2002) and the research of Prohaska et al. (1987), who found that attributions to age and to illness were not mutually exclusive. Participants in this study made use of a number of attributions depending on what they were trying to achieve: sometimes this was a sense of continuity in their identity as being ‘capable’, while at other times it was maintaining a sense of hope for the future and perhaps demonstrating that they should not be ‘written off’ as being old.
Maintaining identity despite age

The analysis highlighted that participants differentiated between their chronological age and their 'felt' age. Some described how reminders of age such as pain and physical appearance were distressing, which was interpreted as relating to a threat to identity. Chronological age was rejected, ignored, or deemed irrelevant in order to manage this threat. These techniques can be understood as examples of accommodation and immunization in the model described by Brandstädter and Greve (1994).

The idea of chronological age not 'fitting' has been explored by a number of researchers, who suggest that age is not simply a chronological dimension, but is influenced by personal meaning and social context. As such, people may have a unique 'age identity'. Social roles can influence age identity, for example, becoming a grandparent can make people feel older (Kaufman & Elder, 2003). In the same way, poor health and less functional ability have been found to relate to older age identity (Bowling, See-Tai, Ebrahim, Gabriel & Solanki, 2005; Logan, Ward & Spitze, 1992). The association between age identity and mood was also explored by Logan et al. (1992), who found a relationship between older age identity and lower life satisfaction and self-esteem. It is interesting to consider causality in this relationship. It may be that poorer well-being acts as another cue for 'getting older', or alternatively seeing oneself as old may have a negative impact on well-being.

Clarke (2001) suggests that this latter explanation may be particularly relevant for women who suffer as a result of the 'double-standards' of ageing in Western society. She suggests that physical signs of advancing age are judged more harshly in women than men, so may lead women to have more negative self-perceptions. This may be particularly pertinent for women who deem physical attractiveness to be an important part of their identity. In future research it would be interesting to explore gender differences in attitudes and feelings about ageing, and see whether older men raise physical appearance as an issue or concern.
The relationship with pain

Participants often described their pain using relational terms, with the conceptualisation of a relationship with an ‘other’ seemingly making intuitive sense. It is therefore helpful to consider how the impact of pain on identity can be understood in a relational context, and the implications of this for therapeutic input.

There were two main types of relationships that participants described. Some fought with a powerful and controlling pain, using determination and carefulness to retain a sense of continuity in identity. This was similar to an understanding of pain found in qualitative research by Aldrich and Eccleston (2000), where it was viewed as a ‘specific and dangerous kind of destroyer: a strong malign external power which threatens to take over and wholly overwhelm the sufferer’ (pp.1632). In this type of relationship pain can be seen as having the potential to rob people of their identity and replace it with the pain identity. In contrast, other participants described a less combative relationship whereby they 'put up' with pain, having learned through experience how to cope with it. In this type of relationship pain is constantly present but the threat to identity is managed.

As with the discussion of identity over time, research into acceptance again provides a useful basis from which to consider these findings, as some conceptualisations have clear relational connotations. For example, McCracken (1998) described acceptance as ‘a willingness to experience continuing pain without needing to reduce, avoid or otherwise change it’. This sounds like the ‘putting up’ with pain that some participants in the current study described. In contrast, Risdon et al. (2003) found that for some people acceptance meant ‘taking control’ of pain, for others ‘not giving in’ was more important, while for others ‘opting out of the battle’ for control was vital. Again, the ‘putting up’ in the current study may reflect not giving in and opting out of a battle. However, the participants in a more combative relationship were perhaps ‘taking control’ of their pain. Therefore both types of relationship could be understood as demonstrating acceptance and creating a sense of continuous identity for participants. McCracken (2005) suggests that therapeutic work with acceptance of pain as a goal may be helpful for chronic pain
patients, and outlines a cognitive-behavioural approach with influences from mindfulness, acceptance and commitment therapy and dialectical behaviour therapy. These approaches may be useful for older adults who are uncomfortable in their relationship with pain.

A somewhat different area of research with relational aspects of pain at its core is that described by Mason (2004). He suggests that people sometimes have a 'primary' relationship with pain at the expense of relationships with significant others. In this way, pain can be seen to threaten identity by affecting valued roles and characteristics that are present only in the context of relationships with others. Indeed, the participants in the current study who withdrew from social contact could be seen as developing a stronger relationship with pain and a lesser relationship with others as a result of this withdrawal, which led to a threatened sense of themselves as 'sociable' people. Mason (2004) suggests that therapeutic work guided by systemic concepts that targets the problematic relationship with pain may be helpful. People can work towards relegating their relationship with pain to 'secondary' and reclaiming primary relationships with significant others. In doing so they could also be expected to reclaim valued aspects of identity. Again, this may be a useful approach to use with older who characterise their pain as a dominant 'other'.

**Concluding comments**

The themes that arose from the analysis show some connections with a number of existing areas of research, for example relating to models of development, acceptance, and illness representation. In addition, some aspects of the experience of older adults with chronic pain seem to be unique to their age group. The analysis therefore highlights a number of directions for clinical intervention and future research with this group, and these are outlined below. However, before discussing these, it is important to consider how the findings have been affected by a number of factors within the research process.
Methodological issues

Sampling issues

The potential 'pool' of participants was limited by a number of factors. They had all accessed their GPs, and had been deemed suitable for referral to a specialist pain management service. There are clearly a significant number of older adults in chronic pain who do not access services for many reasons: for example, because they are managing their pain effectively, or because they are unable or unwilling to ask for input. In addition, the sample may have been skewed in relation to willingness to participate, although it is not possible to know this. The relatively low anxiety and depression scores suggest that those that agreed to take part in the research were maybe less depressed or avoidant than those that said no. The group was heterogeneous in relation to diagnoses for the chronic pain, and participants were from two distinct referral pathways. However, the analysis showed no clear differences between participants in terms of content of the interviews, so it seemed appropriate to view them as a 'homogeneous enough' group.

All of the participants were from a White British background, so the findings must be understood as coming from a Westernised perspective. Smith and Bond (1998) highlight that the concept of identity is culturally bound, and Giordano (1992) suggests that adjustment to ageing and the perceptions, beliefs, values and behaviours of an ageing individual are greatly influenced by cultural factors. In addition, the meaning and response to pain is variable across cultures (Bates, Edwards & Anderson, 1993; McCracken, Matthews, Tang & Cuba, 2001). Finally, the experiences of this specific group of older adults are also bound by cohort effects, and so cannot be generalised to all older adults. If this study were to be repeated with people from another cultural context or era, the findings may therefore be very different.

A final sampling issue relates to gender. The majority of participants in the study were women, and although there did not appear to be any differences in the man’s account, the themes are particularly influenced by female experiences. Some gender differences have been found in relation to the experience of pain (Unruh, 1996), and Sontag (as cited in
Skultety and Whitbourne, 2004) describes the ‘double standards’ of ageing, for example in terms of acceptability of changes in physical appearance. Again, carrying out the research with a group of men may highlight some different themes.

**IPA issues**

Although IPA is clearly a useful research method, it has a number of limitations.

It has been noted that the applicability of IPA is limited to those who are able to articulate their experiences in a relatively sophisticated manner. Indeed, people with dementia were excluded from this study, thus narrowing down the range of experiences explored. However, a limited amount of research has been carried out using IPA with less articulate populations (e.g. Bramley & Eatough, 2005, study with people with Parkinson’s disease), so it may be that recommendations for adaptations will be developed in order that it can be more widely used. In addition, although the participants in this study had the ability to speak, they may have been unwilling or unable to verbally represent certain views (see Table 4).

However, the decision to not meet with participants to discuss the findings in the current study could also be viewed as limiting the credibility of the research. Respondent validation is an issue of current debate amongst qualitative researchers, and varied viewpoints have been raised in terms of its necessity and credibility. Although participants would not be expected to agree with the subjective interpretations made in this study, it may have been useful to obtain their feedback about the themes and included this as a point of discussion.

Hollway (2004) criticises qualitative research methods including IPA for the way they ignore information that is communicated ‘outside language’ through transference and counter-transference. She suggests that ignoring the internal world of participants produces an incomplete picture of their experience, and recommends that researchers should reflect on their subjective experiences at all stages in the research process. Clearly
taking this epistemological stance and approach in research would again produce a very different outcome.

It is recognised that IPA has been criticised for its lack of attention to the role language plays in constructing reality (Willig, 2001). In fact, there are no strict guidelines about the use of IPA, and Smith and Osborn (2003) highlight that critical questions about the use of language can be made within this approach. Over the course of the interviews and analysis, the researcher reflected on participants' use of language, and some themes from these reflections are outlined in Table 4.

**Table 4: Reflections about the meaning of the interview to participants, and their use of language**

| The analysis highlighted that many clients were proud of their ability to 'get on' with things. I wondered whether this meant they presented themselves in a positive way in the interviews, covering up more difficult aspects of their experiences. Indeed, Liz seemed keen to be 'positive': after discussing negative things she immediately described positive aspects of her life. Similarly, Mary used language in a way that emphasised positives, as seen in her statement 'Cause I won't give in to it, but um, when you're sick and bad you've got to give in to it'. She used the word 'you' to describe negative experiences, thereby externalising them, but used the word 'I' to describe positive experiences, thus owning them. Although these different uses of language may indeed have been motivated by a desire to manage outward appearance, an alternative explanation is that I was seeing in practise how participants used favoured mood management strategies. |
| I wondered what the meaning of the interview was for participants, and on a few occasions I had a sense that some had an important agenda. With Anita and Penny, I was told about their complex and busy lives and heard about a number of surprising hobbies and interests. For example, Anita told me that her pain meant that she 'had trouble getting down Ben Nevis last August' and Penny described her love for Harry |
Table 4 (continued):

Potter films. Although they could have simply been describing important aspects of their identity in relation to my questions, I wondered if they felt that the interview was an opportunity to 'fly the flag' for older people. They may have been motivated to challenge stereotypes and assumptions about older people, and being involved in research was a way to do this.

A number of participants stated at the end of the interview that they 'hoped it had been helpful'. I wondered whether this reflected a different motivation for being involved, in that the interview enabled them to be 'useful', perhaps a valued aspect of identity. If this was the case, then they may have been keen to give answers they thought I wanted. It was important for me to show in the interviews that any opinions and ideas were useful to reduce the chances of this bias. In addition, in the analysis I excluded any data that could be perceived as relating to a leading question.

Clinical implications and directions for future research

This research is unique in its focus on identity in older adults with chronic pain. As a qualitative project, the findings are not intended to be generalisable, but readers are invited to consider whether the themes that have arisen fit with their experiences, and to use those ideas which are helpful to them.

Clinicians, particularly clinical psychologists and others offering therapeutic input, may find the following points useful to consider in their work with this group:

- Maintaining a constant sense of identity seemed to be a key priority for these participants. Incorporating questions about valued aspects of the self (e.g. 'what kind of person are you?, what do you like doing with your time?) into assessment may help the development of meaningful goals for input. The pictorial representations of identity and the impact of pain on identity developed by Buchi et al. (1991) could be used to monitor discrepancies between actual and hoped for selves and self-pain enmeshment. In situations where it is not possible to retain valued aspects of the self,
cognitive-behavioural input may be useful, for example to aid the re-evaluation of priorities. In addition, allowing the expression of grief about this loss will be important.

- Attributing pain to age had significant emotional implications for participants, albeit variable ones. Including questions about causal attributions into an assessment may highlight whether these are contributing to distress or protective against it. This may help determine whether they could be helpfully targeted therapeutically.

- Clinicians should be aware of the potential implications of making ageist assumptions. Although there was no clear evidence in this group that they had experienced discrimination on the basis of age, monitoring for such incidents should continually occur. This will ensure that Standard One of the National Service Framework for Older People (2001) ‘Rooting out age discrimination’ is met.

- Participants described their pain in the context of multiple problems in their lives. Comprehensive assessment of clients’ situations should take place in order to achieve an understanding of and sensitivity to this context.

- Some participants described their pain in relational terms. Working therapeutically using this conceptualisation may prove effective, either using formal systemic techniques as described by Mason (2004), or simply by using relational language in discussion with clients about their pain.

The findings also highlight some areas to explore in further research:

- The model of ageing proposed by Brandstädter and Greve (1994) and used in relation to chronic pain by Schmitz et al. (1996) appeared to fit some of the experiences of these participants. It would be useful to test aspects of the model further with this specific group, for example using quantitative studies to test the hypothesis that threats to identity associated with pain and ageing cause distress, and that this leads to actions being taken to maintain consistency, which thereby reduces distress.

- It would be useful to study the variability in participants’ willingness to give up different activities, and test the hypothesis that this related to the relative importance of these to their self-concept. Following on from the work of Harris et al. (2003)
into the emotional impact of role loss, this could be done by breaking down 'role loss' into specific activities to explore their individual effects on mood.

- Longitudinal research into attributions of pain to old age would provide useful information as to the origins of these attributions. It would help to clarify whether making such attributions was related to age or onset of pain, or a response to unsuccessful attempts to 'cure' the pain. It would also be useful to study the emotional implications of such attributions.

- In addition to this quantitative research, carrying out further qualitative research in this area will continue to enrich clinical understanding. Exploring identity and the experience of chronic pain in men, people of different ages, and people from different cultural backgrounds may highlight different issues and themes. Alternatively, exploring the experiences of a similar client group using different qualitative methods would produce outcomes that compliment and add to the findings of this study.
References


Major Research Project


Major Research Project


Major Research Project


Major Research Project


Appendices
Appendix 1: Ethics committee letters

London - Surrey Borders Research Ethics Committee
St Helier Hospital
1st Floor, G Block
Wycher Lane
Carshalton
Surrey
SM5 1AA

Telephone: 020 8296 3525
Facsimile: 020 8296 3525

04 August 2005

Miss Naomi Dawkins
Trainee Clinical Psychologist
University of Surrey
Department of Psychology
University of Surrey
Guildford
GU2 7XH

Dear Miss Dawkins

Full title of study: Exploring identity in older adults with chronic pain: an interpretative phenomenological analysis

REC reference number: 05/Q0806/66

Thank you for your letter of 19 July 2005, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered at the meeting of the Sub-Committee of the REC held on 03 August 2005. A list of the members who were present at the meeting is attached.

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.

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

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>Application</td>
<td>1</td>
<td>06 June 2005</td>
</tr>
<tr>
<td>Investigator CV Naomi Dawkins</td>
<td>1</td>
<td>27 May 2005</td>
</tr>
<tr>
<td>Investigator CV Victoria Senior</td>
<td>1</td>
<td>27 May 2005</td>
</tr>
<tr>
<td>Investigator CV Hilary Rankin</td>
<td>1</td>
<td>27 May 2005</td>
</tr>
<tr>
<td>Protocol</td>
<td>1</td>
<td>27 May 2005</td>
</tr>
<tr>
<td>Summary/Synopsis Flowchart</td>
<td>1</td>
<td>27 May 2005</td>
</tr>
<tr>
<td>Letter from Sponsor</td>
<td>1</td>
<td>27 May 2005</td>
</tr>
</tbody>
</table>

Major Research Project
Management approval

The study should not commence at any NHS site until the local Principal Investigator has obtained final management approval from the R&D Department for the relevant NHS care organisation.

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Notification of other bodies

The Committee Administrator will notify the research sponsor and the R&D Department for NHS care organisation that the study has a favourable ethical opinion.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

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

Yours sincerely

Dr Hervey Wilcox
Chair

Email: sheree.leehane@epsm-stheller.nhs.uk

Enclosures:

Attendance at Sub-Committee of the REC meeting on 03 August 2005

Standard approval conditions

Cc – Research Governance Lead
Our Ref: CC/2005/001
REC Ref: 05/Q0806/66

19 July 2005
Dear Miss Dawkins,

Re: Exploring identity in older adults with chronic pain: an interpretative phenomenological analysis.
SHORT TITLE: Exploring identity in older adults with chronic pain.

In accordance with Research Governance requirements, the R&D Directorate on behalf of the Trust has approved the above-mentioned research study.

Trust approval is given subject to the following terms and conditions being agreed and satisfied, as appropriate:

1. The start of the study is within 12 months of the date of this letter. If the study does not commence within the period stated, a re-application to the R&D Directorate will be required.

2. Any substantial amendment to the research study must be submitted to the R&D Office (see address above). This includes: changes to the protocol; start and end dates of the research study; staff changes; serious adverse events; suspected misconduct.

3. Members of the Research Team who wish to conduct research at Epsom and St Helier University Hospital NHS Trust and are not Trust employees must hold an honorary contract with the Trust prior to commencement of the research study.

4. The study is conducted in accordance with Research Governance Framework requirements (a copy of the Research Governance Framework is available on the Department of Health website www.doh.gov.uk).

5. The study is conducted in accordance with the Data Protection Act 1998 and any subsequent amendments thereto, and all relevant legislation, regulations and guidelines.

Miss N Dawkins
Trainee Clinical Psychologist
Department of Psychology
University of Surrey
Guildford
Surrey GU2 7XH

Epsom and St. Helier
University Hospitals
NHS Trust

Research and Development Directorate
Director: Dr Khudai Haque
Manager: Miss Yvonne Reilly
Accountant: Miss Debbie Siddick
R&D Office: Epsom
Tel: 01372 752525
Fax: 01372 752229
St Helier
Tel: 020 8296 3133
Fax: 020 8296 3145

Miss W Dawkins
Trainee Clinical Psychologist
Department of Psychology
University of Surrey
Guildford
Surrey GU2 7XH

Our Ref: CC/2005/001
REC Ref: 05/Q0806/66

19 July 2005
Dear Miss Dawkins,

Re: Exploring identity in older adults with chronic pain: an interpretative phenomenological analysis.
SHORT TITLE: Exploring identity in older adults with chronic pain.

In accordance with Research Governance requirements, the R&D Directorate on behalf of the Trust has approved the above-mentioned research study.

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2. Any substantial amendment to the research study must be submitted to the R&D Office (see address above). This includes: changes to the protocol; start and end dates of the research study; staff changes; serious adverse events; suspected misconduct.

3. Members of the Research Team who wish to conduct research at Epsom and St Helier University Hospital NHS Trust and are not Trust employees must hold an honorary contract with the Trust prior to commencement of the research study.

4. The study is conducted in accordance with Research Governance Framework requirements (a copy of the Research Governance Framework is available on the Department of Health website www.doh.gov.uk).

5. The study is conducted in accordance with the Data Protection Act 1998 and any subsequent amendments thereto, and all relevant legislation, regulations and guidelines.

Major Research Project
6. The study is conducted in accordance with Good Clinical Practice in the conduct of clinical trials on medicinal products for human use (EU Directive 2001/20/EC), and all relevant legislation, regulations and guidelines.

7. You carry out your obligations, as 'Investigator', as stated in any contract and/or indemnity agreement between the sponsor, the Trust and yourself.

8. The EudraCT number for the study, if applicable.

9. A copy of the Clinical Trial Authorisation (CTA) for the study, if applicable.

10. A requirement of the Research Governance Framework is that Trusts have a duty to monitor research studies. If this study is selected for monitoring, it is your responsibility, as Principal Investigator, to ensure that the research team fully comply and co-operate with the monitor's requirements.

11. The relevant Research Ethics Committee 'favourable opinion' is obtained prior to commencement of the research study, as appropriate.

12. A quarterly report must be provided to the R&D Office (see address to reply to at the top of this letter) and should be signed off by the Investigator.

13. A final report at the end of the study must be provided to the R&D Office (see address to reply to at the top of this letter) St Helier Hospital and should be signed off by the Investigator.

14. Epsom and St Helier University Hospitals NHS Trust should be recognised in any publications resulting from the research study.

15. The Investigator must provide the R&D Office (see address to reply to at the top of this letter) with references and copies of such publications resulting from the research study.

Yours sincerely

[Signature]

Dr K Hague
Director of Research & Development

cc: Dr H Rankin, Lead for Clinical Health Psychology, Centre of Pain Education, Cheviot House, Sutton Hospital.
   Dr Victoria Senior, Lecturer, Department of Psychology, University of Surrey.
31 August 2005

Miss Naomi Dawkins
Trainee Clinical Psychologist
Department of Psychology

Dear Miss Dawkins

Exploring identity in older adults with chronic pain: an interpretative phenomenological analysis (EC/2005/91/PSYCH) - FAST TRACK

On behalf of the Ethics Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the submitted protocol and supporting documentation.

Date of confirmation of ethical opinion: 31 August 2005

The list of documents reviewed and approved by the Committee under its Fast Track procedure is as follows:-

Document Type: Application
Dated: 17/08/05
Received: 19/08/05

Document Type: Research Proposal
Dated: 17/08/05
Received: 19/08/05

Document Type: Approval letter from Epsom and St. Helier University Hospital
Dated: 19/07/05
Received: 19/08/05

Document Type: Approval letter from London – Surrey Borders Research Ethics Committee
Dated: 04/08/05
Received: 19/08/05

Document Type: Summary
Received: 18/08/05

Major Research Project
This opinion is given on the understanding that you will comply with the University’s Ethical Guidelines for Teaching and Research.

The Committee should be notified of any amendments to the protocol, any adverse reactions suffered by research participants, and if the study is terminated earlier than expected with reasons.

You are asked to note that a further submission to the Ethics Committee will be required in the event that the study is not completed within five years of the above date.

Please inform me when the research has been completed.

Yours sincerely

Catherine Ashbee (Mrs)
Secretary, University Ethics Committee
Registry

cc: Professor T Desombre, Chairman, Ethics Committee
Dr Hilary Rankin, Sutton Hospital
Dr Victoria Senior, Dept of Psychology
Appendix 2: Covering letter

Dear 

Re: Research study: Exploring identity in older adults with chronic pain

We are writing to invite you to take part in the above research study. In this research we are interested in the experience of chronic pain in adults over 65 years old. In particular we are interested in finding out how chronic pain has affected your sense of identity. This may include talking about whether it has affected the things you do, your personality, or your beliefs.

Taking part in this research will involve being interviewed by Naomi Dawkins, Trainee Clinical Psychologist. This will take place at the and will take up to an hour. We can arrange a convenient time for this, and your travel expenses will be reimbursed. The interview will be tape-recorded but will remain confidential. Further details are in the enclosed Information Sheet.

You are free to decide whether or not to take part. Deciding not to participate will not affect the care that you receive. If you would like to take part, or would like more information then please telephone Dr Hilary Rankin, Clinical Psychologist at on . Agreeing to take part now does not commit you to the interview – you can change your mind at any time without giving a reason.

With best wishes,

Naomi Dawkins Dr Hilary Rankin
Chief Investigator Clinical Supervisor
Trainee Clinical Psychologist Clinical Psychologist

Major Research Project
Exploring identity in older adults with chronic pain: Information Sheet

You are being invited to take part in a research study. Before you decide it is important for you to understand why it is being done and what it will involve. Please read this information carefully and discuss it with others if you wish. You can ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you would like to take part in this study.

What is the purpose of the study?
The purpose of the study is to find out about the experience of chronic pain for people over 65 years old. In particular we are interested in finding out how chronic pain has affected your sense of identity. This may include talking about whether it has affected the things you do, your personality, or your beliefs. Other studies have found that chronic pain has wide-ranging implications. However, not many studies have been carried out specifically with people over 65.
Why have I been chosen?
You have been invited to take part because you have been referred to the major research project. We hope to interview ten people who are over 65 year old and experience chronic pain.

Do I have to take part?
No – not at all. It is up to you to decide whether or not to take part. If you decide to take part you will be given this information sheet to keep. You will be asked to sign a consent form, and you will be given a copy of it. Even if you agree to take part you are free to change your mind later and will not need to give a reason. If you decide not to take part or decide to withdraw at any time, the standard of care you receive will not be affected.

What will happen to me if I take part?
If you agree to take part in the study, we will contact you to arrange a time for us to interview you. The interview will take place in a private room at " and may take up to one hour. Your travel expenses will be reimbursed. We will ask if we can tape record the interview. We will ask for information such as your age, marital status and history of chronic pain so we can describe the people who have taken part in the study. We will look at your records at " to get information from your initial assessment.
What are the risks of taking part?
There are no known risks in taking part in this study. It is possible that you may feel upset after talking about your experience of chronic pain. If this is the case then you can contact one of the clinical team at [redacted] on the telephone helpline: [redacted]. If you have any comments or complaints about the research then you can contact the Patient Advice and Liaison Service (PALS): 020 8296 2508

What are the benefits of taking part?
There are no known benefits to taking part in the study. You may feel a sense of satisfaction from having an opportunity to talk about your experiences. In addition, this study may in the long-term contribute to improvement in services for people over 65 with chronic pain.

Is the study confidential?
Yes it is. If you agree to take part we will let your GP and [redacted] know that you are a participant in the research. The content of your interview and medical notes will remain confidential to the researchers. The audio-tape and transcript of your interview will be kept secure and will only be used for research purposes. Any information that could be used to identify you from the transcript will be removed. However, if you were to tell us something that caused us to be concerned about your safety, for example if you were feeling very low, then it would be our
duty to discuss these concerns with you and maybe pass them on. Data will be stored in accordance with the Data Protection Act (1998).

**Who has reviewed the study?**

Three committees have reviewed the study and given their approval for it to take place (London - Surrey Borders Local Research Ethics Committee, Epsom & St Helier University Hospitals NHS Trust Research & Development Committee, and University of Surrey Research Ethics Committee). The clinicians at [blank] are also satisfied with the study and have given their permission for you to be invited to take part.

**Who is organising the research?**

Naomi Dawkins, a Trainee Clinical Psychologist not involved in your care will be interviewing you. The research is being supervised by Dr Hilary Rankin, Clinical Psychologist at [blank], and Dr Victoria Senior, Lecturer at the University of Surrey.

**What will happen to the results of the study?**

The results will be produced in a report. This will be circulated to clinicians working in the pain management services. It will also be submitted as part of a PsychD in Clinical Psychology. If possible, it will be published in a journal specialising in pain-related research. Information that could be used to identify you will be removed and
pseudonyms used. If you would like to receive a summary of the findings or the full report you will be sent them when the study has been completed. You will be given the opportunity to discuss the findings.

**What should I do now?**

Think about whether you would like to take part in the study. If you would like information from an independent person, please contact Dr Martin Gardner, Consultant Anaesthetist: **020 8296 4161**

If you would like to be involved or if you have any questions about this study please telephone Dr Hilary Rankin at **020 8296 4315**

Thank you for taking time to read and consider this information.

Best wishes.
Appendix 4: Consent form

Exploring identity in older adults with chronic pain

Consent Form

Name of Lead Researcher: Naomi Dawkins

1. I confirm that I have read and understand the information sheet dated 19 July 2005 (Version 2) for the above study and have had the opportunity to ask questions.

   Please initial box

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

   Please initial box

3. I understand that relevant sections of my notes at the may be looked at by Naomi Dawkins. I give permission for her to have access to my records.

   Please initial box

4. I understand that my GP and will be contacted and informed of my participation in this research study.

   Please initial box

Patient Identification Number:
5. I understand that participation will involve being interviewed and that this interview will be tape-recorded and transcribed for analysis. I give permission for the interview to be tape-recorded and transcribed for analysis.

Please initial box

6. I understand that all information will remain confidential but will be included in an anonymised form in a written report. I understand that the only exception to confidentiality is where concerns are raised during the interview.

Please initial box

7. Would you like a summary of the findings or a full copy of the report when the study is completed?

SUMMARY / FULL REPORT / NO

8. Are you involved in any other research studies? YES / NO

If yes please state........................................................................

9. I agree to take part in the above study

Please initial box

Name of Patient (CAPITALS) Signature

Date:

Researcher (CAPITALS) Signature

Date:

THANK YOU FOR PARTICIPATING

Major Research Project
Appendix 5: GP letter

Dr (Name)
(Address)

(Date)

Dear Dr (Name),

Re: (Participant name) (D.O.B.: )

I am writing to inform you that the above patient has agreed to be interviewed as part of a research project exploring the experience of chronic pain in adults over 65. This interview is planned to take place on (Date) at the [location].

I enclose a Participant Information Sheet which outlines the research procedure. It is not anticipated that taking part in this interview will have any adverse effects for the research participants. In fact, it may be that participants feel a sense of relief at having the opportunity to talk about their experiences of chronic pain. The research has been approved by the London-Surrey Borders Research Ethics Committee, the Epsom and St Helier University Hospitals NHS Trust Research and Development Committee, and the University of Surrey Ethics Committee.

If you have any concerns about this patients involvement in the project or any questions about the research then please do not hesitate to contact myself, Naomi Dawkins, at psm1nd@surrey.ac.uk, or Dr Hilary Rankin, on [phone number] to discuss them.

Best wishes,

Naomi Dawkins
Chief Investigator
Trainee Clinical Psychologist

Dr Hilary Rankin
Research Supervisor
Clinical Psychologist
Appendix 6: Interview schedule

Exploring identity in older adults with chronic pain

Preliminaries
My name is Naomi, I'm a Trainee Clinical Psychologist. Thank you for coming along today – there are a few things I need to stay before we start. You are free to stop the interview at any time. Let me know at any time if you'd like to finish or have a break. Feel free to move round the room if it is more comfortable for you. As the information sheet explains, what we talk about is confidential and your name will not be used in the research. I'll tape-record our conversation so I have a record of what is said. Have you got any questions you'd like to ask before we start?

I'd like to talk to you about your experience of chronic pain. I'll start by going through some background questions and then we'll go on to the main part. There are a few different areas I'd like to explore with you, so although it's useful to talk about things in detail, at times I may need to move the interview on. I hope it won't feel like I'm changing the subject too awkwardly.

Background
Firstly I'd like to find out a bit more about your pain. This is a timeline (give timeline). It is meant to represent your life. I won't be asking about exact dates but it may be helpful to use to explain when things happened. This is where you are now. Then this part (point) represents your past and this (point) represents your future.

Looking at where you are now, you've been referred to the ■ ■. I expect you have had a number of investigations and treatments for your pain in the past.

When did your pain start?
Have there been any changes in your pain since then?
Prompts: Any times that it has been better / worse?
Anything that has helped it / made it worse?

Identity
You've described to me your history of pain. Now I'd like to find out a bit more about you as a person and what things are like for you now. Researchers talk about how people have a 'sense of identity'. By this they mean that people have different things that are important to them and that make them the person they are.

Sometimes people describe themselves by the things that they do, for example, being a volunteer or enjoying cooking. Sometimes people describe themselves using personality characteristics they have, for example, being funny or being impatient. Sometimes people describe themselves according to their religious or political beliefs. And for others it's a mix of these things.

Major Research Project
Thinking about you now (point on timeline), how would you describe yourself? There may be things you like as well as things you don’t like about yourself.

Prompts: How would you like to be seen by others? How would other people describe you? What things do you do with your time? What kind of person are you? What is important to you? Do you have strong beliefs?

Sometimes people feel that pain affects who they are as a person. People also sometimes feel that who they are as a person changes when they get older. And other people feel that changes happen for lots of reasons.

Do you feel that these things that are important to you (give their examples) have been affected by your pain?

Prompts: Are there things you would like to do but don’t? Are there characteristics you would like to have or like not to have?

Have the things you have talked about (give their examples) been affected by getting older?

Prompts: Are there things you would like to do but don’t? Are there characteristics you would like to have or like not to have?

Do you see your pain as a significant part of your life? Of who you are? Do you see your age as a significant part of your life? Of who you are? Is there anything else that has affected who you are? Your life?

When you were younger (point on timeline), what did you think life would be like at this age? How is it like this? How is it different?

Prompts: Did you have ideas or plans about retirement? Did you expect anything to happen when you were older?

Looking forward
You’ve described to me the things that are important to you and what life is like now. I’d now like to ask you a bit about the future

What do you think life will be like in the future (point on timeline)?
In relation to pain? Generally?

Prompt: What do you expect? What do you hope for?

What kind of support and input do you think may be useful in terms of your pain?

Prompt: What should people working with people with chronic pain think about when working with older adults specifically?
Finishing the interview
We've talked about your experience of chronic pain in quite a lot of detail.

Is there anything you'd like to add before we finish?

How do you feel after taking part in this interview?
Prompt: About your pain? In general?

How were the questions?
Prompt: Did they seem relevant or were there others you would have liked to have been asked?

Is there anything I could do or say to make this interview more comfortable?

Thank you very much for taking part.
(Ask them to complete background information sheet, giving help if necessary)
Past       Now       Future
Appendix 7: Demographic questionnaire

Exploring identity in older adults with chronic pain:
Background information

1) How old are you? ________

2) Are you: Male / Female (please circle)

3) Are you: Single.........................
   Married..............................
   (please tick) In a long-term relationship....
   Divorced............................
   Widowed............................

4) Do you live: Alone.....................
   With your partner...................
   (please tick the answers that apply)
   With family.......................
   Other............................
   Please state__________________
   In your own home..............
   In someone else’s home.......
   In supported housing.......... 
   In a group home............... 
   Other............................
   Please state__________________

5) What is your highest educational qualification?
   Please state__________________

Major Research Project
6) **Optional: How would you describe your ethnicity?** (please tick)

a) **White**
   - British ................................................. ___
   - Irish .................................................... ___
   - Any other White background ....................... ___
     Please state _____________________________

b) **Mixed**
   - White and Black Caribbean .............................. ___
   - White and Black African ............................... ___
   - White and Asian ......................................... ___
   - Any other Mixed background ........................... ___
     Please state _____________________________

c) **Asian or Asian British**
   - Indian ................................................... ___
   - Pakistani ................................................ ___
   - Bangladeshi .............................................. ___
   - Any other Asian background ...........................
     Please state _____________________________

d) **Black or Black British**
   - Caribbean ............................................... ___
   - African .................................................. ___
   - Any other Black background ...........................
     Please state _____________________________

e) **Chinese or other ethnic group**
   - Chinese ................................................... ___
   - Any other ................................................ ___
     Please state _____________________________

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Major Research Project
Appendix 8: Sample transcript

Interviewer: Ok. So, um, as I said before, I’m Naomi. I’m a Trainee Psychologist. There’s a few things I just wanted to say before we start. You’re free to stop at any time if you’d like to, if you just let me know if you want to have a break or anything. As it says in the information sheet, everything we talk about is confidential. Your name will be taken out and it won’t be used in the research that we do. I’m taping our conversation but after the research they’ll be kept in a secure place then they’ll be destroyed. Ok so it’s all anonymous. Did you have any questions you wanted to ask?

P3: No, not really no.

I: Ok. Um. So firstly I’m going to talk to you a bit about your experience of chronic pain. I’ll start by going through some background questions and then we’ll go onto the main bit. There’s a few different areas I’d like to get through so I may have to move us on at times. I hope that doesn’t feel to awkward.

P3: No, no, because really I only have about half an hour, you know.

I: Yes. We’ll make sure. We’ve got the clock up there so I’ll keep my eye on it. Ok/

P3: Thanks a lot.

I: Ok, so firstly I’m going to ask you about your pain. So this is a timeline, and it is meant to represent your life. So I won’t be asking about exact dates, but its useful to bear in mind that first of all I’ll be asking a bit about your past, just briefly. Then we’ll mainly talk about how things are now. And then we’ll talk for a little bit about what your thoughts are about the future.

P3: Ok, fine.

Major Research Project
I: Ok, so thinking about you at the moment. You’ve been referred to COPE here. But I expect you’ve had a few investigations and treatments before you came here.

P3: Yes I have.

I: Ok. When did these problems seem to start for you?

P3: What problems to cope with the pain or other problems that I’ve had?

I: Um, I guess pain.

P3: Problems that cause the pain?

I: Mmm.

P3: Um. I was diagnosed with rheumatoid arthritis about fifteen years ago. But prior to that I’d always had heart problems so I was never allowed to do much as a kid because they didn’t know what was wrong then. Um, so I had a limited life really because I was stopped from doing all sport which was a bit sad when I was young. Then when they got to know about heart diseases more and I had my first child...I was ill and I had a hole in my heart which I then had repaired but it was still a long time ago but it was then that I started to lead a normal life as far as sport etcetera was concerned and I’ve always been quite sporty so I found it hard so...I then had been pretty good, and then about fifteen years ago I was diagnosed with rheumatoid arthritis and then about seven years ago I had another heart problem and I had to have surgery again so I’ve had two open surgeries. So I’ve never been I would say a ‘fit’ person, but its surprising what I actually do now. I’m quite lucky. And I cope with rheumatoid arthritis although it is quite a painful complaint. It is.
I: Mmm. And is there...has there been any changes, in terms of your pain, have there been any times when it’s been better or worse?

P3: Um. It very much depends on what I do. Very much. If you get too tired with rheumatoid arthritis it is extremely painful and I find I then don’t sleep and I’m awake half the night with it.

I: Ok. So there’s a kind of...an interaction with your sleep.

P3: And also I’ve got osteoarthritis. Cause I’ve got awful pains in the back where the bones...osteoarthritis...yeah, the bones are apparently crumbling. And I’m taking mediation for that. But despite all that I still swim and do things so I’m not too bad at all.

I: Ok.

P3: But you do have to be very careful how much you do. If you let yourself get too tired you’re just ill.

I: Right. Ill as in ‘in pain’ or...?

P3: Well, you’re so fatigued by the pain. And then I get AF, you know, atrial fibrillation in my heart and it means then I can’t do anything at all and I have to go into hospital so I have to be careful how much I do.

I: Right, so it’s kind of...impacts on your heart difficulties when you’re in pain and tired.

P3: It does seem to. It makes my heart go a bit out of...I get AF, you know, atrial fibrillation. And I’m sure that’s sign...yeah, I’m not being patronising!...And I’m sure that is a lot to do if I let myself get too tired and keep doing things. So I’m a bit selfish these days and I only do what I feel I have the energy for.
I: Right. Ok. And you’ve learnt...

P3: And I worked and retired now, so, you know, to keep well I’m a bit selfish.

I: (Laughs) Ok. That’s...um...how, why have you chosen that word in particular?

P3: Well I think it is a bit selfish just to do what you want to do, you know. Um, yeah, if you only have limited energy you find that you’re a little bit more careful of how you utilise it. And I like doing things like going swimming and walking and so I...have become a bit selfish (laughs). I have somebody come once a week to help me clean the house, and my husband’s quite a bit older than me and so...although he’s very clever and he still teaches students physics and maths he’s not in the least bit domesticated so he leaves it all to me.

I: Right ok. And you’ve got help in...is that quite recently?

P3: Since I had the second heart surgery I started to have somebody come...only once a week, just to help me clean the house.

I: Right, ok.

P3: I wouldn’t say I get help every day, no not at all, and I don’t need it. Once a week just to hoover the house because with a bit back it is quite difficult.

I: And is your back the main part that’s affected by your pain?

P3: I think the back is the sort of final straw. And the back...I’ve had MRIs done and the discs have gone out of alignment at the bottom. And that isn’t, I don’t think, rheumatoid Major Research Project
arthritis, and then that was a bit disappointing. I felt I could cope with all the other but the back. Back pain constantly is...horrendous actually.

I: Right.

P3: It is. And when you first get up in the morning it's pretty hard when you feel about two hundred as you get out of bed and it takes some while for it to wear off.

I: Right, so its worse in the mornings when you...

P3: When you've laid down all night. And also if I've got too tired I don't sleep because it is pretty (whispered) painful, everything is painful at night.

I: So more, than just your back as well is it, there's other...?

P3: Yeah, yeah my feet hurt...awful. (emphatic). But don't...I'm not giving you a sob story because I do things and I still have quite a good life and I'm alive aren't I?!

I: (laughs) Well I guess that was what...my main kind of area of interest in terms of...you as a person and what things are like for you...now. Researchers have talked about how people have what they call a sense of identity. So...about the things that are important to you and what kind of person you see you are and there are different ways that people describe themselves. Sometimes by the things that they do. Sometimes by their personality characteristics. And other times people kind of define themselves according to their beliefs, whether they're religious or political, that kind of thing. So at the moment now, how would describe yourself, whether it's the things you like about yourself or the things you don't like about yourself? (pause) Or how would other people describe you?
P3: I'm not sure really. I'm not sure how they would describe me. I tend not to talk about illness to people, you know some people always talk about their aches and pains. I am to you now cause this was the purpose of my visit. But I tend not to do that, and I think I look quite fit for my age. So I tend not to talk about it, and I try very hard not to sort of feel sorry for myself. I hate pity, and I think people that have got too much self pity, it's...it's bad. So I'm very careful not to be like that. My husband sometimes gets cross with me cause I always say 'yeah I'm fine' um, but that's just the way I am. And I am fine overall, but obviously with a bad background at time I do feel quite ill. If I'm honest.

I: Right. So you're...it sounds like you're really keen to be...to not be talking about your pain and you illness all the time.

P3: Mmm. And to try and be positive. And also mentally you have to be careful not to let it take hold, because with constant back pain, you know, you can get a bit depressed and you can think. Oh, I've arranged to play bridge tonight but I'm really a bit too tired to go, but I just take a couple of pain killers and I go. Cause I think it's important.

I: Ok, so you try to keep active?

P3: Mmm, very much.

I: As much as you can.

P3: I do, yeah I do.

I: So, what you’ve described...you go swimming?

P3: Yeah I do. I try and go swimming. I feel a different person. I can’t swim much, I’m pathetic, I’m really slow and if I’ve done three lengths I think I’m really proud of myself.
and I see these fit people but I don’t take any notice of that. Cause I felt mentally so
much better and physically you do feel better and I sit in the Jacuzzi and that helps my
back. And yeah I do come back feeling very different. I’m really sort of tired but my
husband is very patient and so if the lunch is a bit later he never worries. You know, he’s
very...um...he’s not a bit domesticated but he’s not in the least bit demanding of me. No
not at all.

I: Ok. That...so do you go swimming quite regularly?

P3: Oh yeah I do, yeah I try...um...I very rarely do three times but I try and go twice a
week...yeah I do....yeah I do try and go twice. And its silly really cause I do so little but
I just feel quite proud that I’ve done it and you do feel very different.

I: And is swimming something. An interest you’ve had...I know you mentioned that
when you were younger you weren’t able to do exercise...

P3: No no. When I was about...When I was eighteen and I left school, no I went to a
school and we had wonderful sports facilities cause it was in the country we had tennis
courts and swimming pools but I was told I’d be expelled if I played any sports, so it was
quite hard. They didn’t know what was wrong. They knew it was an enlarged heart, but
you see I’m quite old, and they didn’t know what it was all about in those days. Which
was a bit sad really cause they stopped me doing everything and now with hindsight I feel
they were wrong to have done that. But in the same way my grandmother had bad
rheumatoid arthritis and at 29 they kept her in bed. She never walked again – that was
what thy thought was good for you. And it couldn’t have been worse for my poor
grandmother, and I grew up with her cause she used to live with us. And I remember it so
well. But poor lady got more and more set. In the same way, I’m not blaming anyone but
they stopped me doing everything and I would have loved sport. And I found it hard.

I: So you found it...
P3: So when I was eighteen, my first boyfriend...and I was eighteen, never had a boyfriend, you did in those days...he taught me to swim and to hit the ball at tennis and to do things and I’ve done bits of things like that ever since.

I: Right, ok

P3: But then...I then they told me I should have heart surgery cause it was a hole, but I then married and went to live in Kenya, but they said come back after...if you get pregnant, and I was really ill after I had my second child and I was kept in hospital and I agreed to have the surgery.

I: Right, ok, so...

P3: But I was quite old to have it done, well I was quite old, I was thirty.

I: Right.

P3: And then I sort of did things after that, yeah. And then I had rheumatoid arthritis and then the valve in the heart went, so...sorry, I sound ever so sorry for myself. It’s just why I’m here, isn’t it.

I: Yeah, definitely.

P3: But despite all that I still do things. I still try and hit the ball at tennis and I still go swimming, and we walk. And my husband’s a real fitness fanatic – he’s 85 this month.

I: Wow.

P3: But he walks for miles every day, very fit.
I: Right, ok, so...even though at times you’ve been stopped from doing as much exercise as you’d like to it sounds like that’s been a very important part of your life really, being a sporty person.

P3: Oh yeah, very, and I had two sons and my youngest one is extremely sports minded, yeah. And I love to see it.

I: It’s gone...It’s passed down through the generations.

P3: Oh yeah...but he's a middle aged man now...I mean I’m talking about a long time ago.

I: Right, and are there any other interests and activities that you spend your time doing?

P3: No, not really. I play bridge once a week but no, I don’t actually do anything other than going swimming. But running a house, when you’re getting older it’s, it’s...and [redacted] doesn’t give me much help, um, I find it enough. You get much slower when you’re getting older.

I: Right.

P3: I mean, shopping and cooking a meal you’re quite warn out. Whereas you did it while you were at work in your lunch hours years ago.

I: Yes.

P3: So no, I don’t do much else. No I don’t. Oh, I walk.

I: Yes. And it sounds like you see your life’s quite busy.

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P3: Oh yes, yeah we have quite a full life. I've just come back from Florida.

I: Yes, I think...I heard that you were going to Florida – wow.

P3: Mmm, I have a step-daughter that lives there. So yeah we have quite a good life.

I: And, um, with....what was your job before you retired?

P3: Oh, well, when I was young I went to college for a year and learnt...secretarial, I learnt shorthand and typing and I did that for years and in Kenya I worked you know, most women worked, you know, even though they had children. And then we came back to England and I was divorced, I was middle aged then, and I got a bit hard up and I knew I couldn't do just secretarial work so I worked for a builder and sold houses and worked actually very hard.

I: Wow.

P3: Um, but I earned more money and so I did that.

I: Oh, ok.

P3: I did that for a long, long time. Then I married again about ten years after that and I just did a couple of days work working but I haven't really worked since...so that's about twenty years since I've worked.

I: Right, ok. And was that due to your heart problems or or...

P3: That I stopped working? No, I worked in Hertfordshire and my husband was a keen tennis player, the man I then married, and he said Hertfordshire was a tennis desert, so he
was only living in Surrey, so I gave up my job and he had just retired, and so I didn't work either (laughs)

I: Ok, so you enjoyed a retirement.

P3: Yeah, yeah and we did a lot together yeah. But this was 25 years ago, yeah I'm talking about a long time ago. But no so I haven't worked since then. But I always worked full time even when my children were very small so my heart problems never stopped me working. I had quite a full life.

I: It sounds like it.

P3: Yeah I did.

I: And are you able to see much of your family? Your sons?

P3: Oh yes I do, um, but I feel a bit guilty and I always grumble at my eldest son, he married quite late in life, [redacted] was 38 before he married. He's got four children, and I can't honestly help him, you know I can't bend down to pick the kids up and I feel sometimes guilty because he, um, you know, his wife's mother helps them a lot. And they live right out in the country about sixty miles away and I've gone off driving so I...I see him but I can't...I'm not much help, so I do feel guilty about that. But he should have had them when I was younger shouldn't he? (laughs)

I: (laughs) Right. Ok.

P3: And unfortunately I had another son, who was a manic depressive. He was killed on the road at 38 by a car. So that affected my life very badly. And I think that's what's made me very anxious about driving now, every time I get....Anyway, that's...I never really knew him. I...the inquest was that it was an accident. But [redacted] had
had...been in a psychiatric home and he used to say to me he'd kill himself if it wasn't for me. So I don’t know. But we're talking about six years ago. But it is hard thing to deal with. Yeah, very, awful.... I’m so sorry, I never talk to people about it.

I: No, sorry to ask that question. (handed tissue).

P3: No, no, no. Thank you. And he was very sort archetypal typical manic depressive but it didn’t come out as a youngster. It didn’t come out until he was about eighteen.

I: Right ok, I think that’s...

P3: And he was a wonderful, a wonderful...So I don’t know. I don’t know what really happened. But, um, we’ll say it was an accident. And also, I don’t know if you know much about manic depressives but they all turn and drink too much and [redacted] did just that. When he was about 22 he started. But he was married, and I sometimes think I should have interfered more but it’s quite difficult.

I: Mmm. It’s difficult to know how much to be involved or not.

P3: Yeah, so I have to say that affected my life very badly.

I: Yeah. Mmm.

P3: But he didn’t...he hadn’t had children.

I: Right ok, so...how old are your grandchildren?

P3: Oh. My grandchildren. They’re lovely actually, it sounds as if [redacted]’s a sex maniac. They had two very close together, and they wanted two and then they decided...a boy and a girl...they then decided to have three but the third was twins!
I: Ok, so...

P3: So they had four, six and under.

I: Wow.

P3: But they're lovely kids and he's very happy. So it worked out well. I never though he'd get married, he was a real playboy type, my eldest.

I: Oh really?! So do you hear a lot about them. What they're doing and...

P3: Yes I do and they...he is really loyal. I was ten years I had the boys on my own and I think they sort of feel responsible a bit in a funny way with boys because he phones me a lot to see that I'm alright. And I'm very close to him, very. But he has to work so hard to keep all these children that he never had time to talk much. But I see him probably every four or five weeks.

I: Right, ok.

P3: So it's nice, we have a good relationship. He's a good man. But I wish actually I was a bit younger and I could have helped more, because I couldn't manage it. Her mother has them for a couple of days to give them a break. But I couldn't lift...I couldn't do it...I know I couldn't do it. And he doesn't expect me to, he can see that I've got...

I: Are you involved with them in kind of other ways aside from the kind of lifting up and the physical?

P3: Oh yeah when I go and see him...they live right out in the country...oh yes I do, but it isn't that I see them every day, they live too far away. And my husband is a bit
impatient with young children and so he doesn't encourage it too often but we do see them.

I: Right, ok.

P3: And you know I feel well gosh he’s eighty-five now it’s a bit old to have four little kids running around, isn’t it.

I: Very little children, yeah.

P3: And he’s a real academic, so hasn’t got much patience (laughs)

I: (laughs) Ok, so um.

P3: I don’t know if it helped all that. It just sounded a sob story didn’t it?

I: Well, it sounded to me that you’ve got a lot of things that are important to you in your life and that you’ve tried...and I guess what I was interested about how you feel that your pain has affected the things that you do with your life. And it sounds like it’s affected how much you feel able to help with your grandchildren.

P3: Yes, very much so, yes. Cause I don’t think there’s anything worse than...I have a real dread of not being able to do things and to sort of...well you know what I’m saying...not to be independent. I think independence is a tremendous thing. If I became that I wasn’t independent and couldn’t do things I’d rather be dead, you know. I’m a... very much a euthanasia person and I cannot understand if there’s no quality of life why people really want to carry on. I would hate it. Hate it.

I: And it sounds like you’re able to be independent with looking after your home, and...
P3: Oh absolutely, oh yes, absolutely independent. Mmm, we are, you know, very independent. My husband still teaches A-level Maths and Physics and we have loads of young people come to the house, so you know there's a lot of movement.

I: Mmm, and I guess some people feel that their pain influences what they're able to do. Other people feel that just the process of...of getting older feels that they change in terms of the things they do and how they're spending their time. I don't know whether you feel like you've noticed that as you've got older different things have changed...

P3: No I don't think that actually has much to do with getting older because I was always at hospitals and they always kept telling me I mustn't do this and mustn't do that as a kid so I sort of grew up with that and I hated it. Absolutely hated it. Um, but I don't let my arthritis or back pain stop me doing things but I know how much I...I know my limitations because if I get too tired or do too much I really am in agony. I really am. And then I take too many pain killers and then I don't go to the loo and it's just a vicious circle.

I: You've become quite an expert in managing how...

P3: Yeah, you know how...

I: What you should do...

P3: You really do.

I: And it sounds like...you described yourself as being quite selfish in terms of knowing...of doing...keeping up the things that you want to be...doing.

P3: Mmm. Yeah. Because I feel it's important to me. I want to be independent and I'm...I think some people make the mistake of living through their youngsters and I don't
think that's good for them and I don't think they like it either. And I've never been like that. I always tried to teach my kids to be independent and my mother was the same. And have other interests. You know, it's no good just having the interests of the family, women need a lot more than that. And they do now, they have career women. But in my day not so much. They sort of lived through their youngsters.

I: So you feel like done things quite differently maybe than some people by having...other interests

P3: Yeah. And when mine were ever so young I went back to work, and we were quite criticised in those days, you know, we were 'neglectful'. But now, I mean, my daughter in law sends her twins to a nursery school and she doesn't work so she does it 'cause she thinks it's good for them. Totally different from...I did that cause I, well, had to go to work in those days. But the thinking was different. Very different. Extremely different.

I: Yeah, it sounds like things have changed quite a...

P3: Oh yes it has. We were very criticised well we was neglecting our kids cause we send them to...these were European Army crèches in Nairobi where I lived, and yeah we were quite criticised. But it didn't do them any harm.

I: No, no. So do you um, do you see your pain...would you describe it as being a significant part of your life?

P3: Yes it is. Although you say you're not going to let it, it is a significant part of life, without a doubt. Yes, yeah it is. You sort of stand washing up for twenty minutes and if you've got a bad back it is quite exhausting.

I: So is it significant in that it kind of affects everything that you do, would you...

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P3: Yeah, I would say it does. Without sounding weak I would say it does. It makes me a bit bad tempered at times too.

I: Right, ok. (laughs) Is that something new that you feel like your pain has...

P3: No, I've always been a bit impatient if I'm honest. Yeah, yeah I have, yeah. I'm not a laid back type.

I: Right, ok. And um, in terms of the process of getting older. You said at the beginning of our conversation that you feel like you're about two hundred years old when you wake up in the morning sometimes. I mean, do you...

P3: Mmm, it's depressing. Cause you totter across the room to go to the loo. Yeah, it is depressing.

I: So it sounds like you don't necessarily feel like the age that you age sometimes?

P3: No, you feel a lot older first thing in the morning. You feel, oh God, another day. But you soon get over it. After about an hour you get over it.

I: So, when you were younger, what did you think your life would be like when you were your age now?

P3: I must have been a bit stupid I didn't sort of think that far ahead. I was extremely close to my Mum, with my sisters, I was extremely close to my Mum and when she became ill and needed help I found it terribly sad for her. But I never sort of put myself in her position, I must have been a bit thick, in her position and thinking well its going to happen to me. Then suddenly when I was sixty I thought, I don't believe I've got this old (laughs) and it suddenly came upon me. No, I never used to think about getting old.

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I: I don’t think it’s that uncommon actually.

P3: Isn’t it? No, no I didn’t no. I’m very surprised, and sometimes when I hear somebody say ‘oh no I was born in 1959’ and I’m thinking Christ, you know, I really am getting old. It puts it into perspective.

I: Right, ok. Sounds like you’re a bit surprised by being... by getting older.

P3: Yes I am. But we always joke about it, you know. My son always jokes and goes ‘And how’s my elderly Mum today’! You know, we laugh and joke about things. But I’ve never sort of dreaded old age cause I didn’t think it would happen!

I: (laughs) Right, you didn’t think it was relevant!

P3: No that’s right (laughs)

I: And how about looking into the future? What do you think life will be like in your future?

P3: I don’t know and to be absolutely honest I would prefer just to live from day to day. It’s a bit scary looking too far into the future, and my husband’s twelve years older than me. Um, so, no I only live from day to day. I don’t sort of keep thinking about it. Don’t want to particularly.

I: It’s something a bit scary that you don’t like to think about.

P3: Yeah, block it out, block it out.

I: In terms of what, um... have you got any ideas about what help you might... or support you might find useful in terms of your pain in the future?
P3: No, I don't think that much. I think that um, no I just take painkillers...um...I...I'm a fatalist, what will be will be, you know and if things start to get worse...cause yeah they're telling me that now I'm starting getting it in the hips but I now also know I would never have any more surgery or anything like that. No, definitely not.

I: Because it's? For what reason is that?

P3: Well, I don't know I think I've had enough anaesthetic cause I'm getting terribly forgetful and a bit dozy and I also had another bowel operation a few years ago so I have had a lot of anaesthetic and I went to the doctors and said I think I'm...cause my Mum had Alzheimer's in the end...and I said to the Dr I think I'm probably getting Alzheimer's. He said no you're not, you've just have hours and hours and hours of anaesthetic and it really does affect the memory. Cause my memory is awful. My sister didn't ever...often says to me 'Surely you remember that?' and I just don't. Definitely my memory has been affected and he just...I just casually mention it, and he said if you've had ever such a lot of anaesthetic it can affect the memory.

I: Right, ok, well that's...

P3: Ok, I'm going dozy...And yeah I do absolutely dread the thought of getting Alzheimer's because I nursed my Mum at the end and I think it's the most terrible complaint for anybody to have to live with. Especially those that love them, it's very hard for them. More really because the person that has it doesn't really know. It's horrendous.

I: It sounds like it must have been a difficult time for you with your mother.

P3: Yeah, but it was only the last year and I was very close to her. We had a wonderful relationship, so I can't complain about a year.
I: No, no, and it sounds like it was important for you to be there for that year.

P3: Oh yeah it was. Yeah.

I: Ok. Well, from what you’ve described to me in terms of your life and your pain, you’ve described how even though it’s kind of significant to you because it’s always there, it’s actually very important for you to not let it be significant.

P3: Oh very, yeah, very.

I: That actually you don’t want it to be part of who you are. You present to other people...

P3: Yeah, very much.

I: That you’re fine, and that you, um...you don’t like to complain.

P3: Yeah, no. I can’t bear hypochondriacs. No I am very careful, yeah, I do. And I won’t let it get the better of me I just know I won’t.

I: And it sounds certainly like it’s not, at the moment, stopping you from doing anything that you want to...

P3: No, it doesn’t.

I: Except for maybe with your grandchildren.

P3: Yeah, and I mean I couldn’t go and swim seven or eight lengths of a pool, I wouldn’t...I couldn’t, the pain wouldn’t let me do that and I know I would never get out.
But it still lets me do things, and I walk. My husband won’t walk with me cause he says I walk far too slow. So we don’t even...we don’t walk together, but um, no it doesn’t stop me. And you know, when you’re seventy odd you don’t expect to do the things you did when you were twenty do you?

I: Right, so you’ve got different kind of...

P3: Different outlook.

I: standards for what you think you want to be doing.

P3: Sure. Yeah, and I don’t entertain and have big dinner parties and things like that, not any more.

I: But you have your regular bridge.

P3: Oh yeah, yes. But they just have coffee and biscuits and a gin and tonic, you know, which isn’t a lot of work! (laughs)

I: That sounds very civilised, that sounds nice! (laughs)

P3: Which isn’t a lot of work.

I: Ok. Was there...is there anything that you’d like to add to what you’ve said already in terms of how you are at the moment with your pain and your...

P3: No not really. I think I’ve had ever such a lot of help from the medical profession, I really have. I don’t take any of it for granted I’ve been extremely lucky. At [redacted] and at [redacted] and at [redacted] I’ve had surgery. They’ve all been wonderful to me.
I: And its that with your heart problems or is that with your arthritis as well?

P3: Well, the [Redacted] at [Redacted] I was under when I was young and I had both my children there cause I had a heart problem and a heart surgery. Then I had heart surgery at [Redacted] and they were very good and then at [Redacted] I had a stomach operation and they were good. But I've been in and out of [Redacted] a couple of times cause occasionally my heart goes wonky and I go in for a few days and I found they're always very good to me. Very kind. And they get very scared if your heart goes wonky. As I do.

I: Mmm. It must be frightening.

P3: Yes, yes. But they've always been very good to me.

I: And with the kind of the diagnosis of your arthritis, have you felt that you’ve been given support and input in terms of your arthritis.

P3: Oh yes, yes. But there’s nothing really they can do except different medication and I take Methatrexat, I don’t know whether you know, it’s quite a powerful drug and I take nine at one time once a week and I have to keep having blood tests so, and I think to myself sometimes, oh, you know I might be doing a lot of damage to everything else but on the other hand they tell me that I would barely move if I didn’t take it, so I think you’ve got to let it go out of your head and take it because I couldn’t bear the thought of not being able to move, so I’d rather take…and these powerful drugs, you haven’t got to have much intelligence to know that it is a bit risky, the side effects. And I know there are cause I’m always having my blood checked. But I still think it’s worth doing personally.

I: So, and it sounds like those times when you know you want to do something you might take your tablets and that will allow you to do the things that you want to?

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P3: Exactly, and you know if you’re going to do something a bit energetic you take painkillers before. You get very used to handling it.

I: Yeah, it sounds like you’ve become as I said, a real expert in...

P3: Yeah, you do. Now my husband, who never, fortunately, (bangs wood table) he’s never had an illness in his life, and he now has got a bad back I think he lifted something too heavy. And he’s frightened to take asprin and I have to laugh to myself cause I think, God, how many I take every day. But he’s never been used to it and he’s finding it ever so hard. Yeah, he’s finding it really, really hard. Um, but he’s going to have it now, you know, he’s eighty-five years of age, he’s going to be lucky if it just goes, but I can’t tell him that. But I’m not grumbling about him. He’s brilliant. Very clever man, but he can’t bear it. And he is so careful, he says ‘yes I’ve taken it’ but he just takes Paracetmol, which is such a mild drug. And he pretends he’s taken more than he has, ‘cause he just can’t bear taking anything. But if you’ve been used to pain, you know you have to otherwise you don’t have any quality of life.

I: And it sounds like you’ve been used to having all sorts of medical interventions.

P3: Yeah I have.

I: Throughout your life. You’ve got used to...

P3: Yeah.

I: Um. Ok, so if we finish up now I’ve just got a few rounding up questions.

P3: Sorry, have I gone on too long?
I: No, not at all, not at all. We've got through things very quickly. How do you feel about your pain and how things are having taken part in this interview?

P3: What, with you? Um. Fine, you know. I just...I can handle it, I know I can handle it. Obviously I'm a bit scared that it could get a lot worse but I feel, well it is going to get worse as I get older and that's inevitable and I've got to face up to it. And I'm very much a fatalist, what will be will be. But, um, I'm not a miserable person, you know I've had a good life and I'm carrying on enjoying it.

I: It sounds like you're...although you're living from day to day

P3: Oh yes.

I: Just taking each day as it comes, you're kind of aware that there's a future that you don't really know what it's going to hold.

P3: Yes. And I keep being reminded, if I sort of...my husband is very much, he's not eighty-five and he's still sort of saving for his old age and I say, 'Look we're there' I: (laughs)

P3: And he goes, 'yeah but we might have to go into a home and they're getting more and more expensive', you know what I'm saying don't you. He's still terribly careful, although we've been away, he's still very, very sort of careful. He doesn't...I don't think he realises how old he is. I don't think he...no. And I laugh and I go, well why are you working hard. He says I'm saving for old age.

I: (laughs)
P3: Still, more people should do that really shouldn’t they, worry about it. So I’m not criticising him, no. But we don’t sort of think upon ourselves as being sort of quite old. In fact in our road up until two years ago [redacted] used to run every day for three or four miles, and we’re by far the oldest couple in the road. And I think people sort of look at us and think that we’re a bit funny. We don’t sort of think that we’re that old, no we don’t, no we don’t.

I: Well it certainly sounds like how active you are, that it doesn’t fit in to what people think of as old...old age really.

P3: No, no, definitely.

I: Ok. How were the questions that I asked? Did they seem relevant to you or was there things that you felt like I’d...

P3: Oh yes, no, no, no. Fine, absolutely fine.

I: And is there anything that I could have done to make things more comfortable for you?

P3: No not at all. No, I just hope that my car hasn’t been clamped (laughs). Apart from that, absolutely fine. No, no.

I: Do you want me to walk up with you and check?

P3: No, but I’ll have to come back if it has.

I: Yeah, I’m just thinking about you having to do that walk more than once. I’m sure it won’t be.

Major Research Project
P3: I’m sure it won’t be. No, you don’t have to come up. I’m sure it won’t be, no. I should have brought my mobile phone and I could have phoned. Anyway, I hope it’s been helpful.

I: Yes, it’s been very helpful thank you. Can I give you just a form to fill in your background information in terms of your demographic information.

P3: Oh right. It’s hard to write when you’ve got rheumatoid arthritis cause your hand. Some women’s fingers are awful but your hands get very painful, so it’s a bit scratchy my writing.

(fills in form)

P3: So you’re just spending your time interviewing elderly miserable old ladies, that’s not gone on tape has it?

I: (laughs) I’m just turning it off!
## Appendix 9: Table of themes with examples

<table>
<thead>
<tr>
<th>Maintaining identity despite pain</th>
<th>Liz</th>
<th>Emma</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doing</td>
<td></td>
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<tr>
<td>‘I only do what I feel I have the energy for’</td>
<td></td>
<td>‘that pain, um, is, that is most painful when I’m doing, say doing housework’</td>
</tr>
<tr>
<td>‘I can’t honestly help him…I can’t bend down to pick the kids up’</td>
<td></td>
<td>‘had I not the pain and the inconvenience of this particular thing [hip and back problem]…I’d be able to get along much better’</td>
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<tr>
<td>‘I can’t swim much, I’m pathetic, I’m really slow’</td>
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<td>‘I realised that I was limping’</td>
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<tr>
<td>‘I don’t actually do anything other than going swimming…I find it enough’</td>
<td></td>
<td>hospital appointments….I have more of those sorts of things in my life which can…can conflict with, with what I would like to do’</td>
</tr>
<tr>
<td>‘Despite all that [pain and other health conditions] I still do things’</td>
<td></td>
<td>‘it would be very foolish of me to give up [work]…it helps me deal with life…gives me something to look forward to….otherwise what have I got?’</td>
</tr>
<tr>
<td>‘I know my limits because if I get too tired or do too much I really am in agony’</td>
<td></td>
<td>‘There isn’t anything else I would want to do…I’m not a choir singer’</td>
</tr>
<tr>
<td>you totter across the room to go to the loo’</td>
<td></td>
<td>‘I go to an exercise class once a week’</td>
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<tr>
<td>‘I just take a couple of painkillers and I go’</td>
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<td>‘I do take tablets for the pain’</td>
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<tr>
<td>Maintaining identity despite pain</td>
<td>Bob</td>
<td>Penny</td>
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<tr>
<td>Doing</td>
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<tr>
<td>It does upset the back as well, specially when I'm walking</td>
<td></td>
<td>I can swim but only slowly</td>
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<td>things that I can't manage like changing the bed linen</td>
<td></td>
<td>I can't sit at a desk for very long, but...I can get up and go out</td>
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<td>I found that I couldn't hold a cup of tea properly...and I thought, it's time to pack up'</td>
<td></td>
<td>Now I can't do it [professional badminton]. No way can I do it.</td>
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<tr>
<td>I like gardening but I've got to be very careful because of my hands'</td>
<td></td>
<td>I had two lots of steroid injections</td>
</tr>
<tr>
<td>I have got to do something and if that's what it takes [being in pain] then I will do it</td>
<td></td>
<td>I have always thought I look after people, you know. It's not me that's got to be looked after</td>
</tr>
<tr>
<td>I only go just to get out of the house basically...I think that didn't help being indoors all the time</td>
<td></td>
<td>however hard it is I am going back to work</td>
</tr>
<tr>
<td>I exercise, use a compress on it</td>
<td></td>
<td>I couldn't see any purpose in living in the pain I was in, I couldn't be any help to anyone</td>
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<tr>
<td>[having a voluntary job] kept me going</td>
<td></td>
<td>as soon as I used to get out there and working I stopped thinking about it</td>
</tr>
<tr>
<td>Maintaining identity despite pain</td>
<td>Anita</td>
<td>Rose</td>
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<tr>
<td><strong>Doing</strong></td>
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<tr>
<td>I had trouble getting down Ben Nevis last August</td>
<td>I don't walk very well outside...I can't walk too far</td>
<td></td>
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<tr>
<td>I've done quite a lot of exercise myself, been to a Pilates class</td>
<td>I can't get down...to clean the bath. That is agony to me. And, er, leaning over the bed is agony</td>
<td></td>
</tr>
<tr>
<td>I couldn't do, say, a whole day's physical activity unabated. I couldn't do that</td>
<td>If I go to church...the hard pews really stiffen me up</td>
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<tr>
<td>if I'm not feeling able to do something in particular I will say, listen, my back is really hurting</td>
<td>If I'm tired I can't sing. And I feel it's to do with all of this pain that I have</td>
<td></td>
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<tr>
<td>I've had to keep going, put it that way</td>
<td>I thoroughly enjoy it. Takes my mind off it [pain]</td>
<td></td>
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<tr>
<td>If the life isn't varied and active then there are problems</td>
<td>I suppose that's been drilled into me, you know, you've got to do this or you must...</td>
<td></td>
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<td>I think that's important, to have something to offer</td>
<td>If it's...really severe pain I just have to lie down and it eases up</td>
<td></td>
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<td>keeping it moving is a lot more important than keeping it immobile</td>
<td>I'm conscious of it all the time but I just keep going, you know, I...I've got that attitude</td>
<td></td>
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<td>obviously I have painkillers.</td>
<td>the tablets that I take, I'm pleased with them</td>
<td></td>
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<tr>
<td>Maintaining identity despite pain</td>
<td>Jill</td>
<td>Mary</td>
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<tr>
<td>Doing</td>
<td>I'd have to, as well as the wheelchair I'd have to take my stick as well. So it's all sort of inconvenient, you know. Takes the pleasure out of it...spoils it. It's so inconvenient...I can't go on holiday, I can't go out for the day or anything like that, you know. What kind of things do you do with your time? Not a lot, not a lot at all. I had an injection in my spine to see if that would stop the pain. I couldn't get in and out of the bath.</td>
<td>when you're out for the day you just don't want to do anything. I try and do things normal. We bought a bed now that moves up and down so I'm experimenting at different levels when you feel a bit better I just try and carry on as normal. You push sort of pain away and you get on with things. I've got to cope. TENS...doesn't get rid of it but it deadens it, you know...its good.</td>
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<tr>
<td>Maintaining identity despite pain</td>
<td>June</td>
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<tr>
<td>Doing</td>
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<td></td>
<td>I hobble along bent double</td>
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<td></td>
<td>getting out the car is crippling</td>
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<td></td>
<td>if you've got pain in your back you automatically stop doing things</td>
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<td></td>
<td>I belong to a Guild...I don't want to go there and sit on a chair for two hours because it's going to hurt me so I make excuses not to go</td>
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<td></td>
<td>if I do have a bath my husband has to be on standby because I'd be in there all day! Couldn't get out.</td>
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<td>it is withdrawing from my social life</td>
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<td></td>
<td>a couple of paracetemol is more acceptable to me than being linked up to that [TENS machine]</td>
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<tr>
<td>Maintaining identity despite pain</td>
<td>Liz</td>
<td>Emma</td>
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<tr>
<td>Being</td>
<td>'I'm a bit selfish these days'</td>
<td>'I don't feel quite so, um, not quite so confident'</td>
</tr>
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<td></td>
<td>'With constant back pain, you know, you can get a bit depressed'</td>
<td>'I'm more frightened to go now because...I would not be able to defend myself if I was attacked'</td>
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<td></td>
<td>'I try very hard not to sort of feel sorry for myself'</td>
<td>for my age I'm not too bad I suppose</td>
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<td></td>
<td>'I still have quite a good life'</td>
<td>I've been told I keep a good set of books, so I manage...I'm not too bad up there</td>
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<td></td>
<td>I do so little but I just feel quite proud that I've done it</td>
<td>'my voice is...is just as good as ever, if not better'</td>
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<td></td>
<td>'I wouldn't say I get help every day, no not at all, and I don't need it'</td>
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<tr>
<td></td>
<td>'I've had a good life'</td>
<td></td>
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<tr>
<td></td>
<td>'I'm alive aren't I?!'</td>
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</tr>
<tr>
<td>Maintaining identity despite pain</td>
<td>Bob</td>
<td>Penny</td>
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<tr>
<td>Being</td>
<td>I've got quite a sense of humour, but it [pain] certainly took it away from me when...I had this pain, I'm afraid I used to get really niggly with her at times you've got to make the most of it. And why be down in the dumps if you can be happy</td>
<td>I went down into a little bit of depression as well It's affected my personality completely. I never used to moan, I never used to groan I finding that with a little bit of effort I can do things a couple of days I've just wished I was dead I said it's absolutely fantastic, really, a year ago I could hardly walk when I look around and see some people, and I see amputees of 34, 35, and I feel awful, I've had such a good life I have done everything that I wanted to in life...I must just be a lucky person</td>
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<tr>
<td>Anita</td>
<td>I don't always feel very positive. I mean there's times it gets me down and I cry.</td>
<td>I fly off the handle sometimes, I can't control it, it's just, I'm in pain. I think, well you know there's people worse off than me...that's how I get through, I say, oh, you know, I could be a lot worse.</td>
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<tr>
<td>Maintaining identity despite pain</td>
<td>It doesn't affect my beliefs or anything like that. I see no relationship [between art and pain].</td>
<td>I have a lot of hobbies as well. A lot of friends, a lot of hobbies. I go down and say to...[husband], I've got to pull myself up.</td>
</tr>
<tr>
<td>Being</td>
<td>I will slam up a little bit when I'm in a lot of pain so the extraversion will change. Myself a little bit more indoors or not as outgoing.</td>
<td>I'll have a lot of hobbies as well. A lot of friends, a lot of hobbies. I go down and say to...[husband], I've got to pull myself up.</td>
</tr>
<tr>
<td>Rose</td>
<td>You get days when you're really cheesed off and depressed with it.</td>
<td>I fly off the handle sometimes, I can't control it, it's just, I'm in pain. I think, well you know there's people worse off than me...that's how I get through, I say, oh, you know, I could be a lot worse.</td>
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<tr>
<td>Maintaining identity despite pain</td>
<td>Jill</td>
<td>Mary</td>
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<tr>
<td><strong>Being</strong></td>
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<td>I get very bad tempered and say things sometimes what I regret afterwards</td>
<td>you can get down. And I don't want to get down and I don't want to become a miserable person</td>
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<td>[limitations in activity] Really makes me depressed</td>
<td>I was really fed up cause you…it was just making my life horrible</td>
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<td>it makes you so cross as well that I can't do things I want to do</td>
<td>I've always believed in life as helping everybody that you could do, and that's what we do…it's always been like that</td>
<td></td>
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<tr>
<td>I can still get around and do a bit of the dusting</td>
<td>there's far more people that are worse off than what you are. You see people in wheelcharis and very deformed</td>
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<td>I manage to get my own breakfast and, um, make my own bed and fix everything to go in the washing machine…all the time I'm capable of doing that sort of thing I'll, um, I shall feel better</td>
<td>you push them [negative thoughts] out of your mind</td>
<td></td>
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<td>I think we're very lucky in this area really. When you hear about other places</td>
<td>I wouldn't let myself think about it</td>
<td>Count your blessings</td>
</tr>
<tr>
<td>June</td>
<td>Pain makes you withdraw</td>
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<td></td>
<td>I'm getting quite solitary actually</td>
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<td></td>
<td>I've achieved what I set out to do, and what you're put on earth for, haven't I?</td>
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<td>I've got pain, well, who hasn't when they get old?</td>
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<td></td>
<td>Better than having arthritis. I mean, I've seen friends of mine struggles with arthritis...I'm incredibly lucky</td>
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<td></td>
<td>I just consider that I'm lucky. I mean I've got a very comfortable, I have no financial worries whatsoever, um, really my health isn't that bad</td>
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<table>
<thead>
<tr>
<th>Maintaining identity despite pain</th>
<th>Being</th>
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<tbody>
<tr>
<td>It's a very nice life actually</td>
<td>But I'm perfectly content</td>
</tr>
<tr>
<td>Maintaining identity despite pain</td>
<td>Liz</td>
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<tr>
<td>Others' perceptions</td>
<td>'I'm not giving you a sob story'</td>
</tr>
<tr>
<td></td>
<td>'I tend not to talk about illness to people'</td>
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<tr>
<td>Identity over time</td>
<td>'Shopping and cooking a meal you're quite worn out, whereas you did it in your lunch break years ago'</td>
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<td></td>
<td>'I don't entertain and have big dinner parties and things like that, not any more'</td>
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<td></td>
<td>'I'm a fatalist, what will be will be'</td>
</tr>
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<td></td>
<td>'if I became that I wasn't independent and couldn't do things I'd rather be dead'</td>
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<td></td>
<td>'I would prefer just to live from day to day'</td>
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<tr>
<td>Maintaining identity despite pain</td>
<td>Bob</td>
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<tr>
<td>Others' perceptions</td>
<td></td>
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<tr>
<td>It does hurt... but I don't tell that to my daughter or my son</td>
<td>It would never ever admit until about the last six months that I have a back problem</td>
</tr>
<tr>
<td>I'm glad when I'm on my own so that people don't really see me like it [niggly]</td>
<td>it [was] a smiling depression</td>
</tr>
<tr>
<td>I might get niggly with my daughter.... she doesn't deserve it for me to jump at her</td>
<td>People... say, you've never done anything but moan over the last two years</td>
</tr>
<tr>
<td>Identity over time</td>
<td></td>
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<tr>
<td>I used to look after... well I still try and look after myself but my daughter helps me out a lot</td>
<td>I still like to swim, I still like to walk but of course I can't</td>
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<tr>
<td>I just hope I can carry on like it, you know. It's not so bad if it's like this but if it does get worse then it....</td>
<td>I was so fit and so healthy, even till I was 60, 63, you know</td>
</tr>
<tr>
<td>you never know with life do you?</td>
<td>do you do windsurfing regularly? Not any more</td>
</tr>
<tr>
<td>Maintaining identity despite pain</td>
<td>Anita</td>
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<td>----------------------------------</td>
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<tr>
<td>Others' perceptions</td>
<td></td>
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<tr>
<td>If people ask me if I've got a disability I simply say no</td>
<td>I don't go on about it...people don't want to hear that [people] only see the best side of me</td>
</tr>
<tr>
<td>I can't go around wincing all the time</td>
<td>Nobody can see pain, they don't understand, you know I'm right nasty, sometimes, to [husband]</td>
</tr>
<tr>
<td>Identity over time</td>
<td></td>
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<tr>
<td>[practical tasks] I'm finding a bit more challenging one of the things I would have to look at is who's going to be around to help me if this pain gets worse I think what would kerfuffle me is if I felt the pain was so bad I couldn't get on with something</td>
<td>I used to love cooking a lot but I find, er, some days I can't cope with that I haven't baked for months have I? Used to love baking but, you know... I just take it as it comes, you know I have days when I'm not at all positive and I worry and think what's going to happen to us? I just have to take one day at a time now</td>
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<td>Maintaining identity despite pain</td>
<td>Jill</td>
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<tr>
<td>Others' perceptions</td>
<td>None</td>
</tr>
<tr>
<td>Identity over time</td>
<td>I always used to get on the bus and go shopping...I can't do that now. I used to be, um, very friendly and outgoing, but now...I get very bad tempered. I was quite fit then. I'm only hoping that I won't have to be put in a home. That's my, um, dread for the future. I would hate it if I had to go in a home. Absolutely dread it.</td>
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<td>Maintaining identity despite pain</td>
<td>June</td>
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<tr>
<td>Others' perceptions</td>
<td>None</td>
</tr>
<tr>
<td>Identity over time</td>
<td>I used to be out and about and busy busy busy. And now because I've had all this pain and my back hurts and everything, I've withdrawn from a lot of it all your life, kneel down, do that, that's fine. And then suddenly, oh gosh, how am I going to get up? I've just been fit all my life The only thing that would frighten me is in...there again, is intense pain I'm fatalistic</td>
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<table>
<thead>
<tr>
<th>Pain in the context of ageing</th>
<th>Liz</th>
<th>Emma</th>
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</thead>
</table>
| Age as explanation            | when you first get up in the morning it's pretty hard when you feel about two hundred as you get out of bed  
‘When you’re seventy odd you don’t expect to do the things you did when you were twenty do you?’  
Well it is going to get worse as I get older and that’s inevitable and I’ve got to face up to it  
‘I don’t think that actually has much to do with getting older’ | ‘naturally it [aging process] does make a difference to your life’  
‘you don’t retire from the theatre’  
‘I was working towards getting better at, and getting more prestigious work all the time’  
for my age I’m not too bad I suppose |
| Maintaining identity despite age | ‘I don’t believe I’ve got this old….it suddenly came upon me’  
‘We don’t sort of think that we’re that old’  
‘Look, we’re there’ [old age] | None                                                                 |
<table>
<thead>
<tr>
<th><strong>Pain in the context of ageing</strong></th>
<th><strong>Bob</strong></th>
<th><strong>Penny</strong></th>
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</thead>
<tbody>
<tr>
<td>Age as explanation</td>
<td>I'm 72 now so it...time goes on and these things do affect you.</td>
<td>I had actually thought...when I'm old I'll try and qualify for the old age Olympics</td>
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<td></td>
<td>Maybe had I not got pain I'd have something else wrong with me as I'd got older</td>
<td>there's a lot of old women hobble around on sticks from the age of 60 isn't there? But I was never going to be one of them</td>
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<tr>
<td></td>
<td>[getting older] has never bothered me...we've all got to get old sometime</td>
<td>my brain kept telling me was only 68, 67, you know, and I've got so many years in me yet</td>
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<td></td>
<td></td>
<td>once I do turn seventy next year...I'll probably be a much...a lot calmer, because then I'll be able to turn round and say to people, well I am seventy</td>
</tr>
<tr>
<td>Maintaining identity despite age</td>
<td>People say you're not old but I am old, I'm 72 years old and that's not young</td>
<td>I cannot accept that I'm nearly seventy and that I should be slowing down</td>
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<td></td>
<td>I'm a young man at heart</td>
<td>people talk about the peacefulness of old age, but I'm not peaceful</td>
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<td></td>
<td>I might be an old man but I'm...young in my ways [getting older] has never bothered me...we've all got to get old sometime</td>
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<tr>
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<td>Rose</td>
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<tr>
<td><strong>Age as explanation</strong></td>
<td>if I am concerned about [my age] I am not going to get out and do stuff we're all going to get physically infirm as time goes on in one sense or another, if only general wearing out...if you don't get serious disease that's a great blessing I used to think I wish I was sixty and older so I could retire...I thought it would be more settled I haven't really got time to think about my age too much</td>
<td>sometimes I sing better than I do other times. That's partly my age</td>
</tr>
<tr>
<td><strong>Maintaining identity despite age</strong></td>
<td>I don't do age I've got quite a young attitude I think, I may not look too young, but I've got....quite a young attitude technically I suppose in legal terms I'm a little old lady...and of course I can use that to good effect in making an argument say with the council</td>
<td>I don't think [age] has made much difference as far as me</td>
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<tr>
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<td>Jill</td>
<td>Mary</td>
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<tr>
<td>Age as explanation</td>
<td>it will come a time when I won't even be able to get in that shower</td>
<td>it's quite frightening as you're getting older...cause I've always been sort of...tried to be independent and help other people, but er, now it's...not so nice</td>
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<td></td>
<td>I didn't realise it [old age] was going to be like this I'm a lot slower now that I'm older and got all these aches and pains</td>
<td>You suddenly realise, oh god, I'm getting that much older, and things start going wrong</td>
</tr>
<tr>
<td>Maintaining identity despite age</td>
<td>I wonder if I look as old as I am</td>
<td>you think, oh my goodness, I'm 65, I'm getting old</td>
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<td></td>
<td>I don't actually feel old, you know</td>
<td>it [getting older] can make you feel down</td>
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<td>I'm an old lady now and not a young lady</td>
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<tr>
<td>Age as explanation</td>
<td>I'm 74 so therefore I've got aches and pains you've had your allotted span, and everything ...everything is just clapped out</td>
<td></td>
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<tr>
<td>Maintaining identity despite age</td>
<td>I hate getting old. I loathe it. I cannot believe I'm the age I am because inside I'm ex...the same as I've always been it's a gas fire and I have to lean down to switch it off at night...And that's when it hits you. Whereas all your life, kneel down do that, that's fine. I'm me. Inside I'm exactly the same person I can be the me that I've always been, my thoughts and what I'm doing, as long as I don't look in the mirror</td>
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<tr>
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<td>Emma</td>
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<tr>
<td>Ageism</td>
<td>elderly miserable old ladies</td>
<td>‘people will think, looking at me, well, I’m older…’I won’t choose her I’ll have the younger girl’</td>
</tr>
</tbody>
</table>

- ‘What, problems to cope with the pain or other problems I’ve had?’
- ‘I think the back is the sort of final straw’
- ‘the valve in the heart went’
- ‘I absolutely dread the thought of getting Alzheimer’s’
- ‘I had [a] son. He was killed on the road at 38 by a car. So that affected my life very badly’
- ‘It’s a bit scary looking too far into the future, and my husband’s 12 years older than me’

- In discussion of Alzheimer’s - ‘you hear awful things…(bangs table)’
- ‘I was widowed in the war…that has altered my personality and my life a lot’
- the hip is painful…back pain
<table>
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<tbody>
<tr>
<td>Ageism</td>
<td>I don't want to meet anybody [for a relationship] near my age</td>
<td>None</td>
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<td></td>
<td>you might think, poor old devil, you know, he wants putting down</td>
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<td></td>
<td>My doctor...I don't know whether he thought I was putting it on [initially]</td>
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<tr>
<td>Multiple problems</td>
<td>I've got enough problems as it is</td>
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<td></td>
<td>there's other things to...content with. There's so much to remember</td>
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<td>not only that, I became diabetic</td>
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<td></td>
<td>And I had a heart attack in 1998</td>
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<td></td>
<td>I have been going through a bad patch...mainly</td>
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<td>because what two, nearly three years ago my wife died</td>
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<td>two very very lovely friends, close friends...were</td>
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<td></td>
<td>both killed in a car accident</td>
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<tr>
<td>Pain in the context of ageing</td>
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<tr>
<td>Ageism</td>
<td>I think people over 65 are considered a very grey area of not worthy of helping and dealing with. I think if you have pain and you are older these two are not a good combination...people are less prepared to listen to elderly people employers will be discriminatory</td>
<td>None</td>
</tr>
<tr>
<td>Multiple problems</td>
<td>I have some money worries at the moment and that's really taxing me but that's a different thing pain is not totally dissociable from other elements in life...if you have pain at the centre, all these other factors come in and they might make a greater tangle I had a very ill husband in '98 and he died of cancer I had a relationship that broke up earlier this year and I'm deeply, deeply distressed about it to this day what I don't want is an addition sum of loads of pain, plus that probem, plus a dilemma, etc etc</td>
<td>Being in a small flat it's very difficult to, you know, do everything you want to do with music I worry about [husbands] illness Well that's...that's a different issue isn't it. [husband]'s got two very severely handicapped children left leg....hip....spine I had a hard life with my first husband. And I think that affected me in lots of ways...I've never really gotten over it, you know.</td>
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<tr>
<td>Ageism</td>
<td>sometimes you get the feeling that they don't believe what you're saying</td>
<td>sometimes I think old people can exaggerate a little bit with their pains and what's wrong with them</td>
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<td></td>
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<td>just had to wait and wait and wait for it...for it all...everything to happen</td>
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<tr>
<td>Multiple problems</td>
<td>also I've got trouble with my bladder</td>
<td>I had a friend who [died of cancer] still quite...haven't quite got over</td>
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<td>my high blood pressure</td>
<td>I'd had miscarriages</td>
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<td>my feet get swollen as well</td>
<td>I've got some other problem in my head...they think there's a nerve in my head that's affecting my eyesight</td>
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<td>I was suffering from bad depression when my husband died, cause I didn't think he would die</td>
<td>I got breast cancer</td>
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<td>we had a daughter, and she was fourteen when she died...it was never the same after that</td>
<td>I've always suffered pain from my stomach</td>
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<td>is your pain mainly in your leg at the moment or is it your back? Well both</td>
<td>in the back of the head...shoulders as well</td>
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<td>Pain in the context of ageing</td>
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<tr>
<td>Ageism</td>
<td>fancy...going round interviewing old people...how depressing!</td>
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<td></td>
<td>It's old age, we're all living too long, that's the trouble</td>
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<td></td>
<td>I think old age is ugly</td>
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<td>The appearance of old age...I found repulsive</td>
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<tr>
<td>Multiple problems</td>
<td>I'm a bit deaf, I can't remember much and I've got a bad back</td>
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<td>I'm also suffering with...memory loss</td>
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<td>my hearing's going</td>
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<td></td>
<td>it'll be good for keeping Alzheimer's at bay</td>
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Major Research Project
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<thead>
<tr>
<th>The relationship with pain</th>
<th>Liz</th>
<th>Emma</th>
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<tbody>
<tr>
<td>Pain and control</td>
<td>‘mentally you have to be careful not to let it take hold’</td>
<td>‘always ask him more than he wants to tell you’</td>
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<td></td>
<td>‘The pain wouldn’t let me do that’</td>
<td>‘terribly painful’</td>
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<td></td>
<td>‘Although you say you’re not going to let it, it is a</td>
<td>‘I shall go on trying and, um, I’m not going to give up’</td>
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<td></td>
<td>significant part of life, without a doubt’</td>
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<td></td>
<td>I would never have any more surgery or anything like that</td>
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<td></td>
<td>‘I don’t let my arthritis or back pain stop me doing things’</td>
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<td></td>
<td>‘I won’t let it get the better of me, I just know I won’t’</td>
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<td></td>
<td>‘Back pain constantly is…horrendous actually’</td>
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<tr>
<td>Living with pain</td>
<td>You get very used to handling it</td>
<td>None</td>
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<tr>
<td>The relationship with pain</td>
<td>Bob</td>
<td>Penny</td>
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<td>Pain and control</td>
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<td>there are times when I just don't know what to do with myself because of it</td>
<td></td>
<td>It did rule my life for about two years...it doesn't rule me any more....but I'm not ruling it yet, it's just part of me</td>
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<td>I get reliefs and then all of a sudden...it comes again</td>
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<td>the pain is excruciating</td>
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<td>you don't let the pain get on you</td>
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<td></td>
<td></td>
<td>it's been absolutely hell living through these last two years, psychologically and painfully</td>
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<td></td>
<td></td>
<td>I'm conquering it</td>
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<td>Living with pain</td>
<td>None</td>
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<td>I've got a chronic pain which I'm now beginning to learn to live with'</td>
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<td></td>
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<td>all the life that I'd planned has got to be altered around</td>
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<td></td>
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<td>it's...helped me accept myself as I am</td>
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<td>I've mentally adjusted myself</td>
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<tr>
<td>Pain and control</td>
<td>[when pain is bad] the focus then comes more on the pain than other things that you would be doing</td>
<td>In the end it [pain] beat me</td>
</tr>
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<td></td>
<td>lack of control, sometimes, the element of pain</td>
<td>I'm not giving in because I love to sing...I'm not giving up cause I enjoy it so much</td>
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<td></td>
<td>it does help to feel in charge</td>
<td>Most of the times I can work my way through it, but there are times when I really can't</td>
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<td>my pain is up and down</td>
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<td></td>
<td></td>
<td>I can never tell when it's going to start</td>
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<td></td>
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<td>The pain makes you very tired, you know, it wears you down</td>
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<tr>
<td>Living with pain</td>
<td>There might still be an element of the unknown but I think you have to plan</td>
<td>you've got to put up with it, you know, so, er, you drive yourself through it if you can</td>
</tr>
<tr>
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<tr>
<td>Pain and control</td>
<td>I said, well I won't take that chance [of surgery] then</td>
<td>if it's not there when you wake up you know you've got a good day, but if it's there when you wake up you think, oh here it comes</td>
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<td>I try to rise above it</td>
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<td>it [pain] can wash out days...I've lost part of a week sometimes</td>
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<td>it does get to you the pain</td>
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<td>I'm determined I'm not going to go there</td>
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<td></td>
<td>Cause I won't give in to it, but um, when you're sick and bad you've got to give in to it</td>
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<tr>
<td>Living with pain</td>
<td>I've had to learn to live with it they said they couldn't do anything so...looks like</td>
<td>None</td>
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<td>I've just got to put up with it</td>
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<tr>
<td>Pain and control</td>
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<td>it is agonising...crippling</td>
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<td>Living with pain</td>
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<tr>
<td>It's [pain] part of me now, you see. It's part of me all the time</td>
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<td>it's part and parcel of me now</td>
<td></td>
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<tr>
<td>if I've got to put up with this...so be it. What else can I do?</td>
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<td>In a way you get to learn to live with it</td>
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